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# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2016

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
*Washington, DC.*

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on departmental and nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

## DEPARTMENTAL WITNESSES

### PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS AND THE PUBLIC BROADCASTING SERVICE

On behalf of America's 171 public television licensees, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations and PBS. We urge the Subcommittee to support level funding of $445 million in 2-year advance funding for the Corporation for Public Broadcasting (CPB) in fiscal year 2018, $40 million for the Public Television Interconnection System in fiscal year 2016 and $25.7 million for the Ready To Learn program at the Department of Education in fiscal year 2016.

#### CORPORATION FOR PUBLIC BROADCASTING: $445 MILLION (FISCAL YEAR 2018), 2-YEAR ADVANCE FUNDED

Local stations and PBS are committed to serving the public good in education, public safety, civic leadership, and other essential fields. Federal funding for CPB makes these services possible and is deserving of continued support. The overwhelming majority of Americans agree. In a bipartisan Hart Research Associates/American Viewpoint poll, nearly 70 percent of American voters, including majorities of Republicans, Independents, and Democrats, support Federal funding for public broadcasting. Additionally, polls show that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only military defense. Over 70 percent of the Federal funding for CPB goes directly to local stations, resulting in a successful public-private partnership of locally owned and controlled, trusted, community entities.

*Education*

Local public television stations are America's largest classroom, meeting their communities' lifelong education needs by providing the highest quality educational content and resources on multiple media platforms and in-person. Public television's exceptional content is available to nearly every household in America and has helped more than 90 million pre-school age children get ready to learn and succeed in school. PBS, in partnership with local public television stations, has created PBS LearningMedia, an online portal where more than 1.6 million K–12 educators and users and 39,000 homeschoolers access more than 100,000 standards-based, curriculum-aligned interactive digital learning objects created from public television content, as well as material from the Library of Congress, National Archives and other high-quality sources. Overall PBS LearningMedia impacts 30 million students. Public television stations also operate virtual high schools that bring high-quality instruction in specialized fields to remote areas.

Through the American Graduate Initiative, CPB and public media stations are working to confront the dropout crisis in America's high schools by providing resources and services to lower the drop-out rate in their communities. In addition, by operating the most comprehensive non-profit GED programs in the country, public television stations have helped hundreds of thousands of individuals get their high-school equivalency certificate. Public television stations have also made it a top priority to help retrain the American workforce, including veterans, by providing digital learning opportunities for those looking for training, licensing, and more.

*Partners in Public Safety*

Public broadcasting stations throughout the country are leading innovators and irreplaceable partners to local public safety officers. The public television interconnection system provides the redundant path for the Warning Alert and Response Network enacted by Congress in 2006, through which local stations use their broadcast equipment to help send emergency alert text messages to cell phone subscribers through their providers—reaching citizens wherever they are. This digital infrastructure also enables stations to provide State and local officials with critical community emergency alert, public safety, first responder and homeland security services and information during emergencies. Stations are increasingly partnering with their local emergency responders to customize and utilize public television's infrastructure for public safety in a variety of critical ways, with many serving as their States' Emergency Alert Service (EAS) hub for weather and AMBER alerts.

*Supporting Civic Leadership*

Public television strengthens the American democracy by providing citizens with access to the history, culture and civic affairs of their communities, their States and their country. Local public television stations often serve as the State-level "C–SPAN" by airing State government proceedings. Local stations also provide more public affairs programming, local history, arts and culture, candidate debates, specialized agricultural news, and citizenship information of all kinds than anyone else.

*Public Broadcasting is a Smart Investment*

All of this is made possible by the Federal funding to CPB that amounts to about $1.35 per year, per American. On average, this Federal funding makes up approximately 15 percent of local stations' budgets. However, for small and rural stations, whose local fundraising is more difficult due to a smaller and often economically strained population base, Federal funding can represent 30–50 percent of their total budgets. It is also more costly to serve rural areas due to challenging topography and distances between communities. As a result, public broadcasters can be the only local broadcaster serving rural communities. For all stations, Federal funding is the "lifeblood" of public broadcasting, providing critical seed money to stations to build additional support from State legislatures, foundations, corporations, and "viewers like you."

Thus, for every dollar in Federal funding, local stations raise six dollars in non-Federal funding, creating a strong public-private partnership and an impressive 6 to 1 return on investment while supporting approximately 20,000 jobs across America.

*Two-Year Advance Funding*

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, proposed by President Ford and embraced by Congress in 1976, enables the leveraging of funds to ensure a successful public-private partnership, provides stations with the necessary lead time to plan in-depth programming and accompanying educational materials, and establishes a firewall insulating programming decisions from political interference—all of which contribute to unprecedented levels of public trust. For the twelfth consecutive year, the American people have ranked PBS as one of the most trusted national institutions.

Local stations leverage the 2-year advance funding to raise State, local and private funds, ensuring the continuation of this strong public-private partnership. These Federal funds act as the seed money for fundraising efforts at every station, no matter its size. Advance funding also benefits the partnership between States and stations since many States operate on 2-year cycles.

Finally, the 2-year advance funding mechanism gives stations and producers, both local and national, the critical lead time needed to raise the additional funds necessary to sustain effective partnerships with local community organizations and engage them around high-quality programs. Producers like Ken Burns spend years developing programs like The Civil War, Cancer: The Emperor of All Maladies and future programs on the history of the Vietnam War and the history of country music.

It would be impossible to produce this in depth programming and the educational materials that accompany them without the 2-year advance funding.

PUBLIC TELEVISION INTERCONNECTION SYSTEM: $40 MILLION

The public television interconnection system is the infrastructure that connects PBS and national, regional and independent producers to every local public television station around the country. The interconnection system is essential to bringing public television's educational, cultural and civic programming to every American household, no matter how rural or remote. Without interconnection, there is no Nation-wide public media service. The interconnection system is also critical for public safety, providing key redundancy for the communication of presidential alerts and warnings, and ensuring that cellular customers can receive geo-targeted emergency alerts and warnings.

Congress recognized the need for interconnection when it created CPB and authorized it to "assist in the establishment and development of one or more interconnection systems" in the Public Broadcasting Act of 1967. As long as public television has existed there has been a need for interconnection. As technology has advanced, public television has worked to make the interconnection system more efficient while increasing the timely access to programming for every station around the country. Congress has always provided Federal funding for periodic upgrades to and replacement of the interconnection system when it was needed. The last two rounds of interconnection funding were provided by Congress in fiscal year 1991–1993 and fiscal year 2004–2007.

*The Next Interconnection System*

Current interconnection satellite leases, support contracts, and existing financing expire on September 30, 2016. CPB and the public television system are committed to ensuring that the next interconnection system efficiently supports our universal service and public service commitments, while taking advantage of technological advances. PBS operates the interconnection system and has designed a primarily terrestrial broadband-based interconnection system to replace the aging, one-way "push" system that has limited distribution efficiencies and cannot facilitate current and emerging applications. The majority of content would be distributed through leased fiber-optic data lines and would allow stations to connect to—and collaborate with—one another, producers, and PBS. Minimal satellite capacity would be retained for redundancy. For fiscal year 2016, $40 million in interconnection is necessary for the down payment on a multi-year $197 million request. It is critical that Congress provide interconnection funding in fiscal year 2016 to ensure that implementation of the next interconnection system can begin in time to avoid any interruption of service to the millions of Americans served by PBS and over 350 noncommercial educational stations across the country.

*Ready To Learn: $25.7 million (Department of Education)*

The Ready To Learn (RTL) competitive grant program uses the power of public television's on-air, online, mobile, and on-the-ground educational content to build the literacy and STEM skills of children between the ages of two and eight, especially those from low-income families. Through their RTL grant, CPB and PBS are delivering evidence-based, innovative, high-quality transmedia content to improve the math and literacy skills of high-need children. CPB and PBS, in partnership with local stations, have been able to ensure that the kids and families that are most in need have access to these groundbreaking and proven effective educational resources.

*Results*

RTL is rigorously tested and evaluated to assess its impact on children's learning and to ensure that the program continues to offer children the tools they need to succeed in school. Highlights of recent studies show that: use of PBS KIDS content and games by low-income parents and their preschool children improves math learning and helps prepare children for entry into kindergarten; use of RTL content has been associated with a 29 percent improvement in reading ability in children grades K–2; and parents who used RTL math resources in the home became considerably more involved in supporting their children's learning outcomes. In combination, RTL games, activities and videos provide early learners with the critical math and literacy skills needed to succeed in school.

*An Excellent Investment*

In addition to being research-based and teacher tested, RTL also provides excellent value for our Federal dollars. In the last 5-year grant round, public broad-

casting leveraged an additional $50 million in non-Federal funding to augment the $73 million investment by the Department of Education for content production. RTL exemplifies how the public-private partnership that is public broadcasting can change lives for the better.

CONCLUSION

Americans across the political spectrum rely on public broadcasting on television, on the radio, online, and in the classroom—because we provide essential education, public safety, and informed citizenry services that are not available anywhere else. And none of this would be possible without the Federal investment in public broadcasting. A 2007 GAO report concluded that CPB's federally appropriated Community Service Grants to public television stations are an irreplaceable source of revenue for public broadcasting, and a 2012 study conducted by an independent third party for CPB came to the same conclusion. For all of these reasons we request that Congress continue its commitment to the highly successful, hugely popular public-private partnership that is public broadcasting by providing level funding of $445 million in fiscal year 2018 for the 2-year advance of the Corporation for Public Broadcasting, $40 million in fiscal year 2016 for the Public Television Interconnection System and $25.7 million in fiscal year 2016 for the Ready To Learn Program.

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PREPARED STATEMENT OF THE CORPORATION FOR PUBLIC BROADCASTING

Chairman Blunt, Ranking Member Murray and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests level funding of $445 million for fiscal year 2018, $40 million in fiscal year 2016 for the first year of a $197 million multi-year request to replace the current public television interconnection system, and $25.74 million for the Department of Education's Ready To Learn program.

Forty-seven years after passage of the Public Broadcasting Act, this uniquely American public-private partnership is keeping its promise to the American people—that we would provide high quality trusted content that educates, inspires, informs and entertains. We ensure a safe place where children can learn; high-quality educational content for teachers in the classroom and children schooled at home; reliable and trusted news and information; and emergency alert services. Through our commitment to lifelong learning public media is providing an education continuum from the youngest to oldest Americans.

Through the 1,400 locally owned and operated public radio and television stations throughout the country, we support more than 20,000 local jobs in rural and urban communities. Over 70 percent of CPB's appropriation goes directly to local stations who work in partnership with their communities to best serve local interests and concerns. Public media reaches nearly 99 percent of the American population—with an overwhelming majority of them consuming public media throughout the year.

The Federal appropriation is the essential investment that ensures your constituents will have access to public media for free and commercial free. President Ronald Reagan said, "government should provide the spark and the private sector should do the rest." America's local public media stations utilize the "spark" of the Federal investment—approximately 10 to 15 percent of a stations' budget—and raise the rest from their viewers, listeners, donors and contributors. The result is a uniquely entrepreneurial system with a track record of value delivered to all citizens.

Congressionally mandated studies have affirmed that although private donations and existing funding sources account for the majority of public media's funding, there is no alternative to Federal funding when it comes to ensuring a strong, commercial free service comprising high quality and trusted content for free to the American public.

Our trusted, noncommercial services available for free to all Americans is especially important to those living in rural communities where the local public media station is sometimes the only source of broadcast news, information and educational programming. For these smaller stations serving rural, minority and other underserved communities, the Federal dollars provide much more than just a spark, in some cases CPB's investment can represent as much as 40 percent of their budget.

Public media's contribution to education—from early childhood through adult learning—is well documented. We are America's largest classroom, with proven educational content available to all children, including those who cannot afford preschool. Further, our content is repeatedly regarded as "most trusted" by parents, caregivers and teachers.

CPB's work with the Department of Education's Ready To Learn program is an excellent example of how public media brings together high-quality educational content with on-the-ground work in local communities. Twenty years ago, Congress recognized the reach and potential of public media to help disadvantaged children become better prepared to enter school. Over time, as technology has evolved, so have we. For the past 5 years, public media has provided coordinated and connected learning experiences for children across multiple platforms, including TV, Internet, mobile, and in multiple settings, such as classrooms, summer and after-school programs, and at home.

While innovation on multiple platforms is important, television is still the primary tool to reach low-income and rural families. More than 80 studies during the last several Ready To Learn competitive grant rounds have proven that this program's content builds and improves early literacy skills for high-need children, ages two to eight. Continued funding will allow public media to carry-on this critical work.

Public media is also differentiated from commercial media through content that matters and engagement that counts. An example of this is CPB's "American Graduate" initiative, which tells the story behind the statistic of one million young people failing to graduate from high school every year. Our stations told the stories and communities throughout the country responded. Over the past 4 years more than 80 public media stations located in at-risk communities in 33 States have worked with more than 1,400 national and community-based partners to bring together diverse stakeholders and community organizations all working toward a national graduation rate of 90 percent by 2020. We are pleased to report that as a result of our and others combined efforts, in 2014, the high school graduation rate rose to 85 percent for the first time in our Nation's history.

Public media is utilizing today's technology to provide content of value to millions of citizens. CPB strategically focuses investments through the lens of what we refer to as the "Three D's" —Digital, Diversity and Dialogue. This refers to support for innovation over multiple platforms, including digital; content that is for, by and about Americans of all backgrounds; and services that foster dialogue between the American people and the public service media organizations that serve them.

The Public Broadcasting Act ensures diversity in programming by requiring CPB to fund independent and minority producers. CPB fulfills this obligation, in part, by funding the Independent Television Service, the five Minority Consortia entities in television (African American, Latino, Asian American, Native American and Pacific Islander), several public radio consortia (Latino Public Radio Consortia, African American Public Radio Stations, and Native Public Media) and numerous minority public radio stations. In addition, CPB, through its Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

Thomas Jefferson said, "An informed citizenry is at the heart of a dynamic democracy," and our commitment to early and lifelong learning, available to all citizens, helps strengthen that ideal. As newspapers across the country have scaled back their operations, public media has stepped into the void. Local stations have been working to fill the gap by building creative ventures and partnerships. CPB has helped these endeavors by funding 11 journalism collaborations comprised of 57 stations. These regional reporting hubs are providing their communities with much-needed local, regional and statewide coverage.

Today's journalists work in a much different media and political environment than in years past. The January attacks by radical Islamists on the staff of Charlie Hebdo and others in Paris have shown us that our freedom of expression cannot be taken for granted. In an effort to underscore our support of freedom of the press and freedom of expression, CPB announced an investment of several million dollars to support four of public media's flagship journalism enterprises—FRONTLINE, NPR's International Coverage, PBS NewsHour, and PRI's The World.

The work of public media goes beyond broadcast. Public television and radio stations are increasingly effective partners with State and local public safety, law enforcement and first responder organizations—connecting these agencies with one another, with the public, and with vital data-casting capabilities in times of crisis. CPB is supporting stations, both financially and by defining best practices, so that they may create more public-private partnerships locally and regionally, bringing more services and benefits to their communities. For example, CPB's Veterans Coming Home project builds on public media's strengths to address the needs of veterans in local communities. Stations and their partners are communicating veterans' stories through award winning reporting, documentaries and online content; convening local events such as job fairs and town hall meetings that connect veterans with re-

sources; and collaborating with local organizations to identify local services available to veterans.

Ever since the FCC set aside a block of spectrum exclusively for non-commercial educational use in 1953, public media has been efficiently utilizing this spectrum as a vehicle to serve families all across America. The FCC's upcoming spectrum incentive auction and subsequent repacking process present a unique set of challenges for public media. The Federal appropriation will allow CPB to adequately advise and support stations as they prepare for this unprecedented spectrum incentive auction and the repacking process that will follow.

INTERCONNECTION

As we near the expiration of our current Interconnection System satellite leases in September 2016, we must look ahead to the system that will serve public television stations for the next decade. Congress recognized the need for an interconnection system in 1967 when it passed the Public Broadcasting Act; it has maintained that commitment ever since with the funding of five generations of interconnection systems. Since 1988, Congress has supported a separate appropriation for public media's interconnection needs.

Interconnection is the backbone of public broadcasting. It is used by PBS and many other public television entities to distribute television content and related materials to non-commercial, educational television licensees across the entire country. Without it, there is no nationwide public media service.

Additionally, interconnection also serves as the failsafe mechanism for Presidential emergency alerts. Transmitting across 367 stations in all States and territories, PBS' Warning Alert and Response Network provides redundancy which enables wireless carriers to bypass network congestion caused by emergencies. The next interconnection system will employ two-way capability, paving the way for enhanced collaboration during times of emergency.

CONCLUSION

Public media's treasure trove of content and services is available to all Americans for about $1.35 per American per year. As a result of the Federal investment, public media stations are training teachers and helping to educate America's children. We are providing journalism beyond just a sound-bite that truly provides citizens with the information they need to make informed decisions about local issues; to have in-depth knowledge through fact based reporting about national and global news. We make the arts accessible to all Americans; and provide emergency alert services for communities. CPB ensures that 95 cents of every dollar received goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead.

CPB's fiscal year 2018 request of $445 million and fiscal year 2016 requests of $40 and $25.74 million for interconnection and Ready To Learn, respectively, balance the fiscal reality facing our Nation with our statutory mandate to provide a valuable and trusted service to all Americans. Today, the challenges we face are more complex than ever and require attention to education, innovation, and collaboration. Public media has been inspiring and entertaining our hearts and minds for almost half a decade, and Congress' support of our request will allow stations to continue providing high quality trusted content and materials that educate and strengthen our civil-society.

Mr. Chairman and members of the subcommittee, this is only part of the story of America's public media system. Public media is truly a national treasure. I thank you for allowing me to submit this testimony and appreciate your consideration of our request for funding.

[This statement was submitted by Patricia de Stacy Harrison, President and CEO, Corporation for Public Broadcasting.]

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## PREPARED STATEMENT OF THE NATIONAL PUBLIC RADIO

Dear Chairman Blunt, Senator Murray and Members of the Subcommittee: Thank you for this opportunity to urge the Subcommittee's support for an annual Federal investment of $445 million to public broadcasting through the Corporation for Public Broadcasting, (CPB) for fiscal year 2018. Public radio joins with our public television partners in urging the Subcommittee's support for $40 million in fiscal year 2016 for the first year of a $197 million multi-year request to replace the current public television interconnection system, and $25.74 million for the Department of Edu-

cation's Ready To Learn program. With your support, and these essential funds, every American will continue to have free access to the best in educational, news, information and cultural programming.

I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, our more than 950 public radio station partners, other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and many stations, both large and small, that create and distribute content through the Public Radio Satellite System (PRSS).

Funding provided by Congress to the CPB supports the entire foundation of a system that has been one of America's most successful models of a community-centric grant program. The cost of public broadcasting is only 0.01 percent of the entire Federal budget. The revenue base provided by Congress enables stations to raise $6 for every Federal grant dollar. This Federal financial investment permits local stations to invest more deeply in their own local news and cultural programming which in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and on online.

With support from CPB's community service grants, each of the hundreds of independently operated public radio stations is responsible for curating and creating the mix of programs that best addresses the needs of their local community. These stations and their programming choices are as diverse as the people who live in the communities they serve. Some have all-news formats. Others have all-music formats and still other blend news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the Federal Government invests roughly $90 million dollars in the operation of America's local public radio stations. And these stations provide service to all of America's congressional districts and States.

Stations continue to develop innovative local partnerships. In Missouri, the successful merger between St. Louis Public Radio and the St. Louis Beacon provides local audiences with more reporters covering local beats on air and online. By combining forces, in-depth local service allows journalists to provide more of the story behind the stories. Recently, 7 months after the shooting death of Michael Brown in Ferguson drew national attention to racial disparities, St. Louis Public Radio hosted a second community forum entitled, Ferguson and Beyond: Continuing the Community Conversation. Public radio's Michel Martin once again moderated a public discussion with a panel of community leaders and residents on what's changed since August, and what still needs attention.

In Central Washington, Northwest Public Radio and Spanish-language public radio station KDNA established a bilingual news reporting team. The new initiative pairs the talents of the two stations to bridge the cultural and linguistic gaps between communities by combining their reporting and digital services teams and tackling the issues of their respective communities, bilingually.

Federal funding for public broadcasting is a small investment that pays big dividends. And when it comes to music, public radio plays a unique and critically important role. We have created a value partnership that connects music and those who devote their lives to it from artists, performers and composers to audiences. Our local stations play a significant role in music discovery, preservation, education, and local music economies. And this role is enabled by CPB's community service grants to local public radio stations.

Nationally, more than 260 public radio stations have full-time music formats and an additional 628 play music as part of their programming lineups. On the whole, local public radio stations air more than 5.5 million hours of music per year, the majority of which is local programming and host more than 10,000 in-studio and community-based performances.

Public radio provides a home for genres that are economically unsustainable in the commercial market, including classical, jazz, folk, opera and traditional regional music such as bluegrass and zydeco. In fact, over 90 percent of all broadcast classical music in America is available only on public radio, and the same is quickly becoming true for jazz. Our stations help support and preserve cultural institutions, including local bands, symphony orchestras, philharmonic societies, theater groups, and historical venues. Public radio's role in music is not possible without a diverse revenue base, including CPB's financial support to local stations.

Mr. Chairman and Senator Murray, NPR and the public radio system are committed to being America's public radio where rationale, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take sides. Public radio plays an important, significant and growing role

in news, journalism, talk and music/cultural programming. Our stations are essential to, and part of, the communities they serve.

Through news, talk, music and cultural programming, public radio stations are reaching out to audiences wherever they are. We're embracing America's changing demographics and using digital media to connect better, more quickly and in more diverse ways. Today's public radio isn't going away, it's going everywhere and we are working every day to earn the trust of the 38 million Americans who rely on us for news and insights that guide and inform.

[This statement was submitted by Michael Riksen, Vice President—Policy & Representation, National Public Radio.]

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## PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2016 budget request of $119,918,000 for our retirement, unemployment and other programs.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. The RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (Public Law 111–5) and extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (Public Law 111–92), the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (Public Law 111–312), the Temporary Payroll Tax Cut Continuation Act of 2011 (Public Law 112–78), the Middle Class Tax Relief and Job Creation Act of 2012 (Public Law 112–96) and the American Taxpayer Relief Act of 2012 (Public Law 112–240).

During fiscal year 2014, the RRB paid $12 billion, net of recoveries, in retirement/survivor benefits to about 562,000 beneficiaries. We also paid $86 million in net unemployment/sickness insurance benefits to about 25,000 claimants. Temporary extended unemployment benefits paid were $0.8 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to $1.5 billion to about 111,000 beneficiaries.

### PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide $119,918,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2016. The proposed budget would also provide $7,980,000 for information technology (IT) investments for automation and modernization of our legacy benefit processing systems. In addition, to discretionary funding, agency seeks $3.3M in mandatory funding to enhance program integrity processes supporting benefit programs.

### AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 58 percent of our employees have 20 or more years of service, and over 31 percent of our current workforce will be eligible for retirement by fiscal year 2016. As we continue to modernize our information technology infrastructure to automate and convert manual workloads, our agency will also improve training delivery and reporting within our workforce. In fiscal year 2016, we continue to implement a Learning Management System that will provide a comprehensive functionality for training administration, documentation, tracking, reporting and delivery of e-learning education and training programs. This will allow the agency to improve all aspects involved in the learning process to meet our human capital needs as we experience a high rate of change in personnel. Furthermore, we complement this initiative by implementing an executive training program to prepare and mentor future agency leaders that are ready to replace a significant number of senior leaders within the agency that are eligible to retire.

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b) (9) of the Railroad Retire-

ment Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management. Also, our budget request includes a legislative proposal to clarify the authority of the Railroad Retirement Board to hire attorneys through competitive civil service.

INFORMATION TECHNOLOGY IMPROVEMENTS

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. In fiscal year 2016, IT funding is targeted toward investments in system modernization and network operation improvements. Key projects include system modernization resource needs for $6,486,000 in mainframe applications re-engineering, $1,435,000 for network operations to implement a virtual desktop infrastructure, and $10,000 to implement the mandatory HSPD–12 Logical Access Controls in our enterprise applications. The agency is in critical need of migrating over 12 million lines of code in COBOL that support 4,200 custom programs included in 200 major applications that serve as the framework for our legacy benefit systems/processes. We have developed a solution based on a proof of concept assessment that will migrate the agency to a flexible architecture with open standards, that transition from batch processing to interactive transactional processing. This solution will minimize the significant risks in loss of personnel nearing or at retirement age with skills needed to maintain the legacy benefit processing systems. The RRB will be equipped with modern tools and technology to run more efficiently with simplified logic that is easy to understand and document. With the implementation of the virtual desktop infrastructure, these enhanced applications will be available for use on any desktop, tablet, or smart phone. Desktops are virtual, hosted and centrally managed giving end-users a secure and full personal computer experience wherever they are, thereby providing a rich telework experience. Furthermore, these solutions will produce a return on investment to the taxpayer in savings from a decrease in full time equivalents through attrition once system changes are implemented.

OTHER REQUESTED FUNDING

The President's proposed budget includes $29 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, $580,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits." In addition, the President's proposed budget includes $150,000 for interest related to uncashed railroad retirement checks.

NEW FUNDING SOURCE

The fiscal year 2016 President's Budget also provides $3,300,000 in mandatory funding for the RRB's program integrity activities. The funds will be used to implement an aggressive program focused on efforts to deter and detect disability fraud and minimize improper payments. The objective of the request is in line with extensive review of current operations and recommendations from the General Accounting Office and RRB's Office of Inspector General. The funds will be no-year funds to provide the RRB with the flexibility to hire and train staff, train personnel, and conduct increased medical exams and reviews to support the processing of additional program integrity work.

FINANCIAL STATUS OF THE TRUST FUNDS

*Railroad Retirement Accounts*.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of $21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's Web site. The net asset value of Trust-managed assets on September 30, 2014, was approximately $26.1 billion, an increase of almost $1.1 billion from the previous year. Through January 2015, the Trust had transferred approximately $17.1 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

The RRB's latest annual report required by the Railroad Retirement Act of 1974 and Railroad Retirement Solvency Act of 1983 was released in June 2014. The overall conclusion is, barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system will experience no cash flow problems during the next 25 years. The report recommended no change in the rate of tax imposed on employers and employees. The tax adjustment mechanism will automatically increase or decrease tax rates in response to changes in fund balance. Even under a pessimistic employment assumption, this mechanism is expected to prevent cash flow problems for at least 25 years.

*Railroad Unemployment Insurance Account*.—The RRB's latest annual report required by Section 7105 of the Technical and Miscellaneous Revenue Act of 1988 was issued in June 2014. The report indicated that even as maximum daily benefit rates rose approximately 41 percent (from $68 to $96) from 2013 to 2024, experience-based contribution rates are expected to keep the unemployment insurance system solvent.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system's experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

[This statement was submitted by Michael S. Schwartz, Chairman, Walter A. Barrows, Labor Member, and Steven J. Anthony, Management Member, Railroad Retirement Board.]

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## PREPARED STATEMENT OF THE INSPECTOR GENERAL, RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Subcommittee: My name is Martin J. Dickman, and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the Subcommittee for your continued support of the Office of Inspector General.

### BUDGET REQUEST

The President's proposed budget for fiscal year 2016 would provide $9,450,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG's independent oversight of the Railroad Retirement Board (RRB). During fiscal year 2016, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

### OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB's headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and five domicile investigative offices located in Virginia, Texas, California, Florida, and New York. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies, with which the OIG works joint investigations.

### OFFICE OF AUDIT

The mission of the Office of Audit (OA) is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG's response to audit-related requirements and requests for information.

During fiscal year 2016, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB's service to rail beneficiaries and their families. OA has identified six broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act and Railroad Unemployment Insurance Act Benefit Program Operations; RRB Contracts and Contracting Activities; Railroad Medicare Program Operations; Security, Privacy, and

Information Management; and Improper Payments Act of 2010 Oversight. OA must also accomplish the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002, evaluation of information security pursuant to the Federal Information Security Management Act (FISMA), audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010, review of IG Requirements for Government Charge Card Abuse and Prevention Act of 2012, and Identification of Performance and Management Challenges for fiscal year 2016.

During fiscal year 2016, OA will complete the audit of the RRB's fiscal year 2015 financial statements and begin its audit of the agency's fiscal year 2016 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in fiscal year 2006. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, and Congressional and Presidential concerns.

### OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

OI INVESTIGATIVE RESULTS FOR FISCAL YEAR 2014

| Civil Judgments | Indictments/Informations | Convictions | Recoveries/Receivables |
|---|---|---|---|
| 24 | 35 | 89 | [1] $343,500,000 |

[1] This total amount of financial accomplishments reflect fraud amounts related to programs administered exclusively by the RRB and fraud amounts from other Federal Programs such as Medicare or Social Security, which were included in the disposition resulting from the investigation.

OI anticipates an ongoing caseload of about 400 investigations in fiscal year 2016. During fiscal year 2014, OI opened 184 new cases and closed 236. At present, OI has cases open in 48 States, the District of Columbia, and Canada with estimated fraud losses of over $401 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

Of particular significance is an ongoing disability fraud investigation in New York. To date, 33 individuals have been indicted; 28 of these have pleaded guilty and five more were convicted in Federal court. All individuals prosecuted in connection with this case have been sentenced. In addition, 44 former railroad employees avoided prosecution by admitting their role in the fraud and agreeing to the termination of their benefits. OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in fiscal year 2016.

During fiscal year 2016, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In fiscal year 2016, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the Subcommittee and other members of Congress informed of any agency operational problems or deficiencies.

[This statement was submitted by Martin J. Dickman, Inspector General, Railroad Retirement Board.]

# NONDEPARTMENTAL WITNESSES

## PREPARED STATEMENT OF ACADEMYHEALTH

AcademyHealth is pleased to offer this testimony regarding funding for Federal agencies that support health services research and health data, including the Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics (NCHS), and the National Institutes of Health (NIH). AcademyHealth's mission is to support research that leads to accessible, high value, high-quality healthcare; reduces disparities; and improves health. We represent the interests of more than 5,000 health services researchers, policy analysts, and practitioners that produce and use health services research to improve our Nation's health and the performance of the healthcare and public health systems. For fiscal year 2016, we recommend funding levels of $375 million for AHRQ, $172 million for NCHS, and at $32 billion for NIH.

The United States spent $2.9 trillion—17.4 percent of our economy—on healthcare in 2013. Finding new ways to get the most out of every healthcare dollar is critical to our Nation's long-term fiscal health. Like any corporation making sure it is developing and providing high quality products, the Federal Government—as the Nation's largest healthcare purchaser—has a responsibility to get the most value out of every taxpayer dollar it spends on Medicare, Medicaid, Children's Health Insurance Program, and veterans' and service members' health.

Health services research is our Nation's R&D enterprise for health improvement. Just as medical research discovers cures for disease, health services research discovers cures for the health system (see Figure 1). This research diagnoses problems in healthcare and public health delivery and identifies solutions to improve outcomes for more people, at greater value. And while biomedical and clinical research discoveries can take years and even decades to reach patients, discoveries from health services research can be used now by patients, healthcare providers, public health professionals, hospitals, employers, and public and private payers to improve care today.

Put plainly, health services research helps Americans get their money's worth when it comes to healthcare. We need more of it, not less. Despite the positive impact health services research has had on the U.S. healthcare system, and the potential for future improvements in quality and value, the United States spends less than one cent of every healthcare dollar on this research; research that can help Americans spend their healthcare dollars more wisely and make more informed healthcare choices.

AcademyHealth realizes the pressure Congress and the administration face to reduce the national debt. We respectfully ask that the subcommittee consider the value of health services research in achieving that goal, and to strengthen its capacity to address the pressing challenges America faces in providing access to high-quality, efficient care. The following list summarizes AcademyHealth's fiscal year 2016 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

*Agency for Healthcare Research and Quality*

AHRQ is the only Federal research agency with the sole purpose of producing evidence to make healthcare safer; higher quality; more accessible, equitable, and affordable; and to ensure that the evidence is understood and used. AHRQ funds health services research and healthcare improvement programs in universities, medical centers, research institutions, hospitals, health clinics, and medical practices that are transforming people's health in communities in every State around the Nation. The science funded by AHRQ provides consumers and their healthcare professionals with valuable evidence to make healthcare decisions. For example, medical societies use AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes and rheumatoid arthritis. These evidence-informed recommendations give physicians a foundation for describing what the best care looks

like, so millions of patients living with these and other conditions may determine what the right care might be for them.

AHRQ's research also provides the basis for strategies that prevent medical errors, reduce hospital-acquired infections (HAI), and improve patient experiences and outcomes. For example, AHRQ's evidence-based Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP)—first applied on a large scale in 2003 across more than 100 ICUs across Michigan—saved more than 1,500 lives and nearly $200 million in the program's first 18 months. The protocols have since been expanded to hospitals in all 50 States, the District of Columbia, and Puerto Rico to continue the national implementation of this approach for reducing HAIs.

AcademyHealth joins the Friends of AHRQ—an alliance of health professional, research, consumer, and employer organizations that support the agency—in recommending $375 million in budget authority for AHRQ in fiscal year 2016.

*National Center for Health Statistics*

NCHS is the Nation's principal health statistics agency. Housed within the Centers for Disease Control and Prevention (CDC), it provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as a gold standard for data collection around the world. AcademyHealth appreciates the subcommittee's support of NCHS in recent years. Such efforts have allowed NCHS to reinstate data collection and quality control efforts, continue the collection of vital statistics, and modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—an alliance of health professional, research, consumer, industry, and employer organizations that support the agency—in recommending an overall funding level of $172 million for NCHS in fiscal year 2016. This includes $160 million in budget authority and $12 million in mandatory Prevention and Public Health Fund. This funding level will support the agency's core data collection activities, as well as new initiatives to enhance death data timeliness and security, restore survey expansions to better assess access to and utilization of healthcare services.

*National Institutes of Health*

NIH spends approximately $1 billion on health services research annually—roughly 3 percent of its entire budget—making it the largest Federal sponsor of health services research. We join the research community in seeking at least $32 billion for NIH in fiscal year 2016. NIH has an important role in the Federal health services research continuum, and is well-positioned to ensure that discoveries from clinical trials are effectively translated into healthcare delivery. AcademyHealth supports efforts to help NIH foster greater coordination of its health services research investment among its institutes and across other Federal agencies to avoid duplication.

AcademyHealth also recommends that the Clinical and Translational Science Awards (CTSA) through the National Center for Advancing Translational Sciences (NCATS) sustain investment in the full spectrum of translational research (T1–T4). The CTSA program enables innovative research teams to speed discovery and advance science aimed at improving our Nation's health. The program encourages collaboration in solving complex health and research challenges and finding ways to turn their discoveries into practical solutions for patients. Finally, AcademyHealth supports continued investment by NIH and its many Institutes and Centers in dissemination and implementation research. This research helps us understand which approaches work to improve population health.

In conclusion, the accomplishments of the field of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee gives strong consideration to our fiscal year 2016 funding recommendations for the Federal agencies funding health services research and health data. If you have questions or comments about this testimony or wish to know more about health services research, please contact Dr. Lisa Simpson, President and CEO of AcademyHealth.

FIGURE 1: THE HEALTH RESEARCH CONTINUUM

These components of the health research continuum work in concert, and each plays an essential role—any one type of research on its own cannot effectively or appreciably improve health. Take heart disease as one example ...

| | | | |
|---|---|---|---|
| Basic research discovered the contributions of elevated blood pressure, elevated cholesterol, and tobacco use to heart disease. | Clinical research determined which treatments were safe and effective to treat hypertension, hypercholesterolemia, tobacco addiction, and to prevent and treat heart disease, in general. | Population-based research identified strategies to reduce the risks of heart disease in communities through non-medical interventions, such as reduction of trans fats in food and tobacco control measures to reduce smoking. | Health services research determined how to best deploy these discoveries to achieve the best health outcomes. This research helped identify who had the least access, what barriers existed, and how to mitigate them. This research also led to the development of quality measures that are now used to report on the quality of cardiac care. |

Source: AHRQ: 15 Years of Transforming Care and Improving Health, AcademyHealth, Jan. 2014. Available at: http://academyhealth.org/files/AHRQReport2014.pdf.

[This statement was submitted by Dr. Lisa Simpson, President & CEO, AcademyHealth.]

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## Prepared Statement of the Academic Family Medicine

### FISCAL YEAR 2016 FUNDING REQUESTS

We urge the Committee to appropriate at least $71 million for the health professions program, Primary Care Training and Enhancement, authorized under Title VII, Section 747 of the Public Health Service Act, and appropriate $287 million for the National Health Service Corps (NHSC,) both under the jurisdiction of the Health Resources and Services Administration (HRSA.) In addition, we recommend the Committee fund the Agency for Healthcare Research and Quality (AHRQ) at no less than $375 million in base discretionary funding to support research vital to primary care.

The member organizations of the Council of Academic Family Medicine (CAFM) are pleased to submit testimony on behalf of programs under the jurisdiction of the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ). The programs we support in our testimony are ones that deliver an investment in our Nation's workforce and health infrastructure. They are a down payment on a U.S. healthcare system with a foundation of primary care that will produce better health outcomes and reduce the ever rising costs of healthcare. We understand that hard decisions must be made in these difficult fiscal times, but even in this climate, we hope the Committee will recognize that the production of a robust primary care workforce for the future is a necessary investment that cannot wait and will ultimately produce long term savings.

*Primary Care Training and Enhancement*

The Primary Care Training and Enhancement Program (Title VII, Section 747 of the Public Health Service Act) has a long history of providing indispensable funding for the training of primary care physicians. With each successive reauthorization, Congress has modified the Title VII health professions programs to address relevant workforce needs. The most recent authorization directs the Health Resources and Services Administration (HRSA) to prioritize training in the new competencies relevant to providing care in the patient-centered medical home model. It also calls for the development of infrastructure within primary care departments for the improvement of clinical care and research critical to primary care delivery, as well as innovations in team management of chronic disease, integrated models of care, and transitioning between healthcare settings.

As experimentation with new or different models of care continues, departments of family medicine and family medicine residency programs will need to rely even more on Title VII, Section 747, grants to help develop curricula and research training methods for transforming practice delivery. Some areas in need of support for future training include: training in clinical environments that are transforming or have transformed to include integrated care with other health professionals (e.g. behavioral health, care coordination, nursing, oral health); development and implementation of curricula to give trainees the skills necessary to build and work in interprofessional teams that include diverse professions outside of medicine; and development and implementation of curricula to develop leaders and teachers in practice transformation. Moreover, new competencies will be required for our developing health system. The Advisory Committee on Training in Primary Care Medicine and Dentistry December 2014 report states that "[r]esources currently available through Title VII, Part C, sections 747 and 748 have decreased significantly over the past 10 years, and are currently inadequate to support the [needed] system changes." [1]

In order to address some of these challenges, the Advisory Committee recommends that Congress increase funding levels for training under the primary care training health professions program, both in fiscal year 2016 and for the next 5 years. The current funding level (approximately $38.9 million) is not enough to allow for the pent up demand caused by reduced and stagnant funding levels. There has been a dearth of competitive grant cycles available since the last reauthorization, due to the lack of growth in funding for this program. More importantly, the vital work of these grants to help reform primary care education and the health delivery system needs to be prioritized and given an increase in funding dollars. In order to ensure that training keeps pace with delivery system reform, we must increase the availability of funding enough to allow for robust annual grant cycles.

Primary care health professions training grants under Title VII continue to have a profound impact on States across the country and are vital to the continued development of a workforce designed to care for the most vulnerable populations and meet the needs of the 21st century. We urge your continued support for this program and an increase in funding to $71 million in fiscal year 2016 to allow for a robust competitive funding cycle.

*National Health Service Corps*

The NHSC recruits and places physicians and medical professionals in health professional shortage areas to meet the need for healthcare in rural and medically underserved areas. The NHSC provides scholarships or loan repayments as incentives for medical students to enter primary care and to provide healthcare to underserved Americans. By addressing medical school debt burdens, the NHSC also ensures wider access to medical education opportunities.

Since in 1972, the NHSC has offered financial assistance to recruit and retain healthcare providers to meet the workforce needs of communities across the Nation designated as health professional shortage areas (HPSA). The Government Accountability Office (GAO–01–1042T) described the NHSC as "one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas." More than 40,000 providers have served in the NHSC since its inception. In fiscal year 2014, the NHSC had a field strength of 9,242 primary care clinicians. NHSC physicians and healthcare providers were placed in HPSAs serving patients in every State and territory.

This program has had widespread bipartisan support over the years. We are concerned that by not having funding in the appropriations baseline, the program could cease operations when the trust fund expires. Our total funding request would increase the field strength to over $15,000 Corps members providing help to those wishing to practice in primary care and who would serve nearly 16 million patients. We would like to ensure robust funding for this program which addresses the maldistribution of our healthcare workforce and enables many students from disadvantaged backgrounds to enter primary care while at the same time providing care to underserved individuals.

*Agency for Health Care Research and Quality (AHRQ)*

We are grateful that Congress included budget authority for AHRQ in the fiscal year 2015 omnibus funding bill, and would like to thank the committee for including it in the funding bill. This change strengthens the viability of an agency that is vital to the development of primary care research and implementation of such research into primary care practice around the country. The majority of research funding in the United States supports research of one specific disease, organ system, cellular,

[1] Http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf.

or chemical process—not for primary care. This is in spite of the fact that the overall health of a population is directly linked to the strength of its primary healthcare system. Primary care research includes: translating science into the practice of medicine and caring for patients, understanding how to better organize healthcare to meet patient and population needs, evaluating innovations to provide the best healthcare to patients, and engaging patients, communities, and practices to improve health. AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

There are six areas that we believe AHRQ excels at—and that are not available elsewhere in the biomedical research infrastructure: primary care research through Practice-based Research Networks (PBRNs), practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, mental and behavioral health provision in communities and primary care practices, and training future primary care investigators. Critical to the successful engagement and development of primary care research is the constraint of not having an adequate cadre of well-trained researchers. We believe there is a need to deliberately promote this training as a way to aid in the development of all the areas we have emphasized. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded.

Below are some examples of the work of AHRQ that have been instrumental in supporting primary care practice and patient safety:

—In fiscal year 2015, AHRQ has utilized much of its funding from the Patient Centered Outcomes Research (PCOR) trust fund on research to learn how best to incorporate PCOR best practices into actual primary care practices. Of the almost $55 million in PCOR funded grants, AHRQ awarded approximately $44 million for research related to small and medium practices, the rest is directed toward research related to large health systems. A critical piece of this effort is looking not just at how best to disseminate information to clinicians, but how to implement change in clinician practices. Research into implementation science, including what supports are needed, what facilitation is necessary, etc. are key areas the research will emphasize. While this is not discretionary funding, we highlight it to show how important the agency is to primary care practice.

—We are extremely pleased to find that one of AHRQ's new funding initiatives in the coming year is for research into multiple chronic conditions—a hallmark of primary care practice. These grants are directed to (1) provide clinicians with tools to develop integrated care plans that reflect patients' conditions, values, preferences, etc., and (2) data to examine the impact of integrated care plans and new care models on utilization and quality of care. Additionally, funding will be used for data collection to identify how healthcare teams are organized and if care and outcomes look different in team based practices, compared to traditional practices.

—We note that while AHRQ research is critically important to primary care, it is also important to the health and safety across the Nation in many care settings. Highlighting the success of AHRQ's patient safety initiatives, a 2014[2] report showed hospital care to be much safer in 2013 compared to 2010. The report noted a decline of 17 percent in hospital-acquired conditions. Additionally, the report enumerated a decline in harm to patients of over 1.3 million, 50,000 lives saved, and $12 billion in reduced health spending during that period.

Research related to the most common acute, chronic, and comorbid conditions that primary care clinicians treat is lacking. AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. This research is essential to create a robust primary care system for our Nation—one that delivers higher quality of care and better health while reducing the rising cost of care. Despite this need, little is known about how patients can best decide how and when to seek care, how to introduce and disseminate new discoveries into real life practice, and how to maximize appropriate care. This type of research requires sufficient funding for AHRQ, so it can help researchers address the problems confronting our health system today.

We recommend the Committee fund AHRQ at a base, discretionary level of at least $375 million for fiscal year 2015.

[This statement was submitted by Tom Campbell, MD, Chair, Council of Academic Family Medicine.]

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[2] Publication #15–0011–EF.

PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

Dear Chairman Blunt and Ranking Member Murray: On behalf of the Academy of Nutrition and Dietetics, thank you for the opportunity to submit comments for the fiscal year 2016 appropriations bill. The Academy, with 75,000 members throughout the Nation, is the world's largest organization of food and nutrition professionals, committed to improving the Nation's health through healthy and safe food choices. As Congress begins work on fiscal year 2016 appropriations, we strongly urge you to fully fund Federal nutrition programs, which will provide an investment that will help prevent costly healthcare expenses due to chronic diseases.

*Administration for Children and Families Funding*

The Academy supports the increased funding for Head Start by $1.5 billion, to a total of $10.1 billion. This funding level would ensure that every Head Start program serves children for a full school day and a full school year, as well as including a cost-of-living adjustment for all programs. Head Start's nutrition component provides and promotes nutritious eating and healthy habits along with engaging in nutrition education for children and families.

*Administration for Community Living Funding*

The Academy supports the President's fiscal year 2016 request for $874.5 million for the Title III Nutrition Programs of the Older Americans Act. We support the increases in funding for the Congregate Nutrition Services and for Home Delivered Meals, as well as the $20 million for new nutrition innovation demonstrations. We also support the $160 million request for the Nutrition Services Incentive Program (NSIP). These nutrition services help nearly 2.4 million older adults receive the necessary meals to help them stay healthy and decrease the risk for disability. The additional funds in fiscal year 2016 would support an estimated 208 million meals.

The Academy also supports the President's fiscal year 2016 request for $19 million for Preventative Health Services under the Older Americans Act. This program provides grants to States and Territories in order to support evidence-based activities that educate older adults about the importance of healthy lifestyles and promotes behaviors that can help to prevent or delay chronic disease and disability, thereby reducing the need for costly medical interventions. We also support the Administration's proposal of $8 million for Chronic Disease Self-Management Programs (CDSMP) within the Administration on Aging. CDSMP is a low-cost, evidence-based disease prevention model that engages older Americans to be able to manage their diseases, which improves their health statuses and reduces more costly care such as hospital care and readmissions. Seven out of ten deaths and more than three-quarters of all health expenditures for older adults are the result of chronic conditions such as diabetes, obesity, cancer, arthritis and depression that can be reduced with prevention programs.

Finally for older adults, the Academy supports the President's fiscal year 2016 request of $28.8 million for Elder Rights Support Activities, which will advance ACL's Elder Justice Initiative. Cases of elder abuse, neglect and exploitation are on the rise in this country. One study estimates that 14.1 percent of older adults face some sort of abuse. Elder abuse is a frightening threat to our elderly and their families, and increases the likelihood of the victim suffering an adverse health impact, including heart attacks, dementia, chronic disease, depression, and distress.

*Centers for Disease Control and Prevention Funding*

The Academy supports the continued promotion of public health and prevention programs demonstrated in the budget request of $7 billion to the Centers for Disease Control and Promotion (CDC). In particular, we applaud the $150 million to Diabetes State Programs, $10 million to the Diabetes Prevention Program, $130 million to Heart Disease and Stroke Prevention, and $4 million to the Million Hearts Initiative. We also support the request for $8 million for the Hospitals Promoting Breastfeeding program.

However, the Academy is respectfully concerned about the $140 million cuts to the Center for Chronic Disease Prevention and Health Promotion programs. Chronic diseases, due in part to lifestyle choices, account for seven out of ten causes of death in the U.S. As of 2012, almost half of adults had one or more chronic health conditions. In particular, we are strongly concerned about the $7.5 million cuts to the Division of Nutrition, Physical Activity and Obesity (DNPAO). This cut represents a significant cut in money aimed at primary prevention as compared to clinically-related concerns. This decrease in funding will also eliminate the High Obesity Rate Counties program, which sought to work with communities and local organizations to reduce obesity and related chronic diseases in areas with high adult obesity rates. These programs need to be fully funded in order to address the chronic diseases that

are putting stress on our healthcare system and decreasing our worker's productivity. We would encourage the Committee to invest in maintaining good health and help prevent future and more costly diseases.

*Food and Drug Administration Funding*

The Academy strongly supports the President's fiscal year 2016 request of $1.16 billion to the Food and Drug Administration's (FDA) Foods Program, with $109.5 million going to implementation of the Food Safety Modernization Act (FSMA). Separating these monies from the user fees is critical to implementation of important food safety measures to protect the public from preventable foodborne illnesses. This amount also represents a significant increase over fiscal year 2015 spending, and we urge you to meet this request.

HEALTH RESOURCES AND SERVICES ADMINISTRATION FUNDING

*National Institutes of Health Funding*

The Academy supports the President's fiscal year 2016 request of $31.1 billion for the National Institutes of Health (NIH). We respectfully request that $2.066 billion be appropriated to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), from which $478 million will go to the Division of Digestive Diseases and Nutrition. This program supports discovery, clinical and translational research, as well as targeted training, aimed at understanding the impact of nutrition on digestive diseases. These funding increases show a commitment to investing in nutrition research to prevent chronic diseases, and we applaud this commitment.

The Academy also supports the request for $24.7 million for the Office of Dietary Supplements (ODS) within the Office of the Director at NIH. ODS provides accurate and up-to-date scientific information on dietary supplements to researchers, healthcare providers, and the public, and provides vital research on the role of dietary supplements interventions for certain conditions.

Please feel free to contact me with any questions on these important issues. Thank you again for your time.

[This statement was submitted by Mary Pat Raimondi, MS, RD, Vice President, Strategic Policy and Partnerships.]

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PREPARED STATEMENT OF THE ACADEMY OF NUTRITION AND DIETETICS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Academy of Nutrition and Dietetics (the Academy) is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. The Academy represents 75,000 members, comprised of registered dietitian nutritionists (RDNs), dietetic technicians, registered, and other dietetics professionals holding undergraduate and advanced degrees in nutrition and dietetics. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS).

MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed RDN outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

BETTER HEALTH OUTCOMES

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

LOWER HEALTHCARE COSTS

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] iv Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

IMPROVED PATIENT SATISFACTION

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

CONCLUSION

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

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[8] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

[This statement was submitted by Mary Pat Raimondi, MS, RD, Vice President, Strategic Policy and Partnerships, Academy of Nutrition and Dietetics.]

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PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of more than 200 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. We appreciate the opportunity to submit this statement in support of strengthening the Federal investment in biomedical, behavioral, social, and population-based research conducted and supported by the National Institutes of Health (NIH).

The Ad Hoc Group is deeply grateful to the Subcommittee for its long-standing and bipartisan leadership in support of NIH. We continue to believe that science and innovation are essential if we are to continue to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy.

Despite increases provided in each of the past 2 fiscal years, the NIH budget remains lower than it was in fiscal year 2012 in actual dollars. Additionally, since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation. While the President's fiscal year 2016 budget represents a much needed next step by increasing NIH funding above biomedical inflation, the Ad Hoc Group's members believe that the ongoing and emerging health challenges confronting the United States and the world, and the unparalleled scientific opportunities to address these burdens demand a funding level of at least $32 billion in fiscal year 2016. We look forward to working with Congress and the Administration to achieve this goal through the annual appropriations process.

The Ad Hoc Group also urges Congress and the Administration to work in a bipartisan manner to end sequestration, the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

*NIH: A Public-Private Partnership to Save Lives and Provide Hope*

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. Nearly 84 percent of the NIH's budget is competitively awarded through more than 55,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every State.

The Federal Government has an essential and irreplaceable role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge basic research necessary to yield new innovations and technologies of the future.

Research funded by NIH has contributed to nearly every medical treatment, diagnostic tool, and medical device developed in modern history, from a new treatment for cystic fibrosis to an awareness campaign that resulted in a dramatic decrease in the number of infants lost to Sudden Infant Death Syndrome to a vaccine to prevent cervical cancer. We are all enjoying longer, healthier lives thanks to the Federal Government's wise investment in this lifesaving agency. Examples of recent breakthroughs made by NIH-supported scientists include:

—A Phase I clinical trial to assess the safety, efficacy, and immunogenicity of an intramuscular Ebola vaccine co-created by NIH and GlaxoSmithKline. Results indicated this vaccine was well-tolerated and elicited anti-Ebola antibody responses in healthy adult volunteers. Another promising vaccine candidate began Phase I trials in October 2014 in thirty-nine healthy volunteers. The vesicular stomatitis virus (VSV) Ebola vaccine studies are being conducted in collaboration with the U.S. Department of Defense and NewLink Genetics Corp. A parallel study is ongoing at the Walter Reed Army Institute of Research to evaluate in real time the vaccine's safety when provided at different dosages and compare the immune responses induced by one injection versus two.

—NIH-supported scientists contributed to the first comprehensive 3–D atlas of gene expression in the developing human brain as part of a larger project to profile gene expression throughout the course of brain development. The results provide a powerful map to link areas of the brain to genes tied to

neurodevelopmental disorders and human-specific brain functions. This resource will help reveal the early roots of brain-based disorders, such as autism and schizophrenia.

—A new technology called CRISPR (clustered regularly interspaced short palindromic repeats) is allowing scientists to specifically target genes for deletion, addition, activation, or suppression in what amounts to performing their own genetic microsurgery. Using this system, NIH-supported researchers have altered DNA in human cells, rats, mice, zebrafish, bacteria, fruit flies, yeast, nematodes, and crops. This wide-ranging applicability makes the technology valuable for numerous applications, including conducting large-scale genetic screens in mammalian cells (recently validated by NIH-funded scientists), as well as the promise of new treatments for genetic diseases.

—The Recovery After an Initial Schizophrenia Episode (RAISE) initiative aims to prevent long-term disability in individuals with serious mental illness through early intervention. RAISE comprises two complementary efforts: the Early Treatment Program, which is continuing to follow patients for an additional three to 4 years to investigate the long-term impact of early intervention; and, the Connection Program, which successfully integrated team-based, multi-element services targeting the first episode of psychosis (FEP) in mental health systems in New York and Maryland, and is now evaluating promising strategies for reducing the duration of untreated psychosis among persons experiencing FEP. NIH has collaborated with the Substance Abuse and Mental Health Services Administration to translate early RAISE findings into guidance for States regarding evidence-based approaches to FEP treatment, and assembled a broad range of training resources developed through RAISE for use by State-supported Community Mental Health Centers.

—Current treatments for Hemophilia, a rare bleeding disorder in which the blood fails to clot normally, require a lifetime of frequent injections, often twice a week, of an expensive clotting factor called factor IX to restore normal clotting. A recent NIH-funded clinical trial used gene therapy to reprogram the body's own cells to produce factor IX using special viruses that have been engineered not to cause diseases. When adult men with hemophilia were given an intravenous dose of the therapy, patients who received the higher dose improved markedly, with the effects lasting for the entire 4-year period of the study.

—NIH-funded researchers developed a 3–D scaffold that guides the development of stem cells into specialized cartilage-producing cells, an approach that could allow for the creation of orthopedic implants to replace cartilage in patients with arthritis. This approach could allow for implants that restore function to a joint immediately and drive development of a mature, viable tissue replacement.

—Lung cancer solid tumors are particularly difficult to detect. NIH-funded scientists used genetic data from the Cancer Genome Atlas (TCGA) database to develop a molecular signature for non-small-cell lung cancers. Using this signature and samples from patients with non-small-cell lung cancer, researchers designed a highly sensitive DNA-based blood test that accurately identified all patients with advanced lung cancer, as well as half of patients whose lung cancer was in its earliest stage. This simple blood test was shown to detect solid tumors rapidly and accurately, track their progression over time, and could possibly predict their response to treatment. Efforts are now underway to conduct clinical trials to measure this technique and its potential to improve the detection of many different kinds of solid tumors.

—TB is treated with antibiotic drugs, but the bacteria that cause TB have evolved to become resistant to these medications. An NIH-funded research team analyzed the structure of an existing antibiotic and made various chemical modifications to create a new class of agents that were active against both multidrug-resistant (MDR) and extensively drug-resistant (XDR) bacteria. These compounds were not toxic in laboratory assays or in animals, and a subset of the compounds was highly effective against TB infections in mice. This work represents an initial step in the development of a new class of drugs to treat TB.

—Sickle cell disease is a genetic blood disorder that causes defective hemoglobin, the protein in red blood cells that carries oxygen. It affects millions worldwide, including approximately 100,000 people in the United States. The disease disproportionately affects African Americans, and current treatments are largely ineffective. A recent NIH-funded study showed that a stem cell transplant from a healthy relative could reverse the disease in 87 percent of patients. NIH research also is working towards a drug therapy for sickle cell disease. Through a collaborative agreement, researchers at the National Center for Advancing

Translational Sciences' (NCATS) Therapeutics for Rare and Neglected Diseases (TRND) program and AesRx, a biopharmaceutical company, developed a drug candidate to treat sickle cell disease that specifically targets the underlying disease mechanism. The success of a Phase II clinical trial to evaluate safety and effectiveness has resulted in the recent acquisition of the drug by a pharmaceutical company that will advance the clinical development activities required for regulatory approval and commercialization.

For patients and their families, NIH is the "National Institutes of Hope."

NIH is the world's premier supporter of merit-reviewed, investigator-initiated basic research. This fundamental understanding of how disease works and insight into the cellular, molecular, and genetic processes underlying life itself, including the impact of social environment on these processes, underpin our ability to conquer devastating illnesses. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also supporting the translational efforts necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

*Stagnant Funding Threatens Scientific Momentum*

Over the past decade, NIH has lost more than 23 percent of its budget after inflation, significantly impacting the Nation's ability to sustain the scientific momentum that has contributed so greatly to our Nation's health and our economic vitality. The leadership and staff at NIH and its Institutes and Centers has engaged patient groups, scientific societies, and research institutions to identify emerging research opportunities and urgent health needs, and has worked resolutely to prioritize precious Federal dollars to those areas demonstrating the greatest promise. At the same time, a continued erosion of our national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

Perhaps the most destructive and long-lasting impact of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration. Additional funding is needed if we are to strengthen our Nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

*NIH is Critical to U.S. Competitiveness*

Our country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and sequestration cuts, which jeopardize our competitive edge in an increasingly innovation-based global marketplace.

Other countries have recognized the critical role that biomedical science plays in innovation and economic growth and have significantly increased their investment in biomedical science. This shift in funding is creating an innovation deficit in the U.S. and raises the concern that talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To maintain our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

*NIH: An Answer to Challenging Times*

The research supported by NIH drives not only medical progress but also local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. According to a report released by United for Medical Research, a coalition of scientific advocates, institutions and industries, in fiscal year 2011, NIH-funded research supported an estimated 432,000 jobs all across the United States and generated more than $62 billion in new economic activity.

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation's economy and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe strongly that NIH is an essen-

tial part of the solution to the Nation's economic restoration. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

Therefore, the Ad Hoc Group for Medical Research recommends that NIH receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in medical research.

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PREPARED STATEMENT OF THE AIDS ALLIANCE FOR WOMEN, INFANTS, CHILDREN, YOUTH & FAMILIES

Dear Chairman Blunt and Members of the Subcommittee: AIDS Alliance for Women, Infants, Children, Youth & Families was founded in 1994 to help respond to the unique concerns of HIV-positive and at-risk women, infants, children, youth, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. We are pleased to offer written testimony for the record in opposition of the fiscal year 2016 budget proposal consolidating Ryan White Part D funding into Part C and in support of maintaining Part D of the Ryan White Program as part of the fiscal year 2016 Labor, Health and Human Services, Education, and Related Agencies appropriations measure. This testimony also has the support of the Elizabeth Glaser Pediatric AIDS Foundation.

*Ryan White Part D Funding Request*

Sufficient funding of Ryan White Part D, the program funded solely to provide family-centered primary medical care and support services for women, infants, children, and youth with HIV/AIDS has successfully identified, linked, and retained these vulnerable populations in much needed care and treatment, resulting in optimum health outcomes. We thank the Subcommittee for its continuous support of Ryan White Part D Programs, providing $75,297,000 million to the program in fiscal year 2015, restoring dedicated funding eliminated in the President's fiscal year 2015 budget proposal. While the AIDS Alliance for Women, Infants, Children, Youth & Families understands that these are difficult economic times, we are requesting the Subcommittee to maintain its commitment to the Ryan White Part D program and again restore its dedicated funding eliminated in the President's fiscal year 2016 budget proposal and increase Ryan White Part D funding by $9.9 million in fiscal year 2016.

*Ryan White Part D Background and History*

Over concerns with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing $5 million for the Pediatric AIDS Demonstration Projects in the fiscal year 1988 budget. Those demonstration projects became part of the Ryan White CARE Act of 1990 and today are known as Ryan White Part D and have served approximately 200,000 women, infants, children, youth and family members. Since the program's inception in 1988, Part D programs have been and continue to be the entry point into medical care for women and youth. The family-centered primary medical and supportive services provided by Part D are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth. Part D programs are the only perinatal clinical service available to serve HIV-positive pregnant women and HIV exposed infants, when payments for such services are unavailable from other sources. Ryan White Part D programs have been extremely effective in bringing the most vulnerable populations into and retained in care and is the lifeline for women, infants, children and youth living with HIV/AIDS. The Part D programs continue to be instrumental in preventing mother-to-child transmission of HIV and for ensuring that women, including HIV- positive pregnant women, HIV exposed infants, children and youth have access to quality HIV care. The program is built on a foundation of combining medical care and essential support services that are coordinated, comprehensive, and culturally and linguistically competent. This model of care addresses the healthcare needs of the most vulnerable populations living with HIV/AIDS in order to achieve optimal health outcomes.

In 2012, Part D provided funding to 114 community-based organizations, academic medical centers and hospitals, federally qualified health centers, and health departments in 39 States and Puerto Rico. These federally, directly-funded grantees provide HIV primary care, specialty and subspecialty care, oral health services, treatment adherence monitoring and education services pertaining to opportunities to participate in HIV/AIDS-related clinical research. These grantees also provide support services which include case management (medical, non-medical, and family-

centered); referrals for inpatient hospital services; treatment for substance use, and mental health services. Part D grantees receive assistance from other parts of the Ryan White Program that help support HIV testing and linkage to care services; provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model. This model has continuously provided comprehensive quality healthcare delivery systems that have been responsive to women, infants, children, youth and families for two decades.

*A Response to Women, Infants, Children, and Youth*

The Ryan White Program has been enormously successful in meeting its mission to provide life-extending care and services. Yet, even though we have made significant progress in decreasing HIV-related morbidity and mortality, much work remains to be done. While accounting for less than 5 percent of Ryan White direct care dollars (minus ADAP and Part F), Ryan White Part D programs have been extremely effective in bringing our most vulnerable populations into care and developing medical care and support services especially designed to reach women, children, youth, and families. Part D funded programs played a leading role in reducing mother-to-child transmission of HIV-from more than 2,000 newborn infections annually more than a decade ago to an estimated 187 in 2013 through aggressive efforts to reach out to pregnant women. Appropriate funding is critical to maintain and improve upon this success, as there are still approximately 8,000 HIV-positive women giving birth every year in the United States that need counseling, services and support to prevent pediatric HIV Infections. According to the CDC, youth aged 13–24 accounted for 26 percent of all new HIV infections in the U.S. in 2010. Most new HIV infections in youth (about 57 percent) occur in young Black gay and bisexual males. Of the new HIV infections among youth, 2,100 are among young women; two-thirds of these are among young Black women. Ryan White Part D programs are the entry point into medical care for many of these HIV positive youth and lead the Nation's effort in recruiting and retaining HIV positive youth to comprehensive medical care and support services. According to the Health Resources and Services Administration, more than 37 percent of women receiving medical care in Ryan White Programs do so through Part D. Additionally, Part D provides medical and supportive services to a large number of women over 50 who are heading into their senior years as HIV survivors which is a testament to the high standard of care provided to Ryan White Part D programs. Support and care through the Ryan White Part D program was and continues to be funding of last resort for the most vulnerable women and children, who often have fallen through the cracks of other public health safety nets. Full implementation of the Affordable Care Act (ACA), along with continuation of the Ryan White Program will dramatically improve health access and outcomes for many more women, infants, children, and youth living with HIV disease.

*Proposed Consolidation*

The medical and supportive services provided by Ryan White Part D are unique and are not currently being provided by other parts of the Ryan White Program, including Ryan White Part C. These services are uniquely tailored to address the needs of women, including HIV positive pregnant women, HIV exposed infants, children and youth living with HIV/AIDS. The proposed consolidation of Part D funding into Part C in the Federal budget would eliminate a strong safety net for our most vulnerable populations and weaken the systems of care Part D programs have created and invested in for more than 25 years. Furthermore, the loss of Part D funds in some community areas would profoundly impact access to comprehensive HIV care and treatment for women, infants, children and youth. Many of the population served by Part D will be lost or never enter into care thus increasing the existing gaps in the HIV Care Continuum. Moreover, major program changes that are this controversial should be left to Congress and should not be done through the appropriations process.

*Conclusion*

While we recognize the need to reduce administrative burdens associated with the overall operational aspects of Ryan White programs , the elimination of dedicated funding for Ryan White Part D in fiscal year 2015 and fiscal year 2016, and the proposed Part C/D consolidation would undoubtedly destabilize existing models of care created to address the unique needs of women, infants, children, and youth living with HIV/AIDS and jeopardizes the success of retaining these most vulnerable populations in life-saving HIV/AIDS care and treatment ensuring achieved and maintained viral load suppression. If we believe that one day we will realize an

"AIDS-free generation," then surly we know how essential it is to maintain the Ryan White Program and all of its Parts.

AIDS Alliance for Women, Infants, Children, Youth & Families urges the Committee to reject the President's fiscal year 2016 budget proposal to eliminate dedicated funding for Ryan White Part D and move the funding to Part C, and respectfully request that the Committee include language in the appropriations bill attesting to such. Without the Ryan White Part D program, many of these medically-underserved women, infants, children and youth would not receive the vital primary care and support services provided to them for the last two decades.

On behalf to the women, infants, children, and youth living with HIV/AIDS and the 114 Ryan White Part D funded programs across the country that serve them we sincerely thank you for all that you do to ensure that these populations receive the much needed primary care and treatment needed to sustains their lives.

[This statement was submitted by Dr. Ivy Turnbull, Deputy Executive Director, Aids Alliance for Women, Infants, Children, Youth & Families.]

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PREPARED STATEMENT OF THE AIDS PROJECT RHODE ISLAND

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

AIDS Project Rhode Island is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we served 1,249 people just last year at our Afia Center pantry. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way

by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

BETTER HEALTH OUTCOMES

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
—More ER visits[4] & increased morbidity and mortality[5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

LOWER HEALTHCARE COSTS

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

IMPROVED PATIENT SATISFACTION

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

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—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]
—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]
—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

CONCLUSION

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Stephen R. Hourahan, Executive Director, AIDS Project Rhode Island.]

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PREPARED STATEMENT OF AIDS SERVICES FOUNDATION ORANGE COUNTY

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

AIDS Services Foundation Orange County and its Orange County HIV/AIDS Advocacy Team are part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In Orange County, we provide 5,100 food pantry orders (equivalent to 244,800 meals) and 69,550 cans of nutritional supplements such as Ensure annually to low income, disabled HIV+ individuals. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

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[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

—More ER visits [4] & increased morbidity and mortality [5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.
—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]
—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines. [12]
—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital

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to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Marc Marger, Director of Support Services, Chair of Orange County HIV/AIDS Advocacy Team, AIDS Services Foundation Orange County.]

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## PREPARED STATEMENT OF THE AIDS UNITED

As the committee begins its important deliberations on the fiscal year 2016 Labor, Health and Human Services, Education and Related Agencies (Labor HHS)appropriation bill, we thank you for your continued commitment to addressing HIV/AIDS in the United States. We are close to a time when we can achieve the goals of the National HIV/AIDS Strategy and move towards an AIDS free generation but only if the Federal Government continues to commit the necessary resources. We appreciate that you have recognized this need in the past and ask that you continue to increase funding for domestic HIV/AIDS programs as you formulate the fiscal year 2016 budget and appropriation measures.

Unfortunately, due to sequestration and other budget constraints, domestic HIV/AIDS programs and other non-defense discretionary programs have been cut in recent years, even as new HIV infections continue at 50,000 per year and the number of people needing care and treatment increase. For example, since fiscal year 2012, the Ryan White HIV/AIDS Program has been cut by $73 million, HIV prevention at the Centers for Disease Control and Prevention (CDC) has dropped by $28 million and AIDS research at the National Institutes of Health (NIH) by $60 million.

As you prepare the fiscal year 2016 appropriations LHHS bill we ask that you maintain the Federal Government's commitment to safety net programs that protect the public health, such as the Ryan White HIV/AIDS Program. In order to prevent new infections, we ask that you adequately fund HIV prevention programs at the CDC and throughout the Department of Health and Human Services (HHS), as well as AIDS research at the NIH so that we may find a cure and address other research priorities. Below are the specific discretionary programs we ask you to support with increased resources, along with the accompanying justification.

*The Ryan White HIV/AIDS Program*

Early and reliable access to HIV care and treatment is cost effective and helps people with HIV live healthy and productive lives. Research has found that when people with HIV are on treatment and the virus is suppressed, the chance of HIV transmission is reduced to almost zero. The Ryan White HIV/AIDS Program is a system of care that provides medications, medical care, and essential coverage completion services to approximately 536,000 low-income, uninsured, and underinsured individuals living with HIV/AIDS. With the number of people living with HIV/AIDS at 1.2 million, the demands on the program, now reaching 60 percent of all people diagnosed with HIV in the U.S., continue to grow while many needs remain unmet.

The Ryan White Program, as a payer of last resort, now works in conjunction with Medicaid, Medicare, and the Affordable Care Act (ACA) helping with out-of-pocket costs and supports access to critical medical and services and coverage completion not covered by traditional health insurance. The Ryan White Program also will continue to be the primary source of HIV/AIDS care and treatment for the millions who will not be covered by the ACA, including low-income people who live in non-Medicaid expansion States. Sustained funding of primary care, medications, and coverage completion services in the Ryan White Program will continue to be necessary for those who currently have coverage and are underinsured. We urge you to main-

tain all parts of the program. We also urge you to oppose the Administration's proposal in the recent fiscal year 2016 budget to consolidate Parts C and D, a proposal that Congress rejected last year. Any such major changes to the program should be made through the reauthorization process.

As described above, funding for the Ryan White Program is critical to improving health coverage and outcomes for people living with HIV, therefore, we urge you to fund the Ryan White Program at a total of $2.45 billion in fiscal year 2016, an increase of $136 million over fiscal year 2015, distributed in the following manner:

—Part A: $687 million
—Part B (Care): $437 million
—Part B (ADAP): $943 million
—Part C: $225 million
—Part D: $85 million
—Part F/AETC: $35 million
—Part F/Dental: $18 million
—Part F/SPNS: $25 million

*HIV Prevention*

*CDC HIV Prevention and Surveillance*

Although the United States has significantly reduced the number of infections over 30 years of fighting HIV, there still are 50,000 new infections annually and about 1 in 7 people living with HIV do not know they have the virus. Gay, bisexual, and other men who have sex with men (MSM) continue to be the most impacted by the epidemic and account for 66 percent of all new infections. Between 2008 and 2010, infections among MSM increased by 12 percent, and among MSM aged 13–24 years by 22 percent. Young people, particularly Black and Latino MSM, continue to be the most disproportionately affected by HIV, accounting for one in five new infections in 2012.

AIDS United was pleased to see the new funding announcement (FOA) for programs targeted to fight HIV among gay, bisexual men and transgender people announced on March 31. The FOA will target some funding for the newest prevention tool in the tool box pre-exposure prophylaxis (PrEP) for MSM and transgender people who are HIV-negative but at substantial risk, as well as ongoing medical care and antiretroviral treatment for people living with HIV.

While we are making progress in decreasing new infections among women, black women are still disproportionately affected, accounting for 64 percent of women infected in 2010. Black and Hispanic women ages 13–24 accounted for 82 percent of young women living with HIV in 2010 even though together they represent only about 30 percent of all women in this age group.

Investing in HIV prevention today translates into less spending in the future on care and treatment. We are at a critical juncture in the fight against HIV/AIDS we have the tools to end the epidemic, but we must invest the resources now to bring the vision of an AIDS free generation into reality. In order to achieve the goals of the National HIV/AIDS Strategy, which include reducing new infections, increasing knowledge of HIV-positive status, and reducing HIV transmission, funding for the CDC is needed to carry out its High-Impact Prevention activities.

For fiscal year 2016, we request an increase of $67 million over fiscal year 2015 for a total of $822.7 million for the CDC Division of HIV prevention and surveillance activities. [Note: This request does not include the request for DASH]

*Access to Sterile Syringes*

Numerous studies have shown that syringe exchange programs (SEP) are a cost-effective means to lower rates of HIV/AIDS and viral hepatitis, do not increase substance abuse (nor the use of illegal drugs) and help connect people to medical treatment, including substance abuse treatment. Unfortunately, a crisis of increased injection drug use, a result of prescription opioid addiction, has led to a 75 percent increase in new infections from 2010–2012 according to the CDC and the first indication of increases in HIV. On March 26th, Governor Mike Pence of Indiana declared a public health emergency in response to 79 cases of HIV related to injection drug use in 3 months in a county that normally experiences five or fewer cases of HIV in a year. In contrast, since Congress allowed Washington D.C. to scale up its own local syringe exchange program, there has been an 81 percent decrease in the number of newly diagnosed HIV cases related to injection drug use. In 2008, the first year of the scale up of DC's syringe exchange program, there were 109 cases, compared with 21 in 2012.

Syringe exchange, as part of a comprehensive health and prevention program could have helped to prevent the outbreak of HIV. In fact most SEPs provide comprehensive HIV services, prevention including HIV counseling and testing, reducing

sexual and drug use-related health risks, referral to drug addiction treatment, and referral to other medical and social services. Unfortunately, Congress re-imposed a ban on the use Federal funds for syringe exchange programs in fiscal year 2012 undercutting a potential source of funds for such a program. Ultimately this is a self-defeating policy leading to much higher HIV rates in the U.S. and a higher cost necessary to respond to the epidemic. For example in Indiana the lifetime cost for treatment alone of these 79 cases of HIV will be more than $33 million dollars and it's likely that more cases will be found. Most of these cases would have been averted at a much lower cost with syringe exchange. AIDS United strongly urges the committee to end the Federal ban on syringe exchange by restoring language to allow local public health or local law enforcement authorities to allow syringe exchange unless such local authorities deem a site to be inappropriate.

*HIV/AIDS Research at the National Institutes of Health*

Building on recent progress, robust support for HIV research must continue until better, more effective and affordable prevention and treatment regimens—and eventually a cure—are developed and universally available. For the U.S. to maintain its position as the global leader in HIV/AIDS research for the 35 million people globally and 1.2 million people living with HIV in the U.S., we must invest adequate resources in HIV research at the NIH. NIH research has produced promising recent advances, including the study of the prevention effects of treatment, improved treatment programming and the first partially effective HIV vaccine. In order to realize similar breakthroughs in the future and improve the HIV care continuum, continued robust AIDS research funding is essential.

Consistent with the most recent Trans-NIH AIDS Research By-Pass Budget Estimate for fiscal year 2013, we ask that you request $3.6 billion for HIV research at the NIH, an increase of $600 million over fiscal year 2015.

AIDS United looks forward to a positive outcome for the funding request for HIV/AIDS domestic programs and we thank you for your continued leadership and support of these critical programs for so many people living with HIV, and the organizations and communities that serve them nationwide.

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PREPARED STATEMENT OF CYNTHIA J. ALLEN

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE ALLIANCE FOR CHILDHOOD CANCER AND THE COALITION AGAINST CHILDHOOD CANCER

Dear Senate Appropriations Committee: The undersigned childhood cancer organizations, consisting of patient advocacy groups, healthcare professionals and scientific organizations, represent over 10 million Americans who care deeply about childhood cancer. We want to thank you both for the opportunity to enumerate our funding priorities and to make specific requests for report language related to childhood cancer.

*NIH and NCI Funding*

We join with the leading national cancer organizations in requesting the following funding levels for medical research:

—$33 billion for the National Institutes of Health (NIH)

—$5.4 billion for the National Cancer Institute (NCI)

*Childhood Cancer Funding*

Within these funds, we are committed to working with Congress and the National Institutes of Health to ensure that childhood cancer becomes a higher priority. Each year in the U.S. there are an estimated 15,780 children who are diagnosed with cancer. Approximately 1 in 285 children in the U.S. will be diagnosed with cancer before their 20th birthday. Globally there are more than 250,000 children diagnosed with cancer each year. Cancer remains the most common cause of death by disease for children in America.

Great advances have been made in developing better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for some kids there is no hope for a cure. Two-thirds of children treated for childhood cancer will suffer long-term effects from treatment including loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

In an effort to ensure that childhood cancer is a top priority for the NIH, we respectfully request that the following report language be included in the fiscal year 2016 Labor, Health & Human Services, Education and Related Agencies Appropriations bill.

*National Cancer Institute—Report Language*

The Committee encourages NCI to continue its important investments in pediatric oncology clinical trials, including clinical studies for children with brain tumors, and development of the novel pediatric "MATCH" study, as well as the important pediatric preclinical testing program evaluating new agents for treating pediatric malignancies. The Committee supports NCI's longstanding investment in the Childhood Cancer Survivor Study and encourages continued childhood cancer survivorship research efforts.

*National Institutes of Health: Office of the Director—Report Language*

*Background*.—The Gabriella Miller Kids First Research Act (Public Law 113–94) authorized a pediatric research initiative through the National Institutes of Health. The total funding for research would come to $126 million over 10 years to the NIH Director's Common Fund. The Act was named after Gabriella Miller, who died in 2013 as a result of pediatric cancer.

The Common Fund is supported as a set-aside within the Office of the Director, which includes $12,600,000 to support pediatric research as authorized in the Gabriella Miller Kids First Research Act. The Committee encourages the NIH to prioritize research relating to childhood cancer within the Kids First program.

*National Cancer Institute: Office of Cancer Survivorship—Report Language*

The Committee recognizes the vital work preformed by the Office of Cancer Survivorship. However, it has been brought to the Committee's attention that pediatric cancer has unique needs that need to be addressed. Therefore the Committee requests a report that outlines steps that could be taken to focus resources and attention to the youngest of cancer survivors.

Sincerely,

Alliance for Childhood Cancer
Coalition Against Childhood Cancer (CAC2)
3/32 Foundation
A Kids' Brain Tumor Cure Foundation
American Brain Tumor Association
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Pediatric Surgical Association
American Society of Pediatric Hematology/Oncology (ASPHO)
Andrew McDonough B+ Foundation
Arms Wide Open Childhood Cancer Foundation
Association of Pediatric Hematology/Oncology Nurses (APHON)
Association of Pediatric Oncology Social Workers (APOSW)
Bear Necessities Pediatric Cancer Foundation
Because of Ezra
Braden's Hope for Childhood Cancer
Brooke's Blossoming Hope for Childhood Cancer Fund
Caleb's Crusade Against Childhood Cancer
CancerFree Kids
Cancer Support Community
Chai Lifeline
Chase After a Cure
Childhood Cancer Guides
Children's Brain Tumor Foundation
Children's Cause for Cancer Advocacy
Children's Neuroblastoma Cancer Foundation
Children's Oncology Group
Christina Renna Foundation Inc.
CJ's Journey
ConKerr Cancer
Crosby's Fund
Cure Childhood Cancer, Inc.
Cure4Cam Childhood Cancer Foundation
CureSearch for Children's Cancer
Curing Kids' Cancer
DC Candlelighters
Dragon Master Foundation
Ethan Jostad Foundation
Evan's Victory Against Neuroblastoma Foundation
Flashes of Hope
Francesco Loccisano Memorial Foundation/Frankie's Mission
Friends of Cathryn Foundation
Have Faith Be Strong
Hope & Heroes Children's Cancer Fund
I Care I Cure Childhood Cancer Foundation
Jeff Gordon Children's Foundation
Jeremy Cares Inc.
Journey4ACure
Kids' Cancer Research Foundation
Kids v Cancer
Koontz Oncology Consulting LLC
Leukemia and Lymphoma Society
Luck2Tuck Foundation
Make Some Noise: Cure Kids Cancer Foundation, Inc.
Making Headway Foundation
Martin Truex Jr Foundation
Mattie Miracle Cancer Foundation
Max Cure Foundation
Max's Ring of Fire
Melina's White Light
Morgan Adams Foundation
Nathan's Hope
National Brain Tumor Society
National Children's Cancer Society
National Coalition for Cancer Survivorship
Noah's Light Foundation
Northwest Indiana Cancer Kids Foundation
Open Hands Overflowing Hearts
Pediatric Brain Tumor Foundation
Pediatric Cancer Foundation (Mamornek, NY)
Pediatric Cancer Foundation (Tampa, Fla.)
People Against Childhood Cancer (PAC2)
PJs for Patients
Precious Jules Childhood Cancer Foundation
Rally Foundation for Childhood Cancer Research
St. Baldrick's Foundation
Sammy's Superheroes

Sarcoma Foundation of America
Smashing Walnuts Foundation
Society of Pediatric Psychology
Solving Kids' Cancer
Steven G AYA Cancer Research Fund
Tay-Bandz/Kids Curing Cancer
Team G Foundation
TeamConnor Childhood Cancer Foundation
Tennessee Cancer Coalition—Childhood Committee
The Nicolas Conor Institute (TNCI)
The Truth 365
This Star Won't Go Out
West Virginia Kids Cancer Crusaders
Zoe4Life
Plus 24 individual members of CAC2

[This statement was submitted by Danielle Leach, Alliance for Childhood Cancer, and Vickie Buenger, Coalition Against Childhood Cancer.]

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## PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

The Alzheimer's Association appreciates the opportunity to comment on the fiscal year 2016 appropriations for Alzheimer's disease research, education, outreach and support at the U.S. Department of Health and Human Services.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. As the world's largest nonprofit funder of Alzheimer's research, the Association is committed to accelerating progress of new treatments, preventions and, ultimately, a cure. Through our funded projects and partnerships, we have been part of every major research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer's and reaches millions of people affected by Alzheimer's and their caregivers.

### ALZHEIMER'S IMPACT ON THE AMERICAN PEOPLE AND THE ECONOMY

In addition to the human suffering caused by the disease, Alzheimer's is creating an enormous strain on the healthcare system, families and Federal and State budgets. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over five million Americans are living with Alzheimer's, with 200,000 under the age of 65.

A Federal commitment can lower costs and improve health outcomes for people living with Alzheimer's today and in the future. By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the Federal Government. Leadership from the Federal Government has helped to lower the number of deaths from other major diseases like heart disease, HIV/AIDS, many cancers, heart disease and stroke. While those deaths have declined, deaths from Alzheimer's have increased 71 percent between 2000 and 2013.

Alzheimer's is the most expensive disease in America. In fact, a study funded by the National Institutes of Health (NIH) in the New England Journal of Medicine confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed $1.1 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the Federal budget.[1] The expense involved in caring for those with Alzheimer's is not just a long-term problem. As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

Due to these projected increases, the graying of America threatens the bankrupting of America. Caring for people with Alzheimer's will cost all payers—Medicare, Medicaid, individuals, private insurance and HMOs—$20 trillion over the next 40 years, enough to pay off the national debt and still send a $10,000 check to every man, woman and child in America. In 2015, America will spend an estimated $226 billion in direct costs for those with Alzheimer's, including $153 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alz-

[1] 2015 Alzheimer's Diesease Facts and Figures: http://www.alz.org/facts/downloads/facts__figures__2015.pdf.

heimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher.[2]

A primary reason for these costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidity that complicate the management of the condition(s) and increase costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes. Nearly 30 percent of people with Alzheimer's or another dementia who have Medicare also have Medicaid coverage, compared with 11 percent of individuals without Alzheimer's or dementia. Alzheimer's disease is also extremely prevalent in nursing homes, where 64 percent of Medicare residents live with the disease.

With Alzheimer's, it is not just those with the disease who suffer—it is also their caregivers and families. In 2014, 15.7 million family members and friends provided unpaid care valued at over $217 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with nearly 40 percent reporting symptoms of depression. Caregiving may also have a negative impact on health, employment, income and family finances. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had $9.7 billion in additional health costs in 2013.[3]

CHANGING THE TRAJECTORY OF ALZHEIMER'S

Until recently, there was no Federal Government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (Public Law 111–375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care and services—along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on Federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the Nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA has enabled, for the first time, Congress and the American people to answer this simple question: Did we make satisfactory progress this past year in the fight against Alzheimer's?

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, has developed the first-ever National Plan to Address Alzheimer's Disease in May of 2012 and subsequently released the 2014 Update to the National Plan to Address Alzheimer's Disease this past April. The Advisory Council, composed of both Federal members and expert non-Federal members, is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of Federal agencies involved in Alzheimer's research, care, and services.

As a result of the National Plan, NIH convened a research summit in 2012, which resulted in the development of research milestones and timelines for meeting the goal of effectively treating and preventing Alzheimer's disease by 2025. NIH held a second summit in February of this year to review the progress being made on those milestones and to develop updates on them.

Having a plan with measurable outcomes is important. But unless there are resources to implement the plan and the will to abide by it, we cannot hope to make adequate progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this and following the recommendation of scientists at NIH, Congress passed the Consolidated and Further Continuing Appropriations Act of 2015 (Public Law 113–235) which included a $25 million increase for Alzheimer's research.

The law also included the Alzheimer's Accountability Act (S. 2192/H.R. 4351), which requires NIH to develop a professional judgment budget focused on the milestones established by the National Plan. This will provide Congress with an account

[2] Ibid.
[3] Ibid.

of the necessary resources that NIH believes are needed to reach the critical goal of the National Plan, to effectively treat and prevent Alzheimer's disease by 2025.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in healthcare costs. Specifically, if a treatment became available in 2025 that delayed onset of Alzheimer's for 5 years (a treatment similar to anti-cholesterol drugs), savings would be seen almost immediately, with Medicare and Medicaid saving a cumulative $535 billion in the first 10 years.[4]

Today, despite the Federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to impact this growing crisis significantly. For every $26,000 Medicare and Medicaid spend caring for individuals with Alzheimer's, NIH spends only $100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions, but that progress depends on a prioritized scientific agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than five million Americans with Alzheimer's have never received a formal diagnosis. In fact, a recent report found that only 45 percent of people with Alzheimer's disease or their caregivers say they were told that they or their loved one had the disease. In contrast, people with the four most common cancers (breast, colorectal, lung and prostate cancer) or their caregivers reported diagnosis disclosure rates of more than 90 percent. In cardiovascular disease other than stroke, 90 percent say they were told their diagnosis. This disturbingly low diagnosis disclosure rate for Alzheimer's is reminiscent of how doctors approached disclosing a cancer diagnosis 60 years ago.[5]

Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the healthcare system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people. Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families impacted by the disease. It is vital that we make the investments in Alzheimer's that will fulfill the goals of the National Alzheimer's Plan. The Alzheimer's Association urges Congress to support an additional $300 million for research activities and priorities included in the National Alzheimer's Plan required under Public Law 111–375.

ADDITIONAL ALZHEIMER'S PROGRAMS

*National Alzheimer's Call Center*.—The National Alzheimer's Call Center, funded by the ACL, provides 24/7, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. In the twelve month period ending June 31, 2014, the 24/7 Helpline handled over 300,000 calls through its National Contact Center and 80+ chapters. Additionally, the Association provides a two-to-one match on the Federal dollars received for the call center. The Alzheimer's Association urges Congress to support $1.3 million for the National Alzheimer's Call Center.

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[4] Changing the Trajectory of Alzheimer's Disease: How a Treatment by 2025 Saves Lives and Dollars: http://www.alz.org/documents_custom/trajectory.pdf.

[5] 2015 Alzheimer's Diesease Facts and Figures: http://www.alz.org/facts/downloads/facts_figures_2015.pdf.

*Healthy Brain Initiative (HBI).*—The Centers for Disease Control and Prevention's (CDC) HBI program works to educate the public, the public health community and health professionals about Alzheimer's as a public health issue. Although there are currently no treatments to delay or stop the deterioration of brain cells caused by Alzheimer's, evidence suggests that preventing or controlling cardiovascular risk factors may benefit brain health. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the Federal commitment to a public health response to this challenge is imperative. The fiscal year 2015 omnibus funding bill funded HBI at $3.34 million. The Alzheimer's Association urges Congress to support $3.34 million for the Healthy Brain Initiative.

*Alzheimer's Disease Supportive Services Program (ADSSP).*—The ADSSP at the ACL supports family caregivers who provide countless hours of unpaid care, thereby enabling their family members with Alzheimer's and dementia to continue living in the community. The program develops coordinated, responsive and innovative community-based support service systems for individuals and families affected by Alzheimer's. The Alzheimer's Association urges Congress to support $13.4 million for the Alzheimer's Disease Supportive Services Program.

CONCLUSION

The Association appreciates the steadfast support of the Subcommittee and its priority setting activities. We look forward to continuing to work with Congress in order to address the Alzheimer's crisis. We ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (Public Law 111–375) and enactment of the Alzheimer's Accountability Act (Public Law 113–235) with a commitment equal to the scale of the crisis.

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PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians (AAFP), which represents 115,900 family physicians and medical students across the country, is pleased to submit this statement for the record urging the Committee to invest in our Nation's primary care physician workforce in the fiscal year 2016 appropriations bill to promote the efficient, effective delivery of patient-centered care by providing these appropriations for the Health Resources and Services Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ):

—$71 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act (PHSA);
—$4 million for Rural Physician Training Grants (PHSA Title VII, § 749B);
—$287 million for the National Health Service Corps (PHSA § 338A, B, & I); and
—$375 million for the AHRQ (PHSA § 487(d)(3), SSA § 1142).

Founded in 1947, the AAFP is dedicated to preserving and promoting the science and art of family medicine and ensuring high-quality, cost-effective healthcare for patients of all ages. The AAFP appreciates the opportunity to comment on the fiscal year 2016 appropriations levels needed to achieve those important goals.

*HRSA—Title VII, § 747 Primary Care Training & Enhancement (PCTE)*

The AAFP urges that the Committee provide $71 million for HRSA's PCTE program.

Our Nation faces a shortage of primary care physicians which may worsen as care delivery models shift toward smaller ratios of population to primary care physicians.[1] HRSA is the Federal agency charged with administering the health professions training programs authorized under Title VII of the Public Health Services Act and first enacted in 1963. The AAFP recommends that the Committee provides $7.48 billion in discretionary funds for HRSA in the fiscal year 2016 bill.

Family medicine relies on grants from the PCTE program to support primary care training and the professional development of primary care faculty. PCTE is both effective and essential; it has proven to be critical support for the family physicians workforce. A recent study of the effect of the PCTE funding opportunity announcement addressing faculty development needs found that this sort of targeted Federal

[1] Petterson, S, et al. Estimating the Residency Expansion Required to Avoid Projected Primary Care Physician Shortages by 2035. Ann Fam Med March/April 2015; vol.13 no. 2:107–114. http://annfammed.org/content/13/2/107.full.pdf+html.

funding can bring about changes that contribute to an up-to-date, responsive primary care workforce.[2]

In addition to faculty development, the PCTE program allows grantees to test educational innovations, respond to changing delivery systems and models of care, and improve interprofessional education and training. The Advisory Committee on Training in Primary Care Medicine and Dentistry addressed the importance of learning in integrated systems of care supported by the PCTE program in their report to the Secretary of the U.S. Department of Health and Human Services and Congress released in December 2014. The report highlights the need to "integrate principles of interprofessional education with the building of community-based collaborations and partnerships in primary care practice." Noting that current appropriations levels are inadequate, the report recommends that Congress provide "$123 million to Title VII, Part C, sections 747 and 748 for fiscal year 2016, restoring funding to inflation-adjusted fiscal year 2003 levels." [3]

*HRSA—Title VII Rural Physician Training Grants*

The AAFP asks that the Committee provide $4 million for the Rural Physician Training Grants Program as requested in the Administration's fiscal year 2016 budget.

Another important HRSA Title VII grant program is the Rural Physician Training Grants program which is designed to help medical schools recruit students most likely to practice medicine in rural communities. This modest program authorized by Title VII, § 749B of the PHSA will help provide rural-focused training and experience and increase the number of recent medical school graduates who practice in underserved rural communities. Medical school rural programs have been found to have a significant impact on rural family physician supply.[4] This program will help provide rural-focused experience and increase the number of medical school graduates who practice in underserved rural communities. An appropriation of $4 million will support 10 grantees which will train a minimum of 100 students.

*HRSA—National Health Service Corps*

The AAFP recommends that the Committee provide at least the requested appropriation of $287 million for the National Health Service Corps for fiscal year 2016.

Since in 1972, the National Health Service Corps, also administered by HRSA, has offered financial assistance to recruit and retain healthcare providers to meet the workforce needs of communities across the Nation designated as health professional shortage areas. The AAFP is committed to supporting the objectives of the NHSC in assisting communities in need of additional primary care physicians, and we support the Administration's budget request for the NHSC of $287 million in discretionary appropriations as part of the fiscal year 2016 spending bill.

The Government Accountability Office (GAO–01–1042T) described the NHSC as "one safety-net program that directly places primary care physicians and other health professionals in these medically needy areas." As the only medical society devoted solely to primary care, the AAFP recognizes the importance of the NHSC to the reducing our Nation's serious geographic disparities in healthcare access. Not only does the NHSC program place physicians and medical professionals in health professional shortage areas to meet the needs of patients in rural and medically underserved areas, it also provides scholarships as incentives for medical students to enter primary care and to provide healthcare to underserved Americans. By addressing medical school debt, NHSC scholarships ensure wider access to medical education opportunities. It does so by providing financial support for tuition and other education expenses, and a monthly living stipend for medical students committed to providing primary care in underserved communities of greatest need.

More than 40,000 providers have served in the NHSC. In fiscal year 2014, the NHSC had a field strength of 9,242 primary care clinicians. NHSC physicians and healthcare providers were placed in HPSAs serving patients in every State and territory. However, the need for this important program currently exceeds the available investment.

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[2] Klink KA, Joice SE, McDevitt SK. Impact of the Affordable Care Act on Grant-Supported Primary Care Faculty Development. Journal of Graduate Medical Education Sep 2014, Vol. 6, No. 3 pp. 419–423.

[3] Training Health Professionals in Community Settings during a Time of Transformation: Building and Learning in Integrated Systems of Care. Eleventh Annual Report to the Secretary of the U.S. Department of Health and Human Services and to Congress. December 2014. Http://www.hrsa.gov/advisorycommittees/bhpradvisory/actpcmd/Reports/eleventhreport.pdf.

[4] Rabinowitz,HK, et al. Medical School Rural Programs: A Comparison With International Medical Graduates in Addressing State-Level Rural Family Physician and Primary Care Supply. Academic Medicine, Vol. 87, No. 4/April 2012.

*AHRQ—Primary Care Research?*

The AAFP requests that the Committee provide no less than $375 million in appropriated funds for the Agency for Healthcare Research and Quality (AHRQ) to support research vital to primary care.

The Agency for Healthcare Research and Quality (AHRQ) is the sole Federal agency charged with producing evidence to support clinical decisionmaking, reduce costs, advance patient safety, decrease medical errors and improve healthcare quality and access. AHRQ supports important unique and practical investigations in the biomedical research community.

Evidence-based family medicine practice requires AHRQ-supported primary care research in areas such as Practice-Based Research Networks (PBRNs), practice transformation, patient quality and safety in non-hospital settings, multi-morbidity research, as well as the delivery of mental and behavioral health services in communities by primary care practices. Also important to successful primary care research is AHRQ's support for future primary care investigators. AHRQ has researcher training mechanisms in place, which we believe are important, and need to be expanded to support primary care research.

Primary care research includes:

—translating science into the active practice of medicine and caring for patients

—understanding how to better organize healthcare to meet patient and population needs

—evaluating innovations to deliver the best healthcare to patients

—engaging patients, communities, and practices to improve health.

AHRQ is uniquely positioned to support this sort of best practice research and to help advance its dissemination to improve primary care nationwide.

The AAFP relies on research developed by AHRQ to answer key clinical questions based on AHRQ's Effective Health Care Program to help clinicians make better treatment choices. AHRQ provides the critical evidence reviews needed to answer questions on the common acute, chronic, and comorbid conditions that family physicians see on a daily basis.

AHRQ research also examines health information technology to provide the evidence to inform meaningful use policy and practice so that health IT can be used more effectively to improve the quality of American healthcare.

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## PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

The American Academy of Pediatrics (AAP), a non-profit professional organization of 62,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults, appreciates the opportunity to submit this statement for the record in support of strong Federal investments in children's health in fiscal year 2016 and beyond. AAP urges all Members of Congress to put children first when considering short and long-term Federal spending decisions.

To improve the state of the child in this country, the AAP is focused on meeting the most basic needs of children: access to healthcare and education, sound nutrition, nurturing relationships and safe environments. As pediatricians, we not only diagnose and treat our patients, we also promote preventive interventions to improve overall health. Likewise, as policymakers, you have an integral role in ensuring the health of future generations through adequate and sustained funding of vital Federal programs. As such, we urge you to pass strong policies that invest in children in the earliest days of life. We implore you to take meaningful strides to address chronic poverty and its impacts on the health and well-being of American families.

AAP supports robust funding of the Department of Health and Human Services (HHS) and its individual agencies like the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Health Resources and Services Administration (HRSA), and the Administration for Children and Families (ACF), which all combine to support important programs that ensure the health and safety of children. Federal funding through these agencies support critical programs that address pressing public health challenges including: efforts to prevent infant mortality and birth defects; healthy child development; antimicrobial resistance and infectious diseases; emergency medical services for children; mental health and substance abuse prevention; tobacco prevention and cessation; unintentional injury and violence prevention; child maltreatment prevention; childhood obesity; environmental and chemical exposures; poison control; teen pregnancy prevention and family planning; health promotion in schools; and medical research and innovation.

In addition, we would like to highlight our support for investment of $21.116 million in the Emergency Medical Services for Children at HRSA, $131.78 million for the CDC's National Center for Birth Defects and Developmental Disabilities, $219 million for CDC's Global Immunization program, including $169 million for CDC Polio Eradication, and $50 million for the CDC Measles program, and $650 million for CDC's Section 317 program.

*Emergency Medical Services for Children*

Established by Congress in 1984 and last reauthorized in fiscal year 2015, the Emergency Medical Services for Children (EMSC) Program is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure that state of the art emergency medical care for the ill and injured child or adolescent pediatric services are well integrated into an EMS system backed by optimal resources; and the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

Gaps in providing quality care to children in emergencies continue to persist throughout the country. The EMSC program helps to address these gaps by promoting the quality of care provided in the pre-hospital and hospital setting, reducing pediatric mortalities due to serious injury, and supporting rigorous multi-site clinical trials through the Pediatric Emergency Care Applied Research Network (PECARN).

Fiscal year 2016 Request: $21.116 million; fiscal year 2015 Level: $20.1 million.

*National Center for Birth Defects and Developmental Disabilities*

The National Center for Birth Defects and Developmental Disabilities is a center within CDC that seeks to promote the health of babies, children, and adults and enhance the potential for full, productive living. According to the CDC, birth defects affect 1 in 33 babies and are a leading cause of infant death in the United States. The center has done tremendous work in the way of identifying the causes of birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities. The center also conducts important research on fetal alcohol syndrome, infant health, autism, congenital heart defects, and other conditions like Tourette Syndrome, Fragile X, Spina Bifida and Hemophilia. NCBDDD has proven to be an asset to children and their families and supports extramural research in every State.

Fiscal year 2016 Request: $131.78 million; fiscal year 2015 Level: $131.78 million.

*Global Immunizations at CDC*

Vaccines are one of the most cost-effective and successful public health solutions available. They save the lives of approximately 2.5 million children each year. Recent studies estimate that scaling up the use of existing vaccines in 72 of the world's poorest countries could save 6.4 million lives and avert $6.2 billion in treatment costs and $145 billion in productivity losses by 2020.

Since 1988 a coordinated global immunization campaign has reduced the number of polio cases globally by more than 99 percent, saving more than 10 million children from paralysis and bringing the disease close to eradication. Expanded immunization has also reduced the global mortality attributed to measles, one of the top five diseases killing children, by 74 percent between 2000 and 2010.

The AAP calls on Congress to fully support CDC's Center for Global Immunization, which provides technical assistance and surveillance support to country ministries of health, with a focus on eradicating polio, reducing measles deaths, and strengthening routine vaccine delivery. The Center for Global Immunization enhances global capacity for vaccine safety monitoring and post-marketing surveillance, builds global immunization research and development capacity, and strengthens countries' capacity for vaccine decisionmaking

Fiscal year 2016 Request: $219 million; fiscal year 2015 Level: $208.6 million.

*Section 317 Funding*

Section 317 is a discretionary Federal grant program that provides vaccines to underinsured children and adolescents who are not eligible for the Vaccines for Children program, as well as for uninsured and underinsured adults. Throughout its history, Section 317 has played an important role in ensuring that these individuals are receiving vaccinations that prevent life-threatening diseases. As we have seen in the recent measles outbreak in California, vaccines are a crucial part of our public health infrastructure.

Though the Affordable Care Act now requires that insurers provide first dollar coverage of vaccines, Section 317 still plays a valuable role in other areas, particu-

larly in vaccine infrastructure and in handling outbreaks. Section 317 has helped public health departments around the country to optimize their billing processes so that they can be reimbursed for insured patients to whom they administer vaccines. Additionally, Section 317 plays an important role in containing outbreaks. If a large outbreak were to occur, Section 317 funds could be used to vaccinate individuals in the affected area, and could supplement the efforts of the CDC to effectively combat the outbreak.

In his fiscal year 2016 Budget, the President proposed that Section 317 be cut by $50 million. The AAP urges Congress not to cut these funds from the program. Though the Affordable Care Act is now a part of our healthcare system, many aspects of it are still being rolled out, and it is important that we are not hasty in cutting a program that so clearly works and rely on another one that is still in its relative infancy.

Fiscal year 2016 Request: $650 million; fiscal year 2015 Level: $610 million.

*America's children deserve better*

Twenty percent of children in the United States now live in poverty—up from 17 percent in 2007. During this same time period many families in the United States have seen their savings depleted and one or both parents lose their jobs. Although the country's economic position is improving, such challenging economic conditions have impacted one group of Americans particularly hard: our children. Many children suffer from food insecurity, unstable housing, family dysfunction, abuse and neglect. Such adverse childhood experiences are linked with "toxic stress," a biologic phenomenon associated with profound and irreversible changes in brain anatomy and chemistry that have been implicated in the development of health-threatening behaviors and medical complications later in life including drug use, obesity, and altered immune function. Adults affected by such adverse childhood experiences are more likely to have experienced school failure, gang membership, unemployment, violent crime, and incarceration.

*Children's healthcare is not the cost driver of overall healthcare spending*

The United States continues to spend less on our children's health, education, and general welfare than most other developed nations in the world. Children under age 18 represent 30 percent of the total U.S. population, yet healthcare services for infants, children, and young adults are only 12 percent of total annual healthcare spending. Furthermore, children, including those with special healthcare needs, make up more than 50 percent of all Medicaid recipients, but account for less than 25 percent of Medicaid costs.

*Children's programs are cost-effective and improve our Nation's health and economy*

Children's programs are a cost-effective investment in our Nation's future. For example, every 1 dollar spent on the childhood vaccine series saves the healthcare system $16.50 in future medical costs. Every 1 dollar spent on high-quality home visiting programs saves up to $5.70 as a result of improved prenatal health, decreased mental health and criminal justice costs, and fewer children suffering from abuse and neglect. Every 1 dollar spent on preventative services for a pregnant woman in the WIC program saves Medicaid up to $4.20 by reducing the risk of pre-term birth and its associated costs.

*Healthier children, healthier future*

On behalf of the 75 million American children and their families that we serve and treat, the Nation's pediatricians hope that Congress will respond to mounting evidence that child health has life-long impacts and prioritize children while determining fiscal year 2016 Federal spending levels. Federal support for children's health programs, such as early brain and child development, parenting and health education, and preventive health services, will yield high returns for the American economy. Investing in children is not only the right thing to do for the long-term physical, mental, and emotional health of the population, but is imperative for the Nation's long-term fiscal health as well.

We fully recognize the Nation's fiscal challenges and respect that difficult budgetary decisions must be made; however, we do not support funding decisions made at the expense of the health and welfare of children and families. Rather, focusing on the long-term needs of children and adolescents will ensure that the United States can compete in the modern, highly-educated global marketplace. Strong and sustained financial investments in children's healthcare, research, and prevention programs will help keep our children healthy and pay extraordinary dividends for years to come.

The AAP is focused on meeting the most basic needs of children: access to healthcare and education, sound nutrition, nurturing relationships, and safe envi-

ronments. There are many ways Congress can help meet children's needs and protect their health and well-being. Adequate funding for children's health programs is one of them. The American Academy of Pediatrics looks forward to working with Members of Congress to prioritize the health of our Nation's children in fiscal year 2016 and beyond. If we may be of further assistance please contact the AAP Department of Federal Affairs. Thank you for your consideration.

[This statement was submitted by Sandra G. Hassink, MD, FAAP, President, American Academy of Pediatrics.]

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PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of more than 100,000 nationally certified physician assistants (PAs), the American Academy of Physician Assistants (AAPA) is pleased to submit comments on the fiscal year 2016 appropriation for PA educational programs authorized under Title VII of the Public Health Service (PHS) Act and administered by the Health Resources and Services Administration (HRSA). AAPA respectfully requests that the Senate Subcommittee on Labor, Health and Human Services, and Education and Related Agencies approve continued funding of $280 million for the Title VII health professions education program and provide $12 million of the funding allocated to the Primary Care Training and Enhancement (PCTE) program for PA education programs. These amounts are consistent with the requests submitted by the Health Professions and Nursing Education Coalition (HPNEC) and the Physician Assistant Education Association (PAEA). AAPA also urges the Subcommittee to provide continued, full funding for the National Health Service Corps (NHSC) and community health centers (CHCs) as included in H.R. 2, the House-passed SGR package.

*Overview of PA Practice*

PAs are healthcare providers who are nationally certified and State licensed to practice medicine and prescribe medication in every medical and surgical specialty and setting. PAs practice and prescribe in all 50 States, the District of Columbia, and in all U.S. territories with the exception of Puerto Rico. PAs manage the full scope of patient care, often handling patients with multiple comorbidities. In their normal course of work, PAs conduct physical exams, assist in surgery, diagnose and treat illnesses, order and interpret tests, and counsel on preventative healthcare. As such, PAs are a valuable part of the healthcare team, and they are necessary to ensure the success of the healthcare delivery system as a whole.

*Overview of PA Education*

There are currently 196 accredited PA educational programs in the U.S., all of which are located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant, and the overwhelming majority of PA programs offer a master's degree in PA studies.

The typical PA student has a bachelor's degree and 4 years of healthcare experience prior to beginning a PA program. The curriculum generally consists of 26 months of instruction, which includes 400 hours of basic sciences and nearly 1,600 hours of clinical medicine. Students' clinical education is often divided between primary care medicine—family medicine, internal medicine, pediatrics, and obstetrics and gynecology—and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. Once a PA has graduated, he or she must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants and become licensed by the State in which they will practice. PAs must also log 100 hours of continuing medical education every 2 years and take a recertification exam every 10 years.

*PAs and Title VII Funding*

Title VII of the PHS Act is the only continuing Federal funding which is available to PA educational programs. As a result, AAPA supports allocating $12 million specifically for these programs, which are funded within PCTE. In the 2013–2014 academic year, PA education grants made through PCTE via the Physician Assistant Training in Primary Care program supported the education of 4,071 PA students. Of that number, nearly half were minorities and/or from disadvantaged backgrounds. More than half of the institutions which were awarded grant funds through this program were focused on primary care, and most of them were located in rural and/or medically underserved areas. At the same time, the Expansion of

Physician Assistant Training (EPAT) program under PCTE assisted 429 PA students, 120 of whom graduated at the end of the 2013–2014 academic year. Over 50 percent of these graduates planned to practice in a rural or medically underserved area, and a similar number planned to work in a primary care setting.

In addition to creating more opportunities for PA students to pursue their education, Title VII funding has helped PA programs expand clinical rotations in rural and medically underserved areas. This expansion has benefited local residents who previously had limited access to care while exposing PA students to diverse clinical environments. In many cases, new PAs will choose to remain in the area in which they completed their education. In fact, a review of PA graduates from 1990–2009 showed that PAs who graduated from programs supported by Title VII were 47 percent more likely to work in rural health clinics than graduates of other programs. As such, continued funding of PA educational programs under Title VII is a win-win scenario for underserved communities and for the Nation's healthcare workforce.

*PAs in Primary Care*

Of the more than 100,000 PAs currently practicing in the U.S., more than 30 percent work in primary care settings. PAs are one of three primary care providers who may participate in the NHSC, which provides loan forgiveness and scholarship awards to more than 10,000 healthcare professionals who commit to serving for 2 years in medically underserved areas. Additionally, PAs provide medical care in community health centers (CHCs), and in some cases, serve as CHC directors. CHCs provide cost-effective healthcare throughout the country and serve as medical homes for millions of patients who live in medically underserved areas. CHCs provide a wide variety of healthcare services through team-based care, providing high quality healthcare to CHC patients and significantly reducing medical expenses. AAPA was pleased that funding was approved for both NHSC and CHCs in the House-passed SGR reform package (H.R. 2). In keeping with that language, AAPA strongly supports continued funding of both of these programs.

*Summary*

According to a HRSA study released in November 2013, increased use of PAs along with nurse practitioners could help to alleviate the projected shortage of physicians (20,400 by 2020), reducing this need to only 6,400 primary care providers. As a result, strong Federal support for PA education programs is necessary to ensure that all Americans have access to high quality healthcare.

AAPA appreciates the opportunity to present our views on the fiscal year 2016 appropriations for Title VII. We appreciate Congress's past support of Title VII programs, and we look forward to continuing to work with the Subcommittee to this end.

[This statement was submitted by Sandy Harding, MSW, Senior Director, Federal Advocacy.]

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## PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Blunt, Ranking Member Murray, and members of the Subcommittee, thank you for allowing me to submit this testimony on behalf of our members and the Nation's larger museum community. My name is Ford Bell and I serve as President of the American Alliance of Museums. I respectfully request that the Subcommittee make a renewed investment in museums in fiscal year 2016. I urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its authorized level of $38.6 million.

The Alliance is proud to represent the full range of our Nation's museums—including aquariums, art museums, botanic gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others—along with the professional staff and volunteers who work for and with museums.

Museums are economic engines and job creators: We are proud to report that U.S. museums employ 400,000 people and directly contribute $21 billion to their local economies.

This Subcommittee may be especially interested in the ways museums are providing educational programming and the results of this investment:

—Museums spend more than $2 billion a year on education activities; the typical museum devotes three-quarters of its education budget to K–12 students, and

museums receive approximately 55 million visits each year from students in school groups.

—Children who visited a museum during kindergarten had higher achievement scores in reading, mathematics and science in third grade than children who did not. This benefit is also seen in the subgroup of children who are most at risk for deficits and delays in achievement.

—Students who attend a field trip to an art museum experience an increase in critical thinking skills, historical empathy and tolerance. For students from rural or high-poverty regions, the increase was even more significant.

—Museums help teach the State, local or core curriculum, tailoring their programs in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography and social studies.

—Many museums are tailoring programs to serve homeschooling families.

IMLS is the primary Federal agency that supports the museum field, and OMS awards grants in every State to help museums digitize, enhance and preserve their collections; provide teacher training; and create innovative, cross-cultural and multidisciplinary programs and exhibits for schools and the public.

In late 2010, legislation to reauthorize IMLS for 5 years was enacted (by voice vote in the House and by unanimous consent in the Senate). The bipartisan reauthorization included several provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response and statewide capacity building. The reauthorization also specifically supports efforts at the State level to leverage museum resources, including statewide needs assessments and the development of State plans to improve and maximize museum services throughout the State. That bill (Public Law 111–340) authorized $38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services. The fiscal year 2015 appropriation of $30.1 million represents a nearly 15 percent decrease from the fiscal year 2010 appropriation of $35.2 million.

We applaud the Administration's fiscal year 2016 budget for requesting a significant increase—to $35.1 million—for the Office of Museum Services. It would help museums make an impact in several priority areas identified by the agency, such as STEM education and makerspaces, a comprehensive collections care survey, and early learning. We also applaud the 30 Senators who wrote to you in support of fiscal year 2016 OMS funding, including subcommittee members Durbin, Reed, Shaheen, Schatz, and Baldwin.

Here are a few examples, from just 2014, of how IMLS Office of Museum Services funding is used:

*STEM Education*.—The Missouri Botanical Garden (St. Louis, MO) was awarded $140,605 to work with six urban schools in creating new STEM educational opportunities for teachers and students. Students will focus on garden research themes such as the medicinal uses of plants, their ecological value, or their role as a food source. Multiple experiences at garden sites, follow-up programming, and teacher professional development are all designed in alignment with State standards to increase STEM proficiency.

*Improving Life for People with Dementia*.—Frye Art Museum (Seattle, WA) was awarded $121,824 to expand its arts engagement program for people living with dementia and their care partners to serve participants at later stages of the disease. The museum will offer gallery tours, art-making classes, and an interactive film program; convene a professional development conference on art, creativity and dementia; establish a student internship in creative aging with a local university; publish a report and present the results of the program pilot at conferences; and present an education workshop for caregivers and health providers on techniques for incorporating art into dementia care. Participants in the program will develop connections with care partners to reduce feelings of isolation and depression and to enhance quality of life for people living with dementia.

*Farming Education*.—Rice County Historical Society (Lyons, KS) was awarded $34,545 to create "Agricultural Options," an exhibit on farming that explores the values associated with the land and farming practices that are profitable yet sustainable. The exhibit will identify trends in farming, make connections with environmental issues linked to the land, and enhance the visitor's experience through educational activities. The exhibit's educational activities will include lessons for three grade levels, a driving tour, and interactive sites.

*Collecting Veterans' Stories*.—National Vietnam Veterans Art Museum (Chicago, IL) was awarded $20,050 to develop "Sound Off," a living oral history archive that uses innovative technology to place the learner at the center and engage audiences—especially veterans and their families as well as students—in the arts, history, and civics. The museum will develop and install an onsite recording booth

where veterans can record oral histories of their time in service; develop a new mobile app to record and archive interviews with veterans unable to visit the museum in person; and create a curriculum for high school students to learn about art, history, and civics based on the museum's collection and these oral histories.

*Healthy Kids*.—Children's Museum of Oak Ridge (Oak Ridge, TN) was awarded $137,108 to plan, develop, and construct "Kids in Action," a healthy living exhibit and accompanying educational programs to support healthy nutrition, healthy activity, STEM (Science, Technology, Engineering, and Mathematics) education, and community wellness. Through partnerships with East Tennessee Children's Hospital, Oak Ridge Associated Universities, and the University of Tennessee Agriculture Extension the "Kids in Action" initiative will use fun and engaging activities, including a human body exhibit, to raise awareness in the community about healthy nutrition and exercise.

*Collections Care and Access*.—Redwood Library and Athenaeum (Newport, RI) was awarded $19,455 to inventory, catalog, and update records of its collection of approximately 1,600 paintings, works on paper, sculptures, furniture, and decorative arts. The museum will publish the records and images on its website and on Newportal, a collaborative website of five cultural institutions in Newport County, Rhode Island.

It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the dollar-for-dollar match required of museums, grants often spur additional giving by private foundations and individual donors. Two-thirds of IMLS grantees report that their Museums for America grant positioned the museum to receive additional private funding.

IMLS grants to museums are highly competitive and decided through a rigorous, peer-reviewed process. Even the most ardent deficit hawks view the IMLS grant-making process as a model for the Nation. Due to the large number of grant applications and the limited funds available, many highly-rated grant proposals go unfunded each year. In 2014:

—Only 35 percent of Museums for America/Conservation Project Support project proposals were funded;
—Only 22 percent of National Leadership project proposals were funded;
—Only 17 percent of Sparks Ignition Grants for Museums project proposals were funded;
—Only 64 percent of Native American/Hawaiian Museum Services project proposals were funded; and
—Only 37 percent of African American History and Culture project proposals were funded.

If I can provide any additional information about the essential role of the museums in your community, I would be delighted to do so. Thank you once again for the opportunity to submit this testimony today.

[This statement was submitted by Dr. Ford W. Bell, President, American Alliance of Museums.]

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## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the world's first and largest scientific organization focused on every aspect of high-quality, innovative cancer research. The mission of the AACR and its more than 35,000 members is to prevent and cure cancer through research, education, communication and collaboration. We thank the United States Congress for its longstanding, bipartisan support for the National Institutes of Health (NIH) and for its commitment to funding cancer research. We especially thank Senate Appropriations Chairman Thad Cochran and Vice-Chairwoman Barbara Mikulski for their unwavering support for the NIH, and we appreciate the opportunity to provide testimony on the importance of funding for the NIH and cancer research.

The AACR calls on Congress to provide at least $32 billion for the NIH in fiscal year 2016 (a minimum of a 5.6 percent increase), and to provide a commensurate increase for the National Cancer Institute (NCI). Putting the NIH and NCI back on a path of sustained and predictable funding growth is the only way we will seize the unparalleled scientific opportunities in cancer research that lie before us, and increased funding is paramount to overcoming the challenges we face in conquering this complex disease. Furthermore, we call on Congress to fund the Precision Medicine Initiative, so that the extraordinary knowledge obtained through past Federal investments like the Human Genome Project can be fully realized and translated into therapies for cancer and a myriad of other diseases.

We live in an extraordinary time of scientific opportunity, in which we are rapidly developing the tools necessary to translate basic biological discoveries into therapies that can save and improve millions of lives. Nowhere is this more evident than in precision medicine, an area in which cancer research has been leading the way for more than a decade. If we are to support and foster the goals of the President's Precision Medicine Initiative, a strong commitment to funding medical research is required.

*Investments in Cancer Research are Saving and Improving Lives*

Significant progress has been made against cancer because of the decades of Federal investment in medical research and the dedicated work of researchers, physician-scientists, and patient advocates throughout the biomedical research enterprise. Federal support allows for new and improved approaches to the prevention, detection, diagnosis, and treatment of cancer, and thanks to past investments in basic research, we have never been better positioned to capitalize on our hard-won understanding of what causes and drives cancer. This knowledge of cancer biology is providing the foundation for new treatments and preventive strategies, and it is accelerating progress against the more than 200 diseases we call cancer. Federal investment in cancer research also leads to progress in other fields. For example, drugs originally developed for cancer patients have led to treatments for macular degeneration, atherosclerosis, psoriasis, rheumatoid arthritis, and hepatitis among others.

As is detailed in the AACR Cancer Progress Report 2014, support from the NIH and the NCI for basic, translational, and clinical research has led to decreases in the incidence of many cancers, cures for a number of these diseases, and higher quality and longer lives for many individuals whose cancers cannot yet be prevented or cured. In fact, the number of cancer survivors living today in the United States is estimated to be more than 14 million. Cancer research also is transforming lives by allowing scientists to advance immunotherapeutic development, develop new molecularly targeted therapies and consider ways to overcome drug resistance.

Consider the progress made in just the last 18 months. Cancer patients now have access to:

—7 new drugs to treat a variety of cancers, including a "first in class" immunotherapy to treat a pediatric cancer;

—4 new uses for previously approved cancer drugs;

—1 new cancer screening test; and,

—1 new cancer prevention vaccine.

The vigorous pursuit of new breakthroughs in cancer research and biomedical science is also serving as one of our country's primary paths to innovation, global competitiveness, and economic growth. According to United for Medical Research, NIH funding directly and indirectly supported more than 402,000 jobs in 2012 alone, and generated more than $57.8 billion in new economic activity.

These remarkable achievements would never have been possible without a national commitment to funding cancer research, screening, and treatment programs at the NCI, NIH, and other agencies across the Federal Government. We can continue to make significant advances, but only if we continue to allocate the required resources at the Federal level to do so. The NIH and NCI must be put back on a path of sustained, predictable growth this year and in the years to come.

*Past Investments in Cancer Research are Yielding Dividends Today*

The Nation's historical investment in cancer research is unquestionably having an impact, and we are seeing results in the form of clinical advances and new treatments. While the advances over the past few decades are too numerous to list here, breakthroughs in two areas—precision medicine and cancer immunotherapy—are of particular importance and are described in greater detail below.

*Precision Medicine is Re-shaping the Diagnosis and Treatment of Cancer*

A significant milestone for cancer research was the discovery that cancer develops as a result of alterations in the genetic material of cells. Research in genomics has propelled technological innovations that are making it possible to efficiently read every known component of the DNA from an individual's cancer. Capitalizing on these advances is the goal of large-scale genomic enterprises such as The Cancer Genome Atlas (TCGA) and the International Cancer Genome Consortium (ICGC). These and similar initiatives aim to identify all of the genomic changes in many types of cancer by comparing the DNA in a patient's normal tissue with the tumor DNA, in order to discover the genetic alterations that drive a given cancer. This groundbreaking approach—treating cancer based on the genetic and molecular profile of a patient's tumor—is often referred to as personalized, or precision, cancer medicine.

The success of precision medicine is exemplified in the development of drugs for patients with an aggressive form of breast cancer. More than 45,000 individuals will be diagnosed with a form of breast cancer that overexpresses the protein HER–2. Historically, outcomes for patients with HER–2 positive breast cancer were poor. But with the knowledge gained through genomic-based research and discovery, four HER–2 targeted therapies have been approved in the last 5 years, revolutionizing the treatment of the disease and bringing hope and significantly prolonged survival to tens of thousands of breast cancer patients.

As you can see, these discoveries are changing the way researchers view cancers, categorizing them more by the genetic changes that drive them and less by where they originate—in the breast, brain, lung, or liver, for example. It is also transforming the detection, diagnosis, and treatment of cancer. Although to date, large-scale genomic analyses have been completed for just a few types of cancer, with research into many others underway, the advances made are a step toward a future where most cancer treatment and prevention strategies are based on both a person's genetic makeup and the genetic makeup of their specific cancer. Had the Federal Government not made the wise decision to invest in mapping the human genome, none of this progress would have been possible.

*Cancer Immunotherapy*

Another milestone for cancer research was the discovery that the immune system can identify and eliminate cancer cells the way it does disease-causing pathogens. The study of the structure and function of the immune system is a field of research called immunology and is more than 100 years old. Tumor immunology (sometimes called cancer immunology) is the study of interactions between the immune system and cancer cells.

Because the immune system naturally eliminates some cancers before they become life threatening, researchers thought that it should be possible to develop therapies that would train a patient's immune system to destroy their cancer. Such therapies, referred to as immunotherapies, are beginning to revolutionize the treatment of some cancers, such as metastatic melanoma and chronic lymphocytic leukemia, by taking the brakes off or pressing the accelerator on the body's immune system, or by flagging cancer cells for destruction by the immune system.

While treating cancer by harnessing the body's own immune system is a dream dating back to the 1890s, tangible progress in this area has been recent. Until the first therapeutic cancer vaccine, sipuleucel-T or Provenge, was approved in 2010 for the treatment of prostate cancer, investigational immunotherapies were effective in so few patients that they did not become established treatment options. Today, with expanded knowledge thanks to basic and clinical research funded by the NIH, several types of immunotherapies have been approved and many more are in the pipeline. Researchers also are pursuing their use in combination with one another in the hopes of yielding even more positive results in patients with cancers such as advanced melanoma and chronic myelogenous leukemia, among others. The success of immunotherapies in the past few years underscore how decades of research coupled with innovation in numerous disciplines are paying dividends for many cancer patients. Thanks to Federal investment in research and the persistence and dedication of researchers across the biomedical research enterprise, the dream of immunotherapy is being realized.

*Cancer remains a significant public health challenge*

Even in the face of the tremendous progress discussed above, cancer remains a formidable opponent. An estimated 1.65 million Americans will be diagnosed with cancer this year, and 1 in every 3 women and 1 in every 2 men will likely develop cancer in their lifetimes. It is also projected that more than 589,000 people will die this year in the U.S. from the disease, which is more than 1,600 people each day. In fact, cancer will account for nearly one in every four deaths, making it the second most common cause of disease-related death in the United States. There also remain a number of cancers, including pancreatic, liver and lung cancers, for which the mortality rate remains extraordinarily high and 5-year survival rates are typically less than 50 percent. Further, racial and ethnic minorities, as well as low-income and elderly populations, continue to suffer disproportionately in cancer incidence, prevalence, and mortality.

Because of the steady increase in cancer incidence rates, which is mainly due to our increasingly aging population and the enormous complexity of many cancers, continuing and strengthening our Nation's commitment to cancer research and biomedical science is more critical now than ever. Increasing the Federal investment in cancer research and biomedical science will play a vital role in addressing the current challenges in cancer, while at the same time curbing the overall annual

costs of this devastating disease —the economic burden of which exceeded $263 billion in 2010 and is expected to continue to rise as the number of cancer deaths increases.

*Progress against cancer requires a sustained commitment to funding*

As we look to a future in which cancer care will be transformed by the discoveries made in laboratories across the country, increased funding for cancer research from the Federal Government and other sources is essential if we are to continue to pursue a comprehensive understanding of the biology of cancer. First and foremost, our ability to realize the exciting future that awaits us depends on a strong commitment by Congress to provide the necessary funding for the NIH and the NCI. As a country we must set priorities at this difficult time in our history—and the government can do no better with its money than continue to invest in medical research.

This is a defining time in America's commitment to finally defeat cancer. We must seize the opportunity to invest our Nation's remarkably productive medical research ecosystem by providing at least $32 billion for the NIH in fiscal year 2016 and funding important programs such as the Precision Medicine Initiative. This investment will ensure we can continue to transform cancer care, spur innovation and economic growth, maintain our position as the global leader in science and medical research, and most importantly, bring hope to patients and their loved ones everywhere. The AACR looks forward to working with you to ensure that researchers have the resources they need to continue to deliver hope to those who are confronting this dreaded disease.

[This statement was submitted by Margaret Foti, PhD, MD (hc), Chief Executive Officer, American Association for Cancer Research.]

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## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

On behalf of the 3,600 individual and 54 institutional members of the American Association for Dental Research (AADR), I am pleased to submit testimony describing AADR's fiscal year 2016 requests, which includes at least $32 billion for the National Institutes of Health (NIH) and $425 million for the National Institute of Dental and Craniofacial Research (NIDCR). These funding recommendations represent the minimal needs of the research community while at the same time taking into consideration the continued tight budget climate dictated by the caps established by the Budget Control Act of 2011.

I want to emphasize, the current austerity frame is unworkable and insufficient to meet our Nation's mounting health demands. According to our members, when sequestration hit it was a game-changer. Established faculty had difficulty getting grants renewed, new faculty hit a funding wall and people employed by laboratories in communities throughout the country lost their jobs. Moreover, the current budget climate creates an atmosphere that is very discouraging to new scientific investigators whose research proposals are good enough to be funded, but were not because of the budget cuts. We are at risk of losing them and their promising research ideas—ideas that might lead to significant advances in dental, oral health and craniofacial health. We therefore strongly urge Congress to take the steps necessary to put an end to sequestration permanently and reinvest in America's health.

It is important to note that when adjusted for inflation, the NIDCR budget is 25 percent, or $94 million, less than it was in 2004, resulting in the lowest number of grants awarded in 14 years. This decline in purchasing power is particularly troubling because the improvements in oral health during the last half century are largely credited to research supported by NIDCR. This decline in funding will slow or limit future breakthroughs. NIDCR is the largest institution in the world dedicated exclusively to research to improve dental, oral and craniofacial health. The health of the mouth and surrounding craniofacial (skull and face) structures is central to a person's overall health and well-being. Left untreated, oral diseases and poor oral conditions make it difficult to eat, drink, swallow, smile, talk and maintain proper nutrition. Scientists also have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes and pancreatic cancer.

In spite of these improvements, however, treating oral health conditions is costing this Nation $111 billion in expenditures on dental services in 2013. While tooth decay and gum disease remain the most prevalent cost-drivers, complete tooth loss, oral cancer and craniofacial congenital anomalies, such as cleft lip and palate, are also health and economic burdens to the American people. Moreover, oral health disparities persist for many racial and ethnic groups. By providing $425 million in fiscal year 2016 for NIDCR, dental, oral and craniofacial researchers will be able to

build upon the gains of past decades, creating less invasive, cost-effective and more efficient ways to improve oral health. Below are some examples highlighting the important work supported by NIDCR:

—*Precision Oncology*.—NIDCR-funded researchers are investigating the role genetics play in head and neck cancers, and paving the way for efforts in precision oncology. Examining genetic data may lead to a better understanding of these diseases, leading to the identification of biomarkers that will allow for earlier—perhaps life-saving—detection and enable more effective treatment of head and neck cancers.

—*Point of Care Diagnostics*.—Salivary diagnostics are measures that draw and analyze saliva to test for conditions such as HIV, human papillomavirus (HPV), substance abuse, caries, periodontitis and oral cancer. As a result of research supported by NIDCR over the last decade, diagnostics also are showing great promise in screening for diabetes, heart disease, lung cancer, ovarian cancer and pancreatic cancer.

—*Dental Caries*.—Dental caries, or tooth decay, remain the most prevalent chronic disease in both children and adults resulting in a substantial economic and health burden to the American people. Although caries has significantly decreased for most Americans over the past four decades, disparities remain among some population groups. Additional research is needed to enhance efforts to address dental caries including studies on oral microbiology, oral health literacy and the reduction of free sugars as having additional health benefits.

—*Enhanced Tissue Regeneration*.—NIDCR-funded scientists have developed effective techniques to prevent inflammation from interfering with the use of stem cells to form bone and cartilage for oral, dental and craniofacial purposes. The isolation and enrichment of stem cells is also being explored, which would enhance the cells' ability to regrow bone and cartilage, with potential impacts throughout the health sciences sector.

—*Cleft Lip and/or Cleft Palate*.—Craniofacial anomalies such as cleft lip and/or cleft palate are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Studies supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions.

—*Evidenced-Based Practice*.—NIDCR awarded a 7-year grant that consolidates its dental practice-based research network initiative into a unified nationally coordinated effort. The consolidated initiative, the National Dental Practice-Based Research Network (NDPBRN) is headquartered at the University of Alabama at Birmingham School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral healthcare. These studies help to expand the profession's evidence base and further refine care.

Our members remain concerned that unless Congress provides NIH with stable, predictable and increased funding our ability to attract the next generation of scientists will stall; the Nation's standing as a world leader in science will decline; and innovation necessary to push the boundaries of research will be stymied. Future advances in healthcare depend on a sustained investment in basic research to identify the fundamental causes and mechanisms of disease, accelerate technological development and discovery, and ensure a robust pipeline of creative and skillful biomedical researchers. For these reasons, I implore you to work in a bipartisan manner and provide funding increases for NIH and NIDCR in fiscal year 2016.

In addition to the NIH, AADR members care deeply about the Title VII Health Resources and Services Administration (HRSA) programs training the dental health workforce, the Centers for Disease Control and Prevention (CDC) Division of Oral Health's public health prevention efforts, data from the National Center for Health Statistics (NCHS) and the Agency for Healthcare Research & Quality (AHRQ). Please support AADR's funding recommendations for these agencies depicted in the chart below.

| Agency | Fiscal Year | | | | | |
|---|---|---|---|---|---|---|
| | 2012 | 2013 | 2014 | 2015 | 2016 PBR | 2016 AADR |
| NIH | 30.7b | 29.3b | 30.0b | 30.3b | 31.3b | 32.0b |
| NIDCR | 410.3 | 386.8m | 397.8m | 397.7m | 406.7m | 425.0m |
| NCATS | 574.8m | 542.1m | 631.5m | 635.2m | 660.1m | 660.1m |
| AHRQ | 405.1m | 429.4m | 371.0m | 364.0m | 276.0m | 375.0m |
| CDC, Oral Health | 14.6m | 13.8m | 15.7m | 15.7m | 15.7m | 20.0m |

| Agency | Fiscal Year | | | | | |
|---|---|---|---|---|---|---|
| | 2012 | 2013 | 2014 | 2015 | 2016 PBR | 2016 AADR |
| CDC, NCHS | 153.8 | 153.8 | 155.3 | 155.4m | 172.0m | 172.0m |
| HRSA, Title VII Oral Health | 32.4m | 30.7m | 32.0m | 33.9m | 33.9m | 35.0m |

Thank you for the opportunity to submit this testimony. AADR stands ready to answer any questions you may have.

[This statement was submitted by Paul Krebsbach, DDS, Ph.D., President, American Association for Dental Research.]

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PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

As the national voice for baccalaureate and graduate nursing education, the American Association of Colleges of Nursing (AACN) represents over 760 schools of nursing that educate over 450,000 students and employ more than 17,000 faculty members. Collectively, these institutions produce approximately half of our Nation's Registered Nurses (RNs) and all nurse faculty members, Advanced Practice Registered Nurses (APRNs), and nurse scientists.

AACN respectfully requests that the subcommittee invests in America's health by providing $244 million for HRSA's Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]) and $150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH) in fiscal year 2016. These levels will ensure that our Nation's nurses are prepared to care for the growing number of patients requiring a complex range of healthcare services.

THE ROLE OF NURSES IN OUR HEALTHCARE SYSTEM

As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. RNs comprise the largest sector of the healthcare workforce with over three million licensed providers. Nurses serve in a multitude of settings, including hospitals, long-term care facilities, community centers, local and State health departments, schools, workplaces, and patient homes. Nurses treat patients across the entire life span, and are present when patients and their families contemplate major decisions surrounding their healthcare. RNs and APRNs are responsible for providing patient education to ensure that individuals can follow through with their plan of care, thus helping to curb costly readmissions.

In light of the national effort to improve access to care, it is evident that our system will continue to transform. Innovative delivery models that promote efficiency and effectiveness require a team-based approach. AACN recognizes that in order for the profession to advance in accordance with the demand for high-quality health services, nurses must collaborate with other health professions to provide safe, cost-effective, patient-centered care. In order to do so, it is imperative that individuals seeking to enter into the profession and nurses in pursuit of advanced degrees have the means to achieve these goals, particularly when the cost of higher education is not within financial reach. Investments are necessary to educate the RNs and APRNs who will provide the care that Americans need now and in years to come.

HOW TITLE VIII PROGRAMS SERVE THE PUBLIC TODAY AND IN THE FUTURE

For over five decades, the Nursing Workforce Development programs have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. The programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support to educate nurses for practice in rural and medically underserved communities. Title VIII programs are essential to ensuring that the demand for nursing care is met by supporting future practicing nurses and the faculty who educate them. Moreover, they align with the Institute of Medicine's Future of Nursing: Leading Change, Advancing Health, which calls for

nurses to "achieve higher levels of education and training through an improved education system that promotes seamless academic progression." [1]

Title VIII programs address specific aspects of the nursing pipeline and patient populations so that they are met in accordance with their needs. For example, our healthcare system is experiencing a need for a greater number of APRNs (which include nurse practitioners (NPs), certified registered nurse anesthetists (CRNAs), certified nurse-midwives (CNMs), and clinical nurse specialists (CNSs)). In fact, according to the U.S. Bureau of Labor Statistics, the projected employment of NPs, CRNAs and CNMs is expected to grow 31 percent between years 2012–2022.[2] Greater utilization of APRNs provides a real solution to the challenge of employing high-quality providers in underserved areas. Title VIII programs, such as the Advanced Education Nursing Traineeship (AENT) and Nurse Anesthetist Traineeship (NAT), facilitate this process by providing financial assistance to students pursuing an advanced practice degree. The AENT and NAT programs provide full or partial reimbursement for the cost of tuition and program fees, and in academic year 2013–2014, supported 5,650 students. Of these recipients, 56 percent received training in medically underserved areas, and 48 percent received training in primary care settings. Furthermore, 40 percent of trainees were from minority or disadvantaged backgrounds.[3]

According to U.S. Census Bureau, individuals from ethnic and minority groups account for more than one-third of the U.S. population, and by year 2044, more than half of all Americans are projected to belong to a minority group.[4, 5] AACN data reveals that approximately 30 percent of nursing students at each level (baccalaureate, master's and doctoral) represent minority populations.[6] As America's population becomes increasingly diverse, it is important that our Nation's healthcare workforce reflects the patients it serves and that care is delivered in a culturally competent manner. Strengthening representation from minority groups within the nursing pipeline will be particularly critical in over the next few decades.

The Title VIII Workforce Diversity Grants program specifically targets groups under-represented in nursing by awarding grants and contract opportunities to schools of nursing, nurse-managed health centers, academic health centers, State or local governments, and nonprofit entities looking to increase access to nursing education for these students. In academic year 2013–2014, the program supported 16,997 students and aspiring students, partnering with over 1,000 clinical training sites, of which 54 percent were located in medically underserved areas.[3] The goals of this program directly align with the IOM Future of Nursing report which recommends a renewed focus on diversity in nursing education as the Nation looks to enhance the workforce to meet patient needs.[2]

Other equally important components of education, practice, and patient needs that Title VIII programs address include developing highly-educated nursing faculty, loan repayment and scholarship opportunities for students in exchange for service in a Critical Shortage Facility, supporting education of students who care for geriatric patients, and providing assistance for projects within schools of nursing, academic health centers, and nurse-managed health clinics. The dollars invested in Title VIII programs not only benefit the direct recipients, but also the countless patients that receive care from nurses and nursing students supported by these programs. AACN respectfully requests $244 million for the Title VIII Nursing Workforce Development programs in fiscal year 2016.

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[1] Institute of Medicine. (2010). Future of Nursing: Leading Change, Advancing Health Report Recommendations. Retrieved from: http://www.iom.edu/Reports/2010/The-Future-of-Nursing-Leading-Change-Advancing-Health/Recommendations.aspx.

[2] U.S. Bureau of Labor Statistics. (2014). Occupational Outlook Handbook. Registered Nurses. Retrieved from: http://www.bls.gov/ooh/healthcare/registered-nurses.htm.

[3] U.S. Department of Health and Human Services. (2015). Health Resources and Services Administration fiscal year 2016 Justification of Estimates for Appropriations Committees. Retrieved from: http://hrsa.gov/about/budget/budgetjustification2016.pdf.

[4] U.S. Census Bureau. (2012). U.S. Census Bureau Projections Show a Slower Growing, Older, More Diverse Nation a Half Century from Now. Retrieved from: http://www.census.gov/newsroom/releases/archives/population/cb12-243.html.

[5] U.S. Census Bureau. (2015). Projections of the Size and Composition of the U.S. Population: 2014 to 2060. Retrieved from: http://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf.

[6] American Association of Colleges of Nursing. (2014). Policy Brief: The Changing Landscape: Nursing Student Diversity on the Rise. Retrieved from: http://www.aacn.nche.edu/government-affairs/Student-Diversity-FS.pdf.

NATIONAL INSTITUTE OF NURSING RESEARCH: IMPROVING CARE THROUGH EVIDENCE

As one of the 27 Institutes and Centers at the NIH, NINR's work develops knowledge to:

—Build the scientific foundation for clinical practice;

—Prevent disease and disability;

—Manage and eliminate symptoms caused by illness, and;

—Enhance end-of-life and palliative care.[7]

Broadly speaking, these priorities focus on reducing disease and promoting health and wellness across the entire lifespan. Nurse scientists, often working collaboratively with other health professions, generate the evidence that drives practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation. According to 2013–2014 AACN data, there were 5,290 doctoral students pursuing their PhD within AACN member schools.[8] NINR dollars afford budding researchers opportunities to contribute to these priorities through their innovative work.

In addition, NINR is committed to improving the health of the global community and understands that our Nation does not exist in a silo. The state of healthcare abroad impacts foreign and domestic populations. NINR examines how nursing care can improve regions of the world facing severe health and economic challenges. Examples of NINR-funded global health research include reduction of HIV transmission and strengthening community-based outreach to reduce childhood illness.

Lastly, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. NINR training programs such as the Career Transitions awards and Graduate Partnerships Program develop future nurse researchers, many of whom also serve as faculty in our Nation's nursing schools.

AACN respectfully requests $150 million for the NINR in fiscal year 2016. The Ad Hoc Group for Medical Research requests at least $32 billion for NIH in fiscal year 2016, and the request level of $150 million for NINR denotes the same percentage increase for NIH applied to NINR.

Thank you for considering AACN's request of $244 million for the Title VIII Nursing Workforce Development programs and $150 million for the National Institute of Nursing Research in fiscal year 2016. If you have any questions, or if AACN can be of assistance, please contact AACN's Senior Director of Government Affairs and Health Policy, Dr. Suzanne Miyamoto.

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## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

The American Association of Colleges of Osteopathic Medicine (AACOM) strongly supports restoring funding for discretionary Health Resources and Services Administration (HRSA) programs to $7.48 billion; funding for key priorities in HRSA's Title VII programs under the Public Health Service Act; long-term sustainable funding for the Teaching Health Center Graduate Medical Education (GME) Program; sustainment of the National Health Service Corps (NHSC) and other scholarship and loan repayment programs; $4 million for the Rural Physician Training Grants; $32 billion for the National Institutes of Health (NIH); and $375 million in base discretionary funding for the Agency for Healthcare Research and Quality (AHRQ).

AACOM represents the 30 accredited colleges of osteopathic medicine in the United States. These colleges are accredited to deliver instruction at 42 teaching locations in 28 States. In the 2014–2015 academic year, these colleges are educating over 24,600 future physicians—more than 25 percent of new U.S. medical students. Six of the colleges are publicly controlled; 24 are private institutions.

The Title VII health professions education programs, authorized under the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the healthcare workforce, acting as an essential part of the healthcare safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII programs are the only Federal programs designed to train primary care professionals in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the healthcare workforce.

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[7] National Institute of Nursing Research. (2012). Retrieved from: https://www.ninr.nih.gov/sitestructure/faq#nursingresearch.

[8] American Association of Colleges of Nursing. (2015). 2013–2014 Enrollment and Graduations in Baccalaureate and Graduate Programs in Nursing. Washington, DC.

As the demand for health professionals increases in the face of impending shortages, combined with faculty shortages across health professions disciplines, racial and ethnic disparities in healthcare, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile healthcare system. AACOM appreciates the investments that have been made in these programs, and we urge the Subcommittee to include support for the following programs: the Primary Care Training and Enhancement (PCTE) Program, the Rural Physician Training Grants, the Centers of Excellence (COE), the Health Careers Opportunity Program (HCOP), the Scholarships for Disadvantaged Students (SDS) Program, the Geriatric Education Centers (GECs), and the Area Health Education Centers (AHECs).

The PCTE Program provides funding to support awards to primary care professionals through grants to hospitals, medical schools, and other entities. AACOM supports a minimum of $71 million, a $20 million increase above the $51 million in the President's fiscal year 2013 budget and a necessary increase over the fiscal year 2015 budget request of $37 million, to allow for a competitive grant cycle for the PCTE Program's physician training and development.

The Rural Physician Training Grants will help rural-focused training programs recruit and graduate students most likely to practice medicine in underserved rural communities. Health professions workforce shortages are exacerbated in rural areas, where communities struggle to attract and maintain well-trained providers. According to HRSA, approximately 65 percent of primary care health professional shortage areas are rural. AACOM supports the President's fiscal year 2016 budget request of $4 million for the Rural Physician Training Grants.

The COE Program is integral to increasing the number of minority youth who pursue careers in the health professions. AACOM supports the President's fiscal year 2016 budget request of $25 million for the COE Program.

The HCOP provides students from disadvantaged backgrounds with the opportunity to develop the skills needed to successfully compete, enter, and graduate from health professions schools. AACOM supports an appropriation of $14.2 million for HCOP, which would continue the fiscal year 2015 enacted level.

The SDS Program provides scholarships to health professions students from disadvantaged backgrounds with financial need, many of whom are underrepresented minorities. AACOM supports level funding of $46 million for the SDS Program.

GECs are collaborative arrangements between health professions schools and healthcare facilities that provide the training of health professions students, faculty, and practitioners in the diagnosis, treatment, prevention of disease, disability, and other health issues. AACOM supports the President's fiscal year 2016 budget request of $34.2 million for the GECs.

The AHEC Program provides funding for interdisciplinary, community-based, primary care training programs. Through a collaboration of medical schools and academic centers, a network of community-based leaders work to improve the distribution, diversity, supply, and quality of health personnel, particularly primary care personnel in the healthcare services delivery system, specifically in rural and underserved areas. AACOM supports an appropriation of $75 million for the AHEC Program in fiscal year 2016 and strongly opposes the elimination of this vital program in the President's fiscal year 2016 budget.

AACOM has concerns with the Administration's budget request that would cut nearly $16 billion from Medicare GME. Because GME funding is critical to medical residency training across the country, an imperative juncture of the development of the future healthcare workforce, AACOM believes that current GME funding should not be eliminated and simply shifted into other relevant healthcare workforce programs. Instead, additional investments in GME are critical to an already insufficiently-funded system.

AACOM strongly supports the continuation of the THCGME Program, which provides funding to support primary care medical and dental residents training in community-based settings. THCs currently train more than 550 medical and dental residents and are providing more than 700,000 primary care visits in underserved rural and urban communities. This program will also provide long-term benefits. According to the HRSA, physicians who train in THCs are three times more likely to work in such centers and more than twice as likely to work in underserved areas as physicians who train in other settings. We are pleased to see a 2-year extension of this program in H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015, and look forward to its passage in the Senate. We will continue to work with Congress to support a sustainable and viable funding mechanism for the continuation of this successful program. In addition, we support an investment of $10 million minimally in fiscal year 2016 for THC development grants.

The NHSC supports physicians and other health professionals who practice in health professional shortage areas across the U.S. In fiscal year 2014, the NHSC had a total of 9,242 primary care clinicians providing healthcare services. The NHSC projects that a field strength of 15,000 primary care clinicians will be in health professional shortage areas in fiscal year 2016. In addition, more than 1,100 students, residents, and health providers receive scholarships or participate in the Student to Service Loan Repayment Program to prepare to practice. Of the new NHSC scholarships and loan repayment awarded to students (D.O. and M.D.) in fiscal year 2014, 30 percent were awarded to D.O.s. We are pleased to see a 2-year extension of this program in H.R. 2, the Medicare Access and CHIP Reauthorization Act of 2015, and look forward to its passage in the Senate. AACOM supports the continuation and sustainability of this critical program.

Research funded by the NIH leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our Nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends $32 billion for the NIH.

AHRQ supports research to improve healthcare quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our Nation's health and healthcare. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence; however, more investment is needed. AACOM recommends $375 million in base discretionary funding, restoring the base to fiscal year 2011 levels for the AHRQ. This investment will preserve AHRQ's current programs while helping to restore its critical healthcare safety, quality, and efficiency initiatives.

AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the Subcommittee on these important matters.

[This statement was submitted by Stephen C. Shannon, D.O., M.P.H., President and Chief Executive Officer, American Association of Colleges of Osteopathic Medicine.]

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## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF PHARMACY

The American Association of Colleges of Pharmacy (AACP) is pleased to submit this statement for the record regarding fiscal year 2016 funding. The 134 accredited pharmacy schools are engaged in a wide range of programs funded by the agencies of the Department of Health and Human Services (HHS) and the Department of Education. Recognizing the difficult task of balancing needs and expectations with fiscal responsibility, AACP respectfully requests that the following agencies and programs be funded appropriately as you undertake your deliberations:

—Health Resources and Services Administration (HRSA)—$7.48 billion
  —Title VII & VIII—$524 million
—Agency for Healthcare Research and Quality (AHRQ)—$375 million
—Centers for Disease Control and Prevention (CDC)—$7.8 billion
  —National Center for Health Statistics (NCHS)—$172 million
—National Institutes of Health (NIH)—$32 billion

In addition, AACP respectfully requests that the Fund for the Improvement of Post-Secondary Education (FIPSE) be funded at $100 million and that the maximum Pell grant appropriated discretionally be maintained at $4860.

### U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

*Health Resources and Services Administration (HRSA).*—AACP supports the Friends of HRSA recommendation of $7.48 billion for HRSA in fiscal year 2016. Dr Bryan Love from the South Carolina College of Pharmacy received $94.900 from HRSA to research the connection between antibiotics and food allergies in children. Faculty at schools of pharmacy are integral to the success of many HRSA programs conducting research on rural health delivery via telemedicine. Schools of pharmacy are supported by HRSA to operate some of the 57 Poison Control Centers. AACP supports the Bureau of Health Workforce (BHW) and the National Center for Health Workforce Analysis (NCHWA). Through the Pharmacy Workforce Center, AACP joins HRSA-funded efforts to compile national health workforce statistics to better inform future health professions workforce needs in the United States. AACP supports the Health Professions and Nursing Education Coalition (HPNEC) recommendation of $524 million for Title VII and VIII programs in fiscal year 2016.

AACP member institutions are active participants in BHW programs. Schools of pharmacy participate in Title VII programs, including Geriatric Education Centers and Area Health Education Centers (AHEC). These community-based, interprofessional programs are essential for supporting innovative educational models addressing national issues at the local level through team-based, patient-centered care. They serve as valuable experiential education sites for student pharmacists and other health professions students. Pharmacy schools are eligible to participate in the Centers of Excellence program and the Scholarships for Disadvantaged Students program, to increase the number of underserved individuals attending health professions schools and increase minority health workforce representation. Colleges of pharmacy, including Xavier University of Louisiana, develop and maintain centers of excellence in diversity supported by HRSA Centers of Excellence grants.

*Agency for Healthcare Research and Quality (AHRQ)*.—AACP supports the Friends of AHRQ recommendation of $375 million in budget authority for AHRQ programs in fiscal year 2016. Pharmacy faculty are strong partners with the Agency for Healthcare Research and Quality (AHRQ). Dr. C. Daniel Mullins, at the University of Maryland, received $995,295 to study patient-centered involvement in evaluating effectiveness of treatment.

*Centers for Disease Control and Prevention (CDC)*.—AACP supports the CDC Coalition recommendation of $7.8 billion for CDC core programs in fiscal year 2016 and the Friends of NCHS recommendation of $172 million for the National Center for Health Statistics. Information from the NCHS is essential for faculty engaged in health services research and for the professional education of the pharmacist. The educational outcomes for pharmacy graduates include those related to public health. The opportunity for pharmacists to identify potential public health threats through regular interaction with patients provides public health agencies with on-the-ground epidemiologists providing risk identification measures when patients seek medications associated with preventing and treating travel-related illnesses. Pharmacy faculty are engaged in CDC-supported research and activities including delivery of immunizations, integration of pharmacogenetics in the pharmacy curriculum, inclusion of pharmacists in emergency preparedness, and the Million Hearts campaign. Dr. Leigh Ann Ross and Dr. Lauren S. Bloodworth, at the University of Mississippi received $406,978 from the CDC and the Mississippi State Department of Health for the Pharmacy Cardiovascular Risk Reduction Project.

*National Institutes of Health*.—AACP supports the Adhoc Group for Medical Research recommendation of at least $32 billion for NIH funding in fiscal year 2016. Pharmacy faculty are supported in their research by nearly every institute at the NIH. The NIH-supported research at AACP member institutions spans the full spectrum from the creation of new knowledge through the translation of that new knowledge to providers and patients. In fiscal year 2013, pharmacy faculty researchers received nearly $311 million in grant support from the NIH. Academic pharmacy sustains a strong commitment to increasing the number of biomedical researchers. Dr. Gunda George, at the University of Minnesota, received $8,300,000 to design, synthesize and evaluate non-hormonal contraceptives or men and women. Dr. Eli Chapman and Dr. Donna Zhang, at the University of Arizona received $1,700,000 to study, "Stress response, p97 and Nrf2 in arsenic-medicated toxicity."

U.S. DEPARTMENT OF EDUCATION

The Department of Education supports the education of healthcare professionals by assuring access to education through student financial aid programs, educational research allows faculty to determine improvements in educational approaches; and the oversight of higher education through the approval of accrediting agencies. AACP supports the Student Aid Alliance's recommendations to maintain the discretionary contribution to the $4860 maximum Pell grant. Admission to a pharmacy professional degree program requires at least 2 years of +undergraduate preparation. Student financial assistance programs are essential to assuring student have access to undergraduate, professional and graduate degree programs. AACP recommends a funding level of at least $100 million for the Fund for the Improvement of Post-Secondary Education (FIPSE) as this is the only Federal program that supports the development and evaluation of higher education programs that can lead to improvements in higher education quality.

[This statement was submitted by William Lang, Senior Policy Advisor, American Association of Colleges of Pharmacy.]

## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), the world's largest professional society of research scientists and physicians who study the immune system, respectfully submits this testimony regarding fiscal year 2016 appropriations for the National Institutes of Health (NIH). AAI recommends an appropriation of at least $32 billion for NIH for fiscal year 2016 to fund important ongoing research, strengthen the biomedical research enterprise, and ensure that the most talented scientists, trainees, and students are able to pursue careers in biomedical research in the United States.

### NIH'S ESSENTIAL ROLE IN ADVANCING BIOMEDICAL RESEARCH

As the Nation's main funding agency for biomedical and behavioral research, NIH supports the work of "more than 300,000 researchers at more than 2,500 universities, medical schools, and other research institutions in every State and around the world." [1] More than 80 percent of the NIH budget is awarded to these scientists through nearly 50,000 competitive grants; about 10 percent of the NIH budget supports the work of the almost 6,000 government researchers who work in NIH laboratories or at the NIH Clinical Center.[2]

NIH funding is a vitally important economic engine in the communities and States where these researchers work; in fiscal year 2012, NIH-funded research supported an estimated 402,000 jobs across the United States." [3]

NIH also provides crucial scientific leadership to the entire biomedical research enterprise, both within and beyond our borders. Advancing basic research from bench to bedside requires extensive collaboration among scientists from academia, government,[4] and industry; all depend on NIH personnel and policies to guide and facilitate their efforts in this enormous, complicated, and high-stakes endeavor. In fact, the biotechnology and pharmaceutical industries rely heavily on NIH's investment in basic biomedical research; it is often this research that industry uses or further explores to develop new drugs and medical devices.[5]

### EROSION OF NIH BUDGET SLOWS RESEARCH AND THREATENS U.S. PREEMINENCE

Although NIH funds most biomedical research in the United States, its purchasing power has been dramatically reduced by inadequate budgets that have been further eroded by inflation.[6] In fiscal year 2015, NIH's purchasing power is 22 percent lower than it was in fiscal year 2003, when the 5-year NIH budget doubling period ended.[7] This reduced purchasing power enables NIH to fund only ~16.8 percent of grant applications submitted, a steep decline from the ~32.4 percent it funded when its budget was robust.[8] This loss is not only a barrier to advancing cru-

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[1] Http://www.nih.gov/about/budget.htm. NIH funds also support the work of non-scientist technical personnel.

[2] Ibid.

[3] Http://nih.gov/about/impact/economy.htm.

[4] AAI opposes a Federal policy that limits government scientists' ability to attend privately sponsored scientific meetings and conferences (see http://www.hhs.gov/travel/policies/2012_policy_manual.pdf) and believes that "the rules have had an unintended and deleterious effect . . . [and] made government scientists feel cut off from the rest of the scientific community, wreaked havoc with their ability to fulfill professional commitments, and undermined the morale of some of the government's finest minds." Testimony (Amended) of Lauren G. Gross, J.D., on behalf of The American Association of Immunologists (AAI), Submitted to the Senate Homeland Security and Governmental Affairs Committee for the Hearing Record of January 14, 2014: "Examining Conference and Travel Spending Across the Federal Government" (http://aai.org/Public_Affairs/Docs/2014/AAI_Testimony_to_Senate_HSGAC_01142014.pdf).

[5] "[NIH] . . . annual research funding . . . is the most important source of discoveries in the health sciences that ultimately leads to the development of important new therapeutics . . . ." Statement of Roger Perlmutter, Ph.D., Executive Vice President, Research & Development, Amgen, June 15, 2005 http://www.rdmag.com/articles/2005/06/managing-rapid-biotech-growth.

[6] "In 12 of the past 13 years, NIH funding has either been cut or has failed to outpace rising costs." Federation of American Societies for Experimental Biology, Funding Trends, 2015. http://www.faseb.org/Portals/2/PDFs/opa/2015/2.10.15%20NIH%20Funding%20Cuts%202-pager.pdf?pdf=2.10.15%20NIH%20Funding%20Cuts%202-pager.

[7] Johnson, Judith A., "NIH Funding: fiscal year 1994-fiscal year 2016," Congressional Research Service, R43341, pp. 2–3 (2015). Measured in constant 2012 dollars. Excludes funding from the American Recovery and Reinvestment Act (ARRA).

[8] Research Project Grant Award Rate ("the likelihood of an individual application submission getting funded"). Rockey, Sally, "Comparing Success Rates, Award Rates, and Funding Rates," Rock Talk, March 5, 2014. RPG success rates ("the number of awards made divided by the sum of the applications reviewed that fiscal year where revisions submitted in the same fiscal year

Continued

cially important research, it is also devastating to those who are currently engaged in—or considering—a career in biomedical research. Researchers around the country are closing labs, losing jobs, and in some cases, moving overseas, where support for biomedical research is rapidly growing.[9] Many who do stay in the U.S. are engaged in an unrelenting and time consuming search for funding, when they should be conducting research and mentoring the Nation's future researchers, doctors, inventors and innovators. Most importantly of all, we will never know what research has not been pursued—or how many potential treatments and cures have not been discovered—because of inadequate funding.

THE IMMUNE SYSTEM: ESSENTIAL TO OUR HEALTH, CRUCIAL TO OUR FUTURE

The importance of the immune system to human and animal health cannot be overstated, and has even been noted in Congress. In response to testimony by Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases, Senator Richard Shelby (R–AL), a senior member of the Senate Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee, correctly observed that "immunology kind of transcends it all." [10]

As the body's primary defense against viruses, bacteria, and parasites, the immune system protects its host from a wide range of diseases and disorders. When it is operating properly, the immune system can provide powerful protection against many illnesses, including cancer, Alzheimer's disease, and cardiovascular disease. When it underperforms, it can leave the body vulnerable to infections, such as influenza, HIV/AIDS, tuberculosis, malaria, and the common cold. The immune system can also become overactive and attack normal organs and tissues, causing autoimmune diseases including allergy, asthma, inflammatory bowel disease, lupus, multiple sclerosis, rheumatoid arthritis, and type 1 diabetes.

Immunologists are on the front lines, working to harness the immune system to protect people and animals from chronic and acute diseases and disorders, as well as from natural or man-made infectious organisms (including Ebola, plague, smallpox and anthrax) that could be used for bioterrorism.

RECENT IMMUNOLOGICAL ADVANCES: PROVIDING HOPE FOR TODAY—AND TOMORROW

*Ebola Outbreak: Finding a Vaccine to Save Lives*

The 2014 Ebola virus outbreak in West Africa is the largest in recorded history. Due to the historically low incidence of infection, development of anti-Ebola therapeutics and vaccines had not been a priority for public health officials or pharmaceutical companies. However, ongoing investments in biomedical research by the Federal Government, including NIH and the Department of Defense, have led to the development of several promising vaccine candidates, two of which are now being administered through clinical trials in the outbreak region and may well aid in preventing this deadly disease.[11] Although pharmaceutical companies are now involved in the manufacture of these vaccine candidates and other potential therapies, it is Federal taxpayer dollars that funded the research that is the cornerstone of the current Ebola virus response.[12] Ongoing biomedical research in areas like Ebola and other emerging infectious diseases, where the public health benefit outweighs the potential commercial benefit, depends heavily on Federal dollars.

*A New Way to Stop HIV . . . and Other Infections and Diseases?*

Researchers have recently discovered that Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) systems—immune mechanisms used by bacteria to

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are collapsed and counted as one application") have also decreased drastically, from 32.4 percent to 18.1 percent. See http://nexus.od.nih.gov/all/2014/03/05/comparing-success-award-funding-rates/.

[9] Moses, H., et al. The Anatomy of Medical Research: U.S. and International Comparisons. JAMA 313, 174–189 (2015). Losing our best and brightest to burgeoning overseas interest and investment in biomedical research is neither specious nor unrealistic: after adjusting for inflation. According to Moses et al., while U.S. funding for biomedical and health services research increased at a rate of 6 percent per year from 1994–2004, it decreased to just 0.8 percent annually from 2004–2012.

[10] NIH fiscal year 2015 Budget Request: hearing before the Senate Appropriations Committee Subcommittee on Labor, Health and Human Services, Education, and Related Agencies, April 2, 2014, 113th Congress, second session (Comments of Senator Richard Shelby).

[11] Ledgerwood, J. E. et al. Chimpanzee Adenovirus Vector Ebola Vaccine-Preliminary Report. N. Engl. J. Med. 0, null (0).

[12] Wong, G., et al. Intranasal immunization with an adenovirus vaccine protects guinea pigs from Ebola virus trans-mission by infected animals. Antiviral Res. 116, 17–19 (2015); Stanley, D. A. et al. Chimpanzee adenovirus vaccine generates acute and durable protective immunity against ebolavirus challenge. Nat. Med. 20, 1126–1129 (2014).

defend themselves from virus infection—present a novel therapeutic tool for immunologists, enabling them to successfully disrupt HIV replication, stop the growth of human cervical cancer cells and kill antibiotic-resistant bacteria.[13] Immunologists are also exploring the use of CRISPR to repair defective genes in stem cells, which may treat diseases like sickle cell anemia and immune deficiencies.[14]

*Cancer Immunotherapies: Real Results in the Fight Against Cancer*

Lauded by Science magazine in 2013 as "The Science Breakthrough of the Year," the genetic engineering of a cancer patient's T cells (immune cells) to kill the patient's own cancer cells, a procedure known as immunotherapy, continues to advance.[15] At NIH funded medical centers, scientists and doctors are observing a significant regression of blood cancers (non-solid tumors) in both children and adults.[16] This therapy, which the FDA granted Breakthrough Therapy designation in July 2014 (which can expedite approval of a therapeutic based on clear clinical efficacy), is poised to be used for even more difficult-to-treat solid tumor cancers, and is helping to inform ongoing clinical trials in breast, lung, prostate and brain cancer.[17] The success of these therapies has also attracted the investment of pharmaceutical companies and has led to the development of several new T cell therapy-focused biotechnology companies, illustrating how investment in NIH funded research creates opportunity—and jobs—in the private sector.

*New Therapeutic Provides Real Hope for Autoimmune Treatment*

In January 2015, the FDA approved the first of a new and highly effective class of treatments for psoriasis, a serious autoimmune skin disease.[18] The new treatment inhibits IL–17 signaling, a process which initiates inflammation and which was first discovered by NIH funded researchers in 2005.[19] This treatment has proven effective in Phase II clinical trials, with more than 70 percent of psoriasis patients showing over 75 percent clearance of disease, and nearly half showing 100 percent clearance of disease.[20] Clinical trials targeting similar aspects of this pathway are yielding promising results and may offer hope to those suffering from other autoimmune diseases, including ankylosing spondylitis, rheumatoid arthritis, and multiple sclerosis.[21]

## CONCLUSION

AAI greatly appreciates the strong bipartisan support for NIH and biomedical research that has been expressed by the members and staff of the subcommittee. In order to support important ongoing research, fund a reasonable number of outstanding new grant applications, and restore NIH funding to a level that can sustain a robust and dynamic biomedical research enterprise in the United States, AAI urges the subcommittee to provide NIH with an appropriation of at least $32 billion for fiscal year 2016.

[This statement was submitted by Clifford V. Harding, M.D., Ph.D., American Association of Immunologists.]

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PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

FISCAL YEAR 2016 APPROPRIATIONS REQUEST SUMMARY

[Dollars in millions]

| | Fiscal year 2014 actual | Fiscal year 2015 enacted | AANA fiscal year 2016 request |
|---|---|---|---|
| HHS/HRSA/BHPr Title 8 Advanced Education Nursing, Nurse Anesthetist Traineeship. | $2.94 | $2.25 | $4 million for nurse anesthesia traineeship |
| Total for Advanced Education Nursing, from Title 8 ..... | 61.089 | 63.581 | 66.760 million for advanced education nursing |
| Title 8 HRSA BHPr Nursing Education Programs ..... | 217.50 | 231.62 | 244 |

*About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)*

The AANA is the professional association for more than 48,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 38 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some States are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons. CRNAs provide high quality anesthesia care to all patient types and case complexities.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report To Err is Human found in 2000 that anesthesia was 50 times safer than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. To Err is Human. Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a study published in Health Affairs led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999–2005, the study compared anesthesia outcomes in 14 States that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 States have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out States alike. (Dulisse B, Cromwell J. No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians. Health Aff. 2010;29(8):1469–1475.)

CRNAs have provided the majority of anesthesia to our active duty military in combat arenas since World War I and predominate in Veterans hospitals and the U.S. Armed Services through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. Medicare and private payment differences for anesthesia services. GAO–07–463, Washington DC, Jul. 27, 2007. http://www.gao.gov/products/GAO-07-463).

*Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding*

Our profession's chief request of the Subcommittee is for $4 million to be reserved for nurse anesthesia traineeships and $66.760 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of $244 million. We request that the Report accompanying the fiscal year 2016 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding at least at the fiscal year 2015 level for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request

made by The Nursing Community with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this Subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their healthcare needs, funding the advanced education nursing program at $66.760 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S. The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings. A 2007 AANA nurse anesthesia workforce study found a 12.6 percent CRNA vacancy rate in hospitals and a 12.5 percent faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2002–2016, the annual number of expected nurse anesthesia educational program graduates increased from 1,362 to 2,559, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 85 to 114. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our 114 nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors—and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated and licensed registered nurse who has spent a minimum of 1 year serving in an acute care healthcare practice environment. On average a CRNA applicant obtains 3 years of experience in a critical care unit prior to beginning an anesthesia program. They are prepared in nurse anesthesia educational programs located all across the country, including Alabama, Hawaii, Illinois, Kansas, Louisiana, Maryland, Missouri, Mississippi, New Hampshire, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Washington, West Virginia, and Wisconsin. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of Federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. Nursing Economic$, Vol. 28 No. 3, May-June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded Federal funding in support of CRNA educational programs.

*Support for Safe Injection Practices and the Alliance for Injection Safety*

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects involving injection safety. We support the efforts that the CDC's Division of Healthcare Quality and Promotion has taken regarding its injection safety activities, including provider education and awareness, detection, tracking and response.

[This statement was submitted by Sharon P. Pearce, CRNA, MSN, President, American Association of Nurse Anesthetists.]

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## PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PHYSICIANS

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for fiscal year 2016. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 141,000 internal medicine physicians (internists), related sub-

specialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. As the Subcommittee begins deliberations on appropriations for fiscal year 2016, ACP is urging funding for the following proven programs to receive appropriations from the Subcommittee:

—Title VII, Section 747, Primary Care Training and Enhancement, at no less than $71 million;
—National Health Service Corps, $810 million in total program funding, including at least $287.4 million through discretionary appropriations;
—National Health Care Workforce Commission, $3 million;
—Agency for Healthcare Research and Quality, $375 million.

The United States is facing a shortage of physicians in key specialties, notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), the Congressional Budget Office has estimated, as of March 2015, the demand for primary care services will increase with the addition of 25 million Americans receiving access to health insurance, including an additional 14 million under Medicaid/CHIP, once the law is fully implemented. With increased demand, current projections indicate there will be a shortage of 12,500 to 31,100 primary care physicians by 2025. (IHS Inc., prepared for the Association of American Medical Colleges. The Complexities of Physician Supply and Demand: Projections from 2013 to 2025. March 2015. Accessed at: https://www.aamc.org/download/426260/data/physiciansupplyanddemandthrough2025keyfindings.pdf). Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care (http://www.acponline.org/advocacy/where__we__stand/policy/primary__shortage.pdf).

The health professions' education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of healthcare providers to enhance the supply, diversity, and distribution of the healthcare workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical in helping institutions and programs respond to the current and emerging challenges of ensuring that all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the Subcommittee to fund the Section 747, Primary Care Training and Enhancement program at $71 million, in order to maintain and expand the pipeline for individuals training in primary care. The Section 747 program is the only source of Federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models emphasizing interdisciplinary training that have helped prepare them to work with other health professionals, such as physician assistants, patient educators, and psychologists. Without a substantial increase in funding, for the fifth year in a row, HRSA will not be able to carry out a competitive grant cycle for physician training; the Nation needs new initiatives supporting expanded training in multi-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges $810 million in total program funding for the National Health Service Corps (NHSC), as requested in the President's fiscal year 2016 budget; this amount includes $287.4 million in discretionary spending through new budget authority and $522.63 million in new mandatory funding. Since the enactment of the ACA, the NHSC has awarded over $1 billion in scholarships and loan repayment to healthcare professionals to help expand the country's primary care workforce and meet the healthcare needs of underserved communities across the country. With a field strength of over 9,000 primary-care clinicians, NHSC members are providing culturally competent care to almost 10 million patients at nearly 15,000 NHSC-approved healthcare sites in urban, rural, and frontier areas. The increase in funds would expand NHSC field strength to 15,000 and would serve the needs of more than 16 million patients, helping to address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the healthcare needs of the underserved, and with increased appropriations, they can do more. For fiscal year 2016, the NHSC's funding situation is particularly urgent. NHSC faces a funding cliff because its mandatory funding expires and it has no current budget authority. Unless Congress acts, there will be no fiscal year 2016 funding source in the Federal budget for NHSC. Accord-

ingly, the College also supports the Medicare Access and CHIP Reauthorization Act, H.R. 2, which would keep the NHSC at its fiscal year 2015 funding level for fiscal year 2016 and fiscal year 2017 (through an extension of mandatory resources).

We urge the Subcommittee to fully fund the National Health Care Workforce Commission, as authorized by the ACA, at $3 million. The Commission is authorized to review current and projected healthcare workforce supply and demand and make recommendations to Congress and the Administration regarding national healthcare workforce priorities, goals, and polices. Members of the Commission have been appointed, but have not begun work due to a lack of funding. The College believes the Nation needs a comprehensive workforce policy founded on sound research to determine the Nation's current and future needs for physicians by specialty and geographic areas; the work of the Commission is imperative, now more than ever, to ensure Congress is creating the best policies for our Nation's needs.

The Agency for Healthcare Research and Quality (AHRQ) is the leading public health service agency focused on healthcare quality. AHRQ's research provides the evidence-based information needed by consumers, clinicians, health plans, purchasers, and policymakers to make informed healthcare decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our Nation's health and recommends a budget of $375 million. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare marketplace more efficient by providing quality measures to health professionals, and, ultimately, help transform health and healthcare.

In conclusion, the College is keenly aware of the fiscal pressures facing the Subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance healthcare system and build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the Subcommittee on these issues and looks forward to working with Congress as you begin to work on the fiscal year 2016 appropriations process.

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## PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing $10 million in fiscal year 2016 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act. ACPM also supports the recommendation of the Health Professions and Nursing Education Coalition of $524 million in fiscal year 2016 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians play an integral role in ensuring effective functioning of our Nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral determinants of health and disease. These are the tools employed by preventive medicine physicians who practice at the health system level where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Medical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties that requires and provides training in both clinical and population-based medicine. Preventive medicine residency training programs provide a blueprint on how to train our future physician workforce; physicians trained to provide individual patient care needs as well as practice at the community and population level to identify and treat the social determinants of health. Preventive medicine physicians have the training and expertise to advance the population health outcomes that public and private payers are increasingly promoting to their providers. These physicians have a strong focus on quality care improvement and are at the forefront of efforts to integrate primary care and public health.

According to the Health Resources and Services Administration (HRSA) and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2014 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had the biggest decrease (−29 percent) in the number of first-year ACGME residents and fellows between 2008 and 2013. This decrease represents a worsening trend in the number of preventive medicine residents and is not due to a lack of interest or need but is due to a lack of funding. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities will lead to major gaps in the expertise needed to deliver clinical prevention and community public health. The impact on the health of those populations served by HRSA is likely to be profound.

Despite being recognized as an underdeveloped national resource and in shortage for many years, physicians training in the specialty of Preventive Medicine are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, State, and community need for properly trained physicians in public health, disaster preparedness, prevention-oriented practices, quality improvement, and patient safety.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high-quality applicants. Support for faculty and tuition has been almost non-existent. Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

HRSA—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents the largest Federal funding source for these programs.

Of note, the preventive medicine residency programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

—Thirty-five percent of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost 3.5 times the average for all health professionals. These physicians are meeting a critical need in these underserved communities.

—Nearly one in five preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.

—Fourteen percent of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our Nation's health and prosperity. Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary approach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. ACPM applauds the initiation of programs such as the Community Transformation Grant that take this broad view of the determinants of chronic disease. However, any efforts to strengthen the public health infrastructure and transform our communities into places that encourage healthy choices

must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the leaders of our Nation's local and state health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our Nation's health. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing $10 million in fiscal year 2016 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.

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## PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists, representing 58,000 physicians and partners in women's healthcare, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies. We thank Chairman Blunt and the entire Subcommittee for this opportunity to provide comments on some of the most important programs to women's health.

Today, the U.S. lags behind many other nations in healthy births. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative would help improve maternal and infant health through Federal research investments, including comprehensive data collection and surveillance, biomedical research, and translating research into evidence-based care for women and babies. We urge you to make funding of the following programs and agencies a top priority in fiscal year 2016.

*Data Collection and Surveillance at the Centers for Disease Control and Prevention (CDC)*

In order to conduct robust research, uniform, accurate and comprehensive data and surveillance are critical. The National Center for Health Statistics is the Nation's principal health statistics agency and collects State data from records like birth certificates that give us raw, vital statistics. Information from birth and death certificates is key to gathering vital information about both mother and baby during pregnancy and labor and delivery. Uniform, accurate data collection depends on all States and territories using electronic birth and death records based on the 2003 US-standard birth and death certificates. Although all 50 States are expected to have the electronic birth record systems available by the end of 2015, there are 5 States that are still in the early stages of planning and implementing the electronic death registry system. Even in States where the overall system has been implemented, there remains a need for expanded access and increased training in order to utilize these systems effectively. In most States with electronic systems in place, there remains a reliance on paper record-keeping as well, creating an inefficient hybrid record situation that compromises the efficiency and accuracy of an electronic record system.

States not using the standard records likely underreport maternal and infant deaths and complications from childbirth; causes of these deaths remain unknown. Previous appropriations have helped increase the number of States using electronic birth and death registries, but NCHS needs increased resources to help enroll the remaining States, and to improve the accuracy of birth and death data, including through linking data from Electronic Health Records to state vital records systems. For fiscal year 2016, ACOG requests $172 million for the National Center for Health Statistics, $5 million of which we urge you to designate to modernize the National Vitals Statistics System, helping States fully implement the updated birth and death records systems.

The Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC extends beyond vital statistics and surveys new mothers on their experiences and attitudes during pregnancy, with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, CDC researchers and State health departments are better able to identify behaviors and

environmental and health conditions that may lead to preterm births. Only 40 States use the PRAMS surveillance system today. ACOG requests adequate funding to expand PRAMS to all U.S. States and territories.

*Biomedical Research at the National Institutes of Health (NIH)*

Biomedical research is critically important to understanding the causes of maternal and infant mortality and morbidity, and developing effective interventions to lower the incidence of mortality and morbidity. The National Institute on Child Health and Human Development's (NICHD's) 2012 Scientific Vision identified the most promising research opportunities for the next decade. Goals include determining the complex causes of prematurity and developing evidence-based measures for its prevention within the next 10 years, understanding the long term health implications of assisted reproductive technology, and understanding the role of the placenta in fetal health outcomes. The placenta, one of the least studied human organs, is essential to the viability and proper growth of the fetus. NICHD's Human Placenta Project will help discover the causes of placental failures, and ultimately ways to prevent failure and improve maternal and fetal birth outcomes.

In addition, adequate levels of research require a robust research workforce. The years of training combined with uncertainty in getting grant funding are huge disincentives for students considering a career in bio-medical research. This has resulted in a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. We urge continued investments in the Women's Reproductive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) programs to address the shortfall of women's reproductive health researchers. ACOG supports a minimum of $32 billion for NIH and $1.37 billion within that funding request for NICHD in fiscal year 2016.

*Public Health Programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC)*

Projects at HRSA and CDC are integral to translating research findings into evidence-based practice changes in communities. Where NIH conducts research to identify causes of maternal and infant mortality and morbidity, CDC and HRSA help ensure those research findings lead to improved maternal and infant health outcomes.

Maternal Child Health Block Grant (HRSA): The Maternal Child Health Block Grant at HRSA is the only Federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special healthcare needs, support comprehensive prenatal and postpartum care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early healthcare services help keep women and children healthy, eliminating the need for later costly care. Every $1 spent on preconception care for a woman with diabetes can save up to $5.19 by preventing costly complications. Over $90 million has been cut from the Block Grant since 2003. ACOG requests $639 million for the Block Grant in fiscal year 2016 to maintain its current level of services.

Title X Family Planning Program (HRSA): Family planning and interconception care are essential to helping ensure healthy women and healthy pregnancies. The Title X Family Planning Program provides services to more than 4.5 million low income men and women who may not otherwise have access to these services. Title X clinics accounting for $5.3 billion in healthcare savings in 2010 alone. ACOG supports $327 million for Title X in fiscal year 2016 to sustain its level of services.

Fetal Infant Mortality Review (HRSA): HRSA's Healthy Start Program promotes community-based programs to reduce infant mortality and racial disparities. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to address local issues contributing to infant mortality. Today, more than 172 local programs in 32 States find FIMR a powerful tool to help reduce infant mortality and address issues related to preterm delivery. ACOG has partnered with the Maternal and Child Health Bureau to sponsor the National FIMR Program for 25 years. ACOG supports $0.5 million in fiscal year 2016 for HRSA to increase the number of Healthy Start programs that use FIMR.

Maternal Health Initiative (HRSA): The Maternal Child Health Bureau launched the Maternal Health Initiative to foster the notion of "healthy moms make healthy babies." As part of this effort, ACOG has convened the National Partnership on Maternal Safety to identify key factors to reduce maternal morbidity and mortality.

ACOG requests, at a minimum, level funding for MCHB to advance this important work.

Safe Motherhood, Maternity and Perinatal Quality Collaboratives (CDC): The Safe Motherhood Initiative at CDC works with state health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. Through Safe Motherhood, CDC funds State-based Maternity and Perinatal Quality Collaboratives that improve birth outcomes by encouraging use of evidence-based care, including reducing early elective deliveries. For instance, through the Ohio Perinatal Quality Collaborative, started in 2007 with funding from CDC, 21 OB teams in 25 hospitals have significantly decreased early non-medically necessary deliveries, in accordance with ACOG guidelines, reducing costly and dangerous pre-term births. Avalere estimated that reducing early elective deliveries can save from $2.4 million to $9 million a year. Currently, there are active Perinatal Quality Collaboratives in Maryland and Washington that have both demonstrated significant progress in reducing early elective deliveries, among other quality improvement initiatives. Mississippi launched its first Perinatal Quality Collaborative just a few months ago, in November 2014. None of these three States are currently receiving any Federal funding for their collaborative efforts. There is no existing Perinatal Quality Collaborative in Missouri at this time. The PREEMIE Reauthorization Act, enacted in 2013, authorizes funding to increase the number of States receiving assistance for Perinatal Quality Collaboratives. ACOG urges you to reinstate the pre-term birth sub-line at a funding level of $2 million, as authorized by PREEMIE, and fund the Safe Motherhood Initiative at $46 million to implement PREEMIE and help States expand or establish Maternity and Perinatal Quality Collaboratives.

*Advancing Maternal Therapeutics at the Department of Health and Human Services (HHS)*

Each year, more than 4 million women give birth in the United States and more than 3 million breastfeed their infants. However, little is known about the effects of most drugs on the woman and her child, or the ways in which pregnancy and lactation alter the uptake, metabolism, and effect of medication. Pregnant and breastfeeding women have historically been excluded from most research trials. Although there have been substantial encouraging developments in this arena, including the recent release of a final drug labeling rule on pregnancy and lactation by FDA and relevant research at NIH and CDC, significant gaps remain. In order to achieve meaningful progress, HHS must ensure the coordination of all efforts being made at the agency level. As such, ACOG supports the establishment of a Federal work group to improve coordination and provide guidance on how clinical research might be done appropriately in this area.

*Quality Assessment Programs at the Agency for Healthcare Research and Quality (AHRQ)*

Consumer Assessment of Healthcare Providers and Systems (CAHPS): The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program was established within AHRQ in 1995 to address concerns regarding the lack of available consumer health plan reviews. The information collected through the CAHPS program can be a critical element of patient decisionmaking, while also informing providers and insurers about the impact and reception of their initiatives and services. Unfortunately, the CAHPS program has not yet established a survey to collect data about maternity care. Given the frequency and complex nature of interactions that an expectant mother will have with an effective healthcare system, we support the creation of a CAHPS survey focused on maternity care. ACOG encourages the CAHPS program to direct funds towards the development of a maternity care-oriented assessment.

Again, we would like to thank the Committee for its commitment to improving women's health, and we urge you to fund the programs we have identified in our MOMS Initiative in fiscal year 2016.

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## PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA) represents all 65 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions. ADEA submits this testimony for the record and for your consideration as you begin prioritizing fiscal year 2016 appropriation requests.

ADEA urges you to protect the funding and fundamental structure of Federal programs that provide access to oral healthcare to millions of Americans, train the next generation of oral healthcare professionals and enable globally recognized cutting-edge dental and craniofacial research.

ADEA's academic dental institutions train future practitioners and researchers. Also, as one of the major providers of dental care in some Federal programs, these institutions provide significant dental safety-net care through campus and offsite dental clinics where students and faculty deliver dental healthcare to uninsured and underserved populations. Moreover, since it has been proven that good oral health is inextricably linked to good systemic health, the need to provide access to oral healthcare is critical. However, in order to provide these services, there must be adequate funding. Therefore, we ask the committee to help ADEA's dental schools continue to provide care to all segments of the population, including perhaps your constituents, by maintaining adequate funding for programs focused on access to oral healthcare, training for oral healthcare providers and cutting-edge dental and craniofacial research. Specifically, we request that you maintain and protect funding for:

—Title VII of the Public Health Service Act;
—National Institutes of Health (NIH);
—National Institute of Dental and Craniofacial Research (NIDCR);
—Dental Health Improvement Act;
—Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program; and
—Centers for Disease Control and Prevention (CDC), State-Based Oral Health Programs.

The above programs fund public health programs proven to prevent oral disease, fund research to eradicate dental disease, detect certain cancers and fund programs to develop an adequate dental workforce with advanced training to serve underserved populations including children, the elderly and those suffering from chronic immunocompromised conditions and life-threatening diseases. ADEA respectfully makes the following funding requests:

*$35 million: Title VII, Section 748, Public Health Service Act*

The dental programs in Title VII, Section 748 of the Public Health Service Act, provide critical training in general, pediatric and public health dentistry and dental hygiene. Support for these programs will help ensure an adequate oral healthcare workforce. The funding supports predoctoral oral health education and postdoctoral pediatric, general and public health dentistry training. The investment made by Title VII not only educates dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general or public health dentistry and dental hygiene. There are currently almost 200 open budgeted faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty. ADEA is increasingly concerned that with projected restrained funding, the oral health research community will not be able to grow and that the pipeline of new researchers will be inadequate to the future need.

Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the healthcare workforce. For the last several years, these programs have not received adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population. ADEA is most concerned that the Administration did not request any funds for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for oral health professionals serving underserved and disadvantaged patients by providing a pipeline for such individuals from these populations. This unique workforce program encourages young people from diverse and disadvantaged backgrounds to explore careers in healthcare generally and dentistry specifically. The president's budget request seeks to "rebrand" the HCOP program as the Health Workforce Diversity Program (HWDP). ADEA supports the goals of this proposed new program as long as the current funding follows the new program.

For example, a collaboration between the University of Connecticut's Schools of Dental Medicine and Medicine have used HCOP grants to perform extensive outreach to universities, including Historically Black Colleges and Universities (HBCU). The program supports 30-week and six-week summer science enrichment programs in middle schools and several high school programs. In addition, at the

college level, the two schools conduct a seven-week Health Disparities Clinical Summer Research Fellowship program that explores an introduction to health disparities, cross-cultural issues, principles of clinical medicine and skills for public health research and interventions and techniques for working with diverse populations.

UCONN's program is illustrative of programs that dental schools at the Universities of Iowa, Kansas, Maryland-Baltimore, South Alabama, Marquette and Michigan have sponsored. The Health Resources and Services Administration (HRSA) reports that the average grant is only $670,000 and reaches over 7,100 students from underserved and disadvantaged backgrounds.

If policy makers are serious about eradicating health disparities and providing opportunities for underrepresented minorities and economically disadvantaged individuals in healthcare, they will continue this program at current levels and/or expand it.

Another vital program targeted at enhancing high quality culturally competent care in community-based interprofessional clinical training settings is the Area Health Education Centers (AHEC) program. The infrastructure development grants and point of service maintenance and expansion grants ensure that patients from underserved populations receive quality care in a technologically current setting and that health professionals receive training in treating such diverse populations. ADEA encourages the Committee, in the strongest possible terms, to continue funding the critically important AHEC program.

*$18 million: Ryan White HIV/AIDS Treatment and Modernization Act, Part F: Dental Reimbursement Program (DRP) and Community-Based Dental Partnerships Program*

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. The Dental Reimbursement Program (DRP) is a cost-effective Federal/institutional partnership providing partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. Simultaneously, the program provides educational and training opportunities to dental residents, dental students and allied dental students. However, in fiscal year 2013, DRP only reimbursed 26 percent of the dental schools' unreimbursed costs. The current reimbursement rate is unsustainable. Remembering the adage, good oral care is essential to good overall systemic care, dental care is imperative to the health and well-being of people living with HIV/AIDS.

Adequate funding of the Ryan White Part F programs will help ensure that people living with HIV/AIDS receive critical oral healthcare.

*$425 million: National Institute of Dental and Craniofacial Research (NIDCR)*

Dental research serves as the foundation of the profession of dentistry. Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for millions of Americans and uncovered important links between oral and systemic health. With grants from NIDCR, dental researchers in academic dental institutions have garnered scientific and clinical knowledge used to enhance the quality of the Nation's oral, and overall, health. Dental researchers are poised to make breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples (such as HIV and certain types of cancer); and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic and biological factors. These breakthroughs, which continue America's role as a global scientific leader, require adequate funding.

*$20 million: Division of Oral Health, Centers for Disease Control and Prevention (CDC)*

The CDC Division of Oral Health expands the coverage of effective prevention programs. The Division increases the basic capacity of State oral health programs to accurately assess the needs of the State, organize and evaluate prevention programs, develop coalitions, address oral health in State health plans and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of oral disease affecting children and vulnerable populations. The current path of decreased funding will have a significant negative effect upon the overall health and preparedness of the Nation's States and communities.

ADEA thanks you for your consideration of these funding requests. ADEA and its 65 member institutions, looks forward to working with you to ensure the continuation of congressional support for these critical programs.

Please use ADEA as a resource on any matter pertaining to academic dentistry under your purview. Contact Yvonne Knight, J.D., Senior Vice President for Advocacy and Governmental Relations.

Visit our Web site for additional information about ADEA at http://www.adea.org/
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## PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

### INTRODUCTION

On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding fiscal year 2016 appropriations. ADHA appreciates the Subcommittee's past support of programs that seek to improve the oral health of Americans and to bolster the oral health workforce. Oral health is a part of total health and authorized oral healthcare programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved. ADHA particularly appreciates the Subcommittee's rejection of the block on funding for Section 340G–1 of the Public Health Service Act—a much-needed dental workforce demonstration program. We urge even more vigorous efforts this year to ensure that the fiscal year 2016 HHS funding bill lifts the block and that $2 million be appropriated.

Lifting the block on this dental workforce grants program, officially titled the Alternative Dental Health Care Providers Demonstration Program, would send an important signal to States and to HRSA that innovation in dental workforce is a meritorious undertaking. Even lifting the block and not funding the program would be a positive message to States. Importantly, the authorizing language requires that the grants be conducted in compliance with State law, that they must increase access to dental healthcare in rural and other underserved communities, and that the Institute of Medicine provide a qualitative and quantitative evaluation of the grants. Importantly, nothing in Section 340 G–1 would enable oral health practitioners to perform dental surgery or "irreversible procedures," unless a State specifically allowed such services. Further, because the authorizing language requires HRSA to begin the dental workforce grant program under Section 340G–1 within 2 years of its 2010 enactment (i.e., by 2012) and to conclude it within 7 years of enactment (2017), language directing HRSA to move forward with Section 340G–1 grants despite this timeline is needed.

*Widespread Support for Dental Workforce Innovation*

The American Dental Association (ADA), ADHA and numerous other groups have called for the creation of new types of dental providers. Innovative oral health practitioner models were authorized in Minnesota in 2009, followed by Maine in 2014. A February 2014 Report to the Minnesota Legislature on the early impact of the new providers found that benefits include "direct cost savings, increased dental team productivity, improved patient satisfaction and lower appointment fail rates."[1] Several States have mid-level oral health practitioner legislation pending including Connecticut, Hawaii, Kansas, Massachusetts, New Mexico, North Dakota, South Carolina, Texas, Vermont and Washington State.

Both the W.K. Kellogg Foundation and the PEW Charitable Trust Dental Campaign are investing in State efforts to increase oral healthcare access by adding new types of dental providers to the dental team. Groups as disparate as Families USA and Americans for Prosperity have called for exploration of new dental providers. In a January 2015 report, Families USA called for "improving access to care through greater use of mid-level providers such as nurse practitioners and dental therapists"[2] and Americans for Prosperity wrote in January 2015 that States should be "free to innovate" in the dental workforce to solve access issues.

The National Dental Association, representing 6,000 Black dentists, released its "Position on Access to Care and Emerging Workforce Models" in July 2014, which stated that the NDA "supports the development and continuation of demonstration projects that can demonstrate the impact and effectiveness of Emerging Workforce Models [expanded function dental hygienists, expanded function dental assistants, or dental therapists] on access to care, and total health outcomes."[3]

The U.S. Federal Trade Commission supported dental workforce expansion in November 2014, noting that expanding the supply of dental therapists is "likely to increase the output of basic dental services, enhance competition, reduce costs and ex-

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[1] Http://www.health.state.mn.us/divs/orhpc/workforce/dt/dtlegisrpt.pdf.
[2] Http://familiesusa.org/press-release/2015/families-usa-proposes-health-reform-20.
[3] (Http://ndaonline.org/position-on-access-to-care-and-emerging-workforce-models).

pand access to dental care."[4] The National Governors Association's January 2014 issue brief on "The Role of Dental Hygienists in Providing Access to Oral Health Care" found that "innovative State programs are showing that increased use of dental hygienists can promote access to oral healthcare, particularly for underserved populations, including children" and that "such access can reduce the incidence of serious tooth decay and other dental disease in vulnerable populations."[5]

There is no dispute that new types of dental providers are needed; the disagreement relates to what types of new providers are needed. This underscores the need for demonstration projects under Section 340G–1 exploring what types of new providers work best in various settings. Frankly, it is only the ADA that actively works to block funding for Section 340G–1. They should be required to supply evidence justifying their persistent opposition to Section 340G–1. ADHA urges that a fact-based decision be made on whether or not to lift the block on funding for Section 340G–1.

*Dentist Shortage and Dental Hygienist Surplus Demand Better Utilization of Dental Hygienists*

In February 2015, HRSA projected that all 50 States and the District of Columbia will experience a shortage of dentists by 2025. In contrast, there will be an excess supply of dental hygienists at the national level while five States (MI, MT, ND, SD, and WV) will experience dental hygienist shortages from 21–93 FTEs.[6]

*Title VII Program Grants to Expand and Educate the Dental Workforce—Fund at a level of $35 million in fiscal year 2016*

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased dental hygienists are recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the "General, Pediatric, and Public Health Dentistry" grants. With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future.

*Oral Health Programming within the Centers for Disease Control—Fund at a level of $20 million in fiscal year 2016*

ADHA joins with others in the dental community in urging $20 million for oral health programming within the Centers for Disease Control. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants will serve to facilitate improved oral health leadership at the State level; support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services; enable States to be innovative and promote a data-driven approach to oral health programming.

*National Institute of Dental and Craniofacial Research—Fund at a level of $425 million in fiscal year 2016*

The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving access to oral healthcare services and improved oral status of Americans in the future. ADHA joins with others in the oral health community to support NIDCR funding at a level of $425 million in fiscal year 2016.

CONCLUSION

ADHA is the largest national organization representing the professional interests of more than 185,000 licensed dental hygienists across the country. Thirty-seven States enable patients to directly access oral health services provided by dental hygienists in settings outside the private dental office. Sixteen State Medicaid pro-

[4] Https://www.ftc.gov/system/files/documents/advocacy__documents/ftc-staff-comment-commission-dental-accreditation-concerning-proposed-accreditation-standards-dental/141201codacomment.pdf.

[5] Http://www.nga.org/files/live/sites/NGA/files/pdf/2014/1401DentalHealthCare.pdf.

[6] HRSA March 2015 "National and State-Level Projections of Dentists and Dental Hygienists in the U.S., 2012–2025" http://bhpr.hrsa.gov/healthworkforce/supplydemand/dentistry/

grams provide direct reimbursement to dental hygienists for oral health services provided to Medicaid-eligible individuals.

ADHA urges the Subcommittee to lift the block on funding for Section 340G–1 of the PHSA, dental workforce demonstration grants, in its fiscal year 2016 HHS funding bill and urges vigorous efforts in conference with the House of Representatives to finally remove this unjustified prohibition. Lifting the block on funding for these dental workforce grants would be an important signal to States and to healthcare stakeholders that exploring new ways of bringing oral health services to the underserved is a meritorious expenditure of resources. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated. ADHA recommends funding at a level of $2 million for fiscal year 2016 to support these vital dental workforce demonstration projects.

[This statement was submitted by Kelli Swanson Jaecks, MA, RDH, President, American Dental Hygienists' Association.]

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## PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on behalf of the American Diabetes Association (Association). For fiscal year 2016, the Association urges the Subcommittee to make a substantial investment in research and prevention efforts to find a cure, and improve the lives of those living with, and at risk for, diabetes. We ask the Subcommittee to provide $2.066 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), $140.1 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and $20 million in funding for the National Diabetes Prevention Program (National DPP) at CDC.

The nearly 105 million American adults and children living with diabetes and prediabetes come from all walks of life and each of them has a story. I have been living with type 1 diabetes since I was 13 years old. When I was diagnosed 39 years ago, I was told I shouldn't expect to live to age 50. Thanks to the work of NIDDK and CDC, diabetes treatment has advanced since my diagnosis and has contributed to my ability to lead a productive life. However, not a moment goes by when I'm not thinking about whether my blood sugar is in within the range to prevent diabetes' devastating complications. The constant concern leaves me weary and longing, hoping for a cure everyday. I was told the cure was just around the corner when I was diagnosed; it has been a long, difficult block. Additional Federal resources are needed to make it around the corner to a world free of diabetes and its devastating complications.

In March, I was in Washington for the Association's Call to Congress, with other volunteers from around the country who are living with or affected by diabetes. We shared our stories with our Senators and Representatives to underscore the great need for full funding of diabetes research and prevention programs at NIH and CDC and I am honored to share several of those stories here.

Loretta Hothersall, an advocate from Maine, has diabetes and is a nurse practitioner specializing in diabetes care. Loretta's grandmother, brother, and granddaughter have type 1 diabetes, and her grandfather, mother, aunts, and husband have type 2 diabetes. The overwhelming impact of diabetes on her family led her to a career in diabetes care. Loretta hopes for a greater investment in diabetes prevention through the CDC so future families do not experience the devastating burden of diabetes.

In April of 2014, Stovy Bowlin, from Cedar Creek, Texas faced the fight of his life. He was diagnosed with type 2 diabetes, which was so advanced he underwent emergency surgery to remove an infected abscess on his thigh as a result of the disease. After recovering, Stovy committed to improve his health and reach out to as many individuals with diabetes and prediabetes as possible. He became a certified lifestyle coach of the National DPP and is working to bring this proven community-based lifestyle intervention for people at high risk for diabetes to Cedar Creek. Stovy believes, and the Association agrees, that the program has been proven to make a difference and it needs funding to continue its critical mission.

Cullen and Aiden Darius are a dynamic duo of brothers from California dedicated to fighting diabetes. Cullen is 14, and an honor student who was diagnosed 5 years ago with type 1 diabetes. He excels at history, science, and lacrosse. Unlike his fellow students and teammates, Cullen has to stop and check his blood glucose up to ten times a day, monitor all his meals and snacks, and make sure his blood sugar stays in check during lacrosse games and practices. Aiden, who is 12, is a baseball-loving aspiring professional tennis player and chef. Aiden was diagnosed with type

1 diabetes around his 4th birthday and doesn't remember a time without diabetes. He estimates he has checked his blood with a finger stick 33,000 times and has taken insulin 23,000 times. Last year, Aiden had a seizure. He doesn't recall having the seizure, just the firemen who rushed him to the hospital, but Cullen remembers it and says his brother's seizure is a reminder to us that even with all of the exciting advances in diabetes care, it is a life threatening condition, and those of us who live with diabetes can never take a break. The hope for a cure keeps the Darius brothers going.

Finally, there is Anastasia Albanese-O'Neill, an advocate from Florida, who wants a different life for Cassidy, her 14 year old daughter with type 1 diabetes and Jackson, her 10 year old son, who is at increased risk for diabetes. Her family's collective commitment to creating a brighter future for everyone with diabetes spurred them to enroll in research studies supported by NIDDK. Cassidy participates in the Search for Diabetes in Youth (SEARCH) Study, which assesses the impact of type 1 and type 2 diabetes in youth to improve prevention efforts. The entire family has participated in the TrialNet Natural History Study, which screens and studies close blood relatives of people with type 1 diabetes because they have a 10 to 15 times greater risk for developing the disease. And Jackson participates in The Environmental Determinants of Diabetes in the Young (TEDDY) study, to help scientists unravel the environmental factors contributing to type 1 diabetes. Anastasia's family are dedicated to these NIDDK studies because they will move us forward in the effort to stop diabetes and we urge Congress to follow their lead by making a deeper investment in NIDDK's work.

The disabling, deadly and growing diabetes epidemic is an American story touching all of our lives. According to the CDC, one in three adults in our country—one in two among minority populations—will have diabetes in 2050 if present trends continue. The sobering cost of this horrific disease is lived everyday by those who endure blindness, suffer heart attacks and strokes, wrestle with kidney failure and lose limbs, along with other deadly complications. My life and those of many other people living with, and at risk for, diabetes are better because of NIH research and CDC prevention activities. Progress has been great, but much more must be done.

This story does not have to be a tragedy—the final chapter has yet to be written. America has the power to stop the diabetes epidemic and make this a success story for the ages. We must start right now, with fiscal year 2016 appropriations. Every year, 1.7 million Americans aged 20 years or older are diagnosed with diabetes. That means 4,380 Americans learn they have diabetes each day—one American every 19 seconds. In addition to the horrendous physical toll, diabetes is economically devastating to our country. A 2014 report found the total annual cost of diagnosed and undiagnosed diabetes, prediabetes, and gestational diabetes in our country has skyrocketed by an astonishing 48 percent over 5 years—to $322 billion. People with diagnosed diabetes have healthcare costs 2.3 times higher than those without diabetes. 1 in 10 healthcare dollars is spent treating diabetes and its complications. 1 in 3 Medicare dollars is spent caring for people with diabetes. Despite the escalating cost of diabetes to our nation, the Federal investment for diabetes research and programs at the NIH and CDC has not equaled the shocking pace of the diabetes epidemic.

Individuals with and at risk for diabetes everywhere in our country, deserve a different and brighter future. As the nation's leading non-profit health organization providing diabetes research, information and advocacy, the American Diabetes Association believes the alarming state of our nation's diabetes epidemic justifies increased Federal funding in fiscal year 2016 for diabetes research and prevention programs.

BACKGROUND

Diabetes is a chronic disease impairing the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. Diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations. It is also a leading cause of heart disease and stroke. Additionally, an estimated 18 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk for complications and type 2 diabetes. In those with prediabetes, blood glucose levels are higher than normal and individuals are

at increased risk for type 2 diabetes. Individuals with prediabetes can take action to lower their risk for type 2 diabetes.

THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES AT NIH

To stop diabetes, Congress must support innovative research through NIDDK. While the Association is grateful for the $5 million increase for NIDDK provided in fiscal year 2015, which further helped the efforts to restore sequestration cuts, funding for the Institute is still below pre-sequestration levels. There is an urgent need to increase the investment in discoveries at NIDDK. To meet this need, we request funding for NIDDK of $2.066 billion in fiscal year 2016.

Thanks to groundbreaking research supported by NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. For example, the continuous glucose monitors and insulin pumps I use allow me to better manage blood glucose levels. Because of these advances, my hemoglobin A1C, which provides a snapshot of an individual's blood glucose, went from 12.9 percent to 5.9 percent. Each time I drop my A1C level I greatly increase my chances of fending off diabetes's complications. This is a dramatic development for me and proof of the importance of NIDDK.

Examples of NIDDK-funded innovations include: new drug therapies for type 2 diabetes; the advent of modern treatment regimens, which have reduced the risk of costly complications like heart disease, stroke, amputation, blindness and kidney disease; and ongoing development of the artificial pancreas, a closed looped system combining continuous glucose monitoring with insulin delivery.

While important strides have been made at NIDDK, the Association's fiscal year 2016 funding request reflects our concern that as the diabetes epidemic has grown, funding for the Institute has lost considerable ground. Due to both sequestration and funding not keeping pace with biomedical inflation, important research has been thwarted. For example, the NIDDK was forced to slow the initiation of a comparative effectiveness trial testing different type 2 diabetes medications due to insufficient resources, delaying critical information about the most beneficial treatments for type 2 diabetes. The NIDDK was also unable to fully fund a critically important program preparing pediatricians for careers in pediatric endocrinology research.

With $2.066 billion, the NIDDK will be able to fund additional grants to support scientifically meritorious research. This includes research to develop new therapeutic targets for type 2 diabetes. For example, research opportunities exist to study brown fat tissue, which burns calories to generate heat and is a promising target for the development of treatment strategies to combat obesity and type 2 diabetes. Research is also underway to identify mechanisms underlying the reversal of type 2 diabetes after bariatric surgery

Funding of $2.066 billion in fiscal year 2016 will allow the complete restoration of sequestration cuts, enable NIDDK to support current research projects and scientists, and enable additional studies holding the promise of stopping diabetes.

THE DIVISION OF DIABETES TRANSLATION AT CDC

The prevalence of diabetes has increased dramatically in every State. The Federal Government's role in coordinating efforts to prevent diabetes and its serious complications has never been more essential. In fiscal year 2015, the Committee and Congress recognized this by providing $140.129 million for DDT and its evidenced-based, outcomes-focused diabetes programs. We urge the Federal investment in DDT programs be funded at $140.129 million in fiscal year 2016.

The mission of DDT is to eliminate the preventable burden of diabetes through research, education, and by translating science into clinical practice. DDT has a proven success record in provision of essential information and education to the public, health providers, and patients about the dangers and complications of diabetes. This includes efforts to help those with diabetes manage their disease and avoid devastating complications such as blindness, end-stage kidney disease, and amputation.

Maintaining resources for diabetes prevention, surveillance, and research programs in fiscal year 2016 will strengthen the cornerstone of DDT's work in all 50 States and the District of Columbia. This will occur through the State Public Health Approaches to Chronic Disease Prevention program (SPHA or 1305 state grant program) and the State and Local Public Health Actions to Prevent Obesity, Diabetes and Heart Disease (1422 grant program). The SPHA includes State programming for diabetes, obesity, heart disease and stroke, and school health. We are pleased all 50 States receive basic funding to support implementation of crosscutting approaches to prevent and control diabetes, heart disease and stroke, and obesity, and

enhanced funding to expand the reach of evidence-based diabetes interventions and conduct more comprehensive evaluations of these efforts.

The 1422 grant program builds on the SPHA program and focuses on improving community and health system prevention approaches in populations with highest risk for prediabetes and high blood pressure. These programs support evidence-based community programs to identify, refer, and provide those at high risk for diabetes with cost-effective interventions.

Additionally, investment in DDT in fiscal year 2016 will enable community-based organizations to reduce risk factors for diabetes in populations bearing a disproportionate burden of the disease through the Native Diabetes Wellness Program. This program delivers effective health promotion activities tailored to American Indian/Native Alaskan communities.

THE NATIONAL DIABETES PREVENTION PROGRAM AT CDC

I am alarmed 86 million Americans have prediabetes and are on the cusp of type 2 diabetes. The National DPP is a public-private partnership of community organizations, private insurers, employers, healthcare organizations, faith-based organizations, and government agencies focused on type 2 diabetes prevention. The program is a national network of local sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. We urge Congress to provide $20 million for the National DPP in fiscal year 2016 to continue its nationwide expansion. The program is proven to combat the growing diabetes epidemic.

The National DPP began with a successful NIDDK clinical study showing weight loss of 5 to 7 percent of body weight, achieved by reducing calories and increasing physical activity to at least 150 minutes per week, reduced risk of developing type 2 diabetes by 58 percent in people with prediabetes and by 71 percent for those over 60 years old. Additional translational research was then done, proving the program also works in the less-costly community setting—at a cost of about $300–$400 per participant.

Currently, over 1,095 sites are operating the program. Many of these sites have applied for CDC quality standard recognition, which can lead to third-party reimbursement of the program, ensuring its long-term sustainability. Stopping the diabetes epidemic is not possible without additional investment in the National DPP. Additional funding in fiscal year 2016 will allow CDC to further bring to scale this proven approach and support national training programs, public awareness and provider education campaigns, and informed referral networks.

CONCLUSION

The Association is counting on Congress to significantly invest in diabetes research and programs. We believe the best way to confront the advancing human and economic pain diabetes exacts on our country is with a deeper investment in cutting-edge medical research and prevention strategies at NIDDK and DDT. We can—and must—change our country's story with regard to this devastating disease, and we urge the Subcommittee to reflect the explosive growth of this horrendous disease in its fiscal year 2016 appropriations decisions. Thank you for the opportunity to submit this testimony. The Association looks forward to working with you to stop diabetes.

[This statement was submitted by Janel Wright, JD, Chair, Board of Directors, American Diabetes Association.]

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## PREPARED STATEMENT OF THE AMERICAN EDUCATIONAL RESEARCH ASSOCIATION

Chairman Blunt, Ranking Member Murray and Members of the Subcommittee, thank you for the opportunity to submit written testimony on behalf of the American Educational Research Association. Appreciative of these stringent times, we recommend that the Institute of Education Sciences (IES) receives $703.6 million in fiscal year 2016. This recommendation is consistent with that of the Friends of IES coalition, in which we are a leading member.

AERA is the major national scientific association of 25,000 faculty, researchers, graduate students, and other distinguished professionals dedicated to advancing knowledge about education, encouraging scholarly inquiry related to education, and promoting the use of research to serve public good. Our members work in a range of settings from universities and other academic institutions to research institutes, Federal and State agencies, school systems, testing companies, and nonprofit organizations, engaged in conducting research in all areas of education and learning.

U.S. leaders and citizens broadly agree that education is a pathway to success, not just for individuals, but also for our country's economy. This belief is supported by research. For example, we have learned that, when looking at the bottom income quartiles, bachelor degree graduates are more upwardly mobile,[1] indicating that obtaining a bachelor's degree rather than only a high school diploma leads to larger lifetime earnings and lower rates of future participation in social programs.[2, 3]

We also know that our citizens support investing in education. The Pew Research Center found that 60 percent of survey respondents would increase spending on education, a higher percentage than for any other category. In order, however, to allocate resources to programs and policies that work, we need reliable research to best guide decisions.

The public and policy makers value the provision of high quality education, and our citizens are willing to spend more to improve quality; nonetheless, education research was less than 2 percent of the $67 billion dollars spent on research in 2013 by institutions of higher education (largely Federal grants and contracts). By contrast, 56 percent of the R&D funding went to life sciences, and 31 percent specifically to medical sciences. In 2015, the budget for IES was just over 1 percent of the Department of Education budget, illustrating the underinvestment in research on education as compared to other fields.

IES has made dramatic contributions to the progress of education since it was created in 2002. Yet, we in the United States have a far way to go to provide high quality education to all of our students. In addition to old questions that remain unanswered—like how to best prepare teachers, we have barely begun to understand the opportunities provided by the advances in technology. IES needs increased funding to continue our progress using rigorous research to inform education policy.

*National Center for Education Statistics (NCES)*

NCES is one of the 13 leading Federal statistical agencies in the U.S. It collects, analyzes, and reports on education data and statistics on the condition of education in the United States, conducts long-term longitudinal studies and surveys, and supports international assessments in a manner that meets the highest methodological standards and practices for data confidentiality and data security.

Federal, State, and local policymakers rely on over two dozen NCES-supported survey programs, assessments, and administrative data sets, as do schools, educators and researchers across the country. In addition, the annual Condition of Education provides a comprehensive statistical overview on early childhood, K–12, and postsecondary education in the U.S.

NCES also provides technical assistance to public and private education agencies and to States improving their statistical systems. Grants from the Statewide Longitudinal Data Systems (SLDS) program encourage States to build capacity to link data between early childhood, K–12, and postsecondary systems. The President has requested doubling the amount for this program from $35 million in fiscal year 2015 to $70 million in fiscal year 2016. This would enable States and districts to conduct research and program evaluation in order to generate timely and meaningful information for improving accountability, assessment, and school support systems. One need only look at research that analyzed State administrative data in North Carolina and Washington State on early childhood programs, teacher hiring, and other timely issues to understand the value of investing in such data systems.

NCES is home to the National Assessment of Educational Progress (NAEP), known as the "Nation's Report Card." NAEP is an important resource for identifying long-term trends in educational proficiency in each State and—through the Trial Urban District Assessment— in the largest school districts in the Nation.

Also of significance is that NCES has responsibility for the participation of the U.S. in international assessments and surveys that prominently include the Program for International Student Assessment (PISA), the Trends in International Mathematics and Science Study (TIMSS), and Progress in International Reading Literacy Study (PIRLS). Without continued adequate funding for these international assessments, it will become more difficult to accurately gauge U.S. performance in reading, math, and science in comparison to other countries. This information is particularly useful in a time of increasing global economic competitiveness.

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[2] Carnevale, A.P., Rose, J. and Cheah, B. (2011). The College Payoff. Washington, D.C.: Georgetown Center on Education and the Workforce.

[3] Baum, S., Ma, J., and Payea, K. (2013) Education Pays 2013: The Benefits of Higher Education for Individuals and Society. Washington, D.C.: The College Board.

[1] AHA Annual Survey, Health Information Technology Supplement (2013).

[2] PricewaterhouseCoopers Health Research Institute. New Health Economy (April 2014).

At the current funding level, NCES is unable to adequately fund the most timely information on several high-priority education policy issues: Early childhood education, school crime and safety, and postsecondary educational costs and student progress.

*National Center for Education Research (NCER)*

Over the past decade, NCER-funded research has made significant advances in our understanding on a broad range of questions from how best to support student learning to maximizing school completion and adult education. In some cases, research funded by NCER has challenged some of our pre-conceived assumptions about education. One area with particularly interesting and valuable findings has been that of teacher preparation. In the past, teacher quality was largely measured by licensure. However, additional data and rigorous research have looked at student progress, telling us much more about teacher performance. Some of the results have been surprising—obtaining a master's degree has not, for example, been linked to greater student achievement (except for one study in middle school math). This begs the question, how do we identify and duplicate professional development programs that improve both teacher and student outcomes?

Despite the tremendous promise of NCER-funded research, proposals receiving scores of Outstanding or Excellent go unfunded due to budget constraints. In fiscal year 2014, this meant that a quarter of eligible proposals that met that threshold were unable to be funded. Adequate funding for NCER will allow its R&D centers and research grantees to continue to produce rigorous research.

*National Center for Special Education Research (NCSER)*

NCSER supports research that investigates the conditions that improve developmental and education outcomes for infants, toddlers, children and youth with disabilities or who are at risk of developing disabilities. In the short time since its creation in 2004 with the Individuals with Disabilities Education Act, NCSER-supported research has made important contributions to understanding factors related to children's academic growth, developing measurement systems, documenting skill development and learning and testing interventions designed to improve educational outcomes.

The Centers for Disease Control estimated that 1 in 68 children are identified with Autism Spectrum Disorder, a dramatic increase from the 1 in 150 children with ASD in 2002 with a corresponding growing cost to provide educational services. NCSER is leading the charge to support school-based interventions for this growing population. For example, NCSER funded a project to gauge the efficacy of Learning Experiences and Alternate Program for Preschoolers and their Parents (LEAP), which focuses on enhancing the skills of children with autism through interaction and play with typically-developing peers.

Despite these important research advances that could improve the quality of life for children and families and result in enormous cost savings, NCSER was unable to fund any new research grants in fiscal year 2014 and anticipates not being able to fund projects receiving Excellent and Outstanding ratings in fiscal year 2015.

*National Center for Education Evaluation (NCEE) and Regional Assistance*

NCEE conducts evaluations of large-scale educational projects and Federal education programs and advances the use of IES knowledge by informing the public and reaching out to practitioners with a variety of dissemination strategies and technical assistance programs. The Education Resources Information Center (ERIC) is a well-used resource within the entire Department of Education, receiving 300,000 daily visitors. In addition, the What Works Clearinghouse (WWC) provides valuable information on the findings and methodologies in evaluations of different education practices and policies. Recent WWC reviews of research include studies of the Teacher Transfer Initiative, college counseling during the summer after high school graduation, and the Diagnostic Assessment Tools program.

Adequate funding for IES has the potential to help with some of the other concerns of this committee—improving the educational outcomes of our citizens would help not only future labor and workforce issues but also improve the health of our citizens.

Thank you for the opportunity to submit written testimony in support of $703.6 million for the Institute of Education Sciences in fiscal year 2016. AERA welcomes working with you and your subcommittee on strengthening investments in essential research, data, and statistics related to education and learning. Please call on us if we can provide additional information regarding this budget proposal.

[This statement was submitted by Felice J. Levine, Ph.D., Executive Director, American Educational Research Association.]

## PREPARED STATEMENT OF THE AMERICAN GERIATRICS SOCIETY

Mr. Chairman and Members of the Subcommittee: We submit this testimony on behalf of the American Geriatrics Society (AGS), a non-profit organization of over 6,000 geriatrics healthcare professionals dedicated to improving the health, independence and quality of life of all older Americans. As the Subcommittee works on its fiscal year 2016 Labor-HHS-Education Appropriations bill, we ask that you prioritize funding for the geriatrics education and training programs under Title VII and Title VIII of the Public Health Service Act, additional primary care programs under the Health Resources and Services Administration, and for research funding within the National Institutes of Health/National Institute on Aging.

We ask that the subcommittee consider the following funding levels for these programs in fiscal year 2016:

—$44.7 million for Title VII and Title VIII Geriatrics Workforce Enhancement Programs

—$9.7 million for additional primary care workforce programs under the Health Resources and Services Administration

—An increase of $500 million for aging research within the National Institutes of Health

Sustained and enhanced Federal investments in these initiatives are essential to delivering high quality, better coordinated and more cost effective care to our Nation's seniors, whose numbers are projected to increase dramatically in the coming years. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase threefold to 19 million. To ensure that our Nation is prepared to meet the unique healthcare needs of this rapidly growing population, we request that Congress provide additional investments necessary to expand and enhance the geriatrics workforce, which is an integral component of the primary care workforce, and to foster groundbreaking medical research.

### PROGRAMS TO TRAIN GERIATRICS HEALTHCARE PROFESSIONALS

Our Nation is facing a critical shortage of geriatrics faculty and healthcare professionals across disciplines. This trend must be reversed if we are to provide our seniors with the quality care they need and deserve. Care provided by geriatrics healthcare professionals, who are trained to care for the most complex and frail individuals who account for 80 percent of our Medicare expenditures, has been shown to reduce common and costly conditions that are often preventable with appropriate care, such as falls, polypharmacy, and delirium.

*Title VII and Title VIII Geriatrics Workforce Enhancement Programs ($44.7 million)*

The Geriatrics Workforce Enhancement Program (GWEP) is the only Federal program that increases the number of faculty with geriatrics expertise in a variety of disciplines who provide training in geriatrics, including the training of interdisciplinary teams of health professionals.

In December 2014, the Health Resources and Services Administration (HRSA) announced that they will combine the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the Geriatrics Workforce Enhancement Program (GWEP). According to HRSA, this newly consolidated program will provide greater flexibility to grant awardees by allowing applicants to develop programs that are responsive to specific interprofessional geriatrics education and training needs of their communities. AGS, however, is concerned that this consolidation could result in fewer awards to train and educate geriatrics health professionals, including those who wish to pursue academic careers. At a time when our Nation is facing a severe shortage of geriatrics healthcare providers, the number of educational and training opportunities should be expanded, not reduced.

To address this issue, we request additional funding for GWEP and other key healthcare workforce programs for fiscal year 2016:

—Title VII Geriatrics Workforce Enhancement Program ($34.4 million)

Title VII Geriatrics Workforce Enhancement Program seeks to improve high quality, interprofessional geriatric education and training to the health professions workforce, including geriatric specialists, as well as increase geriatric competencies of primary care providers and other health professionals to improve care in medically underserved areas. We ask the subcommittee to provide a fiscal year 2016 appropriation of $34.4 million for the Title VII Geriatrics Workforce Enhancement Program.

—Title VIII Geriatrics Workforce Enhancement Program ($5 million)

The American healthcare delivery system for older adults will be further strengthened by Federal investments in the Title VIII Geriatrics Workforce Enhancement Program. This program funds curricula development and dissemination, continuing education, and traineeship for individuals preparing for advanced nursing education degrees in geriatric nursing, long-term care, gero-psychiatric nursing or other nursing areas that specialize in the care of older Americans. Our budget request of $5 million will provide support to train and educate nurses caring for older Americans.

—Alzheimer's Disease Prevention, Education, and Outreach Program (GECs) ($5.3 million)

Funding for this program will support the Geriatrics Workforce Enhancement program by providing interprofessional continuing education to health professionals on Alzheimer's disease and related dementias. We are requesting $5.3 million to support this program.

*Additional Workforce Programs under the Health Resources and Services Administration ($9.7 million)*

—National Health Care Workforce Commission ($3 million)

The National Health Care Workforce Commission was established in the Affordable Care Act to identify barriers to healthcare workforce development and to formulate a national strategy to address the shortage; however, Congress has not provided funding for the Commission to be convened. AGS believes that the Commission's work—including research on topics such as workforce priorities and goals; current and projected workforce supply; and needs and assessments of current education and training activities—is an important first-step in the effort to bolster the healthcare workforce in order to meet the needs of the burgeoning number of older Americans. We request $3 million for the Commission so that it can accomplish its essential mission.

—Geriatric Incentive Awards Program ($3.3 million)

Congress authorized this program under the Affordable Care Act to provide financial support to foster greater interest among a variety of health professionals entering the field of geriatrics, long-term care, and chronic care management. Our funding request includes $3.3 million for this program.

—Training Opportunities for Direct Care Workers ($3.4 million)

Under the Affordable Care Act, Congress approved a program that will offer advanced training opportunities for direct-care workers. While this program was left out of President Obama's budget, AGS believes that Congress must fund it to improve training and enhance the recruitment and retention of direct-care works, particularly those in long-term care settings. As our population ages, these workers will be an integral part of efforts to ensure that older adults have access to high quality care. We are requesting $3.4 million for this program.

RESEARCH FUNDING INITIATIVES

*National Institutes of Health/National Institute on Aging (additional $500 million over fiscal year 2015)*

The institutes that make up the National Institutes of Health and specifically the National Institute on Aging, lead the national scientific effort to understand the nature of aging and to extend the healthy, active years of life. As a member of the Friends of the NIA, a broad-based coalition of aging, disease, research, and patient groups committed to the advancement of medical research that affects millions of older Americans, AGS urges an increase of $500 million in National Institutes of Health funding for biomedical, behavioral, and social sciences aging research efforts across all institutes.

Considering the significant amount of funds the Federal Government spends on healthcare costs associated with age-related diseases, it makes sound economic sense to increase Federal resources for aging research. Currently, chronic diseases related to aging, such as diabetes, heart disease and cancer afflict 80 percent of people age 65 and older and account for more than 75 percent of Medicare and other Federal health expenditures. Continued Federal investments in scientific research will ensure that the NIH has the resources to succeed in its mission to establish research networks, assess clinical interventions and disseminate credible research findings to patients, providers and payers of healthcare.

In closing, geriatrics is at a critical juncture, with our Nation facing an unprecedented increased in the number of older patients with complex health needs. Strong support such as yours will help ensure that every older American is able to receive high-quality care.

Thank you for your consideration.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Remarkable strides have been made in the prevention and treatment of cardiovascular disease (CVD) and stroke. However, we must face the hard truth. There is still no cure for America's No. 1 and most costly killer. CVD costs nearly $1 billion a day. Stroke is our No. 5 killer and second leading cause of dementia.

Today, nearly 86 million U.S. adults suffer from some form of CVD and those grim statistics will only get worse. It is projected that by the year 2030, nearly 44 percent of U.S. adults will live with CVD at a cost exceeding $1 trillion annually. Yet inexplicably, CVD research, prevention, and treatment remain disproportionately underfunded with no sustained and stable funding from the National Institutes of Health. Therefore, we emphasize that robust NIH-funded research is vital for a continuing and effective campaign against these deadly and debilitating diseases.

The American Heart Association recognizes the challenges our Nation and Congress face to reduce the budget deficit. However, sequestration is not, and never is the answer. These cuts put at grave risk the health of tens of millions of CVD sufferers, stifle economic growth, and jeopardize our global leadership in medical research. We therefore challenge Congress to appropriate stable and sustained funding for CVD research, prevention, and treatment. Moreover, during the upcoming debate on funding, Congress should recognize that NIH-funded research has a proven return on investment. It drives economic growth, including good, high- paying jobs, stimulates innovation, and maintains America's time-honored leadership in medical research—something that is now under threat with the current budget constraints on the NIH.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

It comes down to this. Research that could move us closer to a cure for cardiovascular disease and stroke goes unfunded. Congress must capitalize on 50 years of progress or our Nation will pay more in lives lost and healthcare costs. Our recommendations tackle these issues in a fiscally responsible way.

*Capitalize on Investment for the National Institutes of Health (NIH)*

Robust NIH-funded research helps prevent and cure disease, transforms patient care, stimulates economic growth, fosters innovation, and maintains U.S. leadership in pharmaceuticals and biotechnology. NIH is the world's leader of basic research—the foundation for all medical advances—and an essential Federal Government function that the private sector cannot ever replace. But, our country's competitive edge in scientific research has been eroded in recent years by scarce funding.

In addition to improving health, NIH generates a solid return on investment. In fiscal year 2012, NIH supported 400,000 U.S. jobs and created about $60 billion in new economic activity. Every $1 in NIH funding created $2 in economic activity in 2007. Yet, due to scarce resources over the past decade, NIH lost more than 20 percent of its purchasing power. Sadly, this decline occurred at a time of unprecedented scientific opportunity as other countries wisely increased investment in science—some by double digits. These cuts have disheartened early U.S. career investigators who may decide against pursuing a career in research unless Congress takes action.

*American Heart Association Advocates*.—We urge Congress to appropriate $33 billion for NIH to begin to restore its purchasing power, and advance cardiovascular disease research.

*Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment*

NIH research plays a pivotal role in reducing CVD death rates. Today, scientists are close to discoveries that could result in revolutionary treatments and even cures. In addition to saving lives, NIH studies are economical. For example, investments in the NIH Women's Health Initiative postmenopausal estrogen plus progestin trial generated a total economic return of $140 for every $1 invested in the trial and led to 76,000 fewer cases of cardiovascular disease. The first NIH tPA drug trial led to a 10-year net $6.47 billion reduction in stroke care costs.

*Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)*

Much of the decline in cardiovascular disease death rates is a result of NHLBI-funded research. However, this begs the question, "Why has NHLBI extramural heart research fallen 17 percent in constant dollars since 2002?" Stable and sustained NHLBI funding remains key to building on investments that have led to major advances. Look at losartan as an alternative treatment for Marfan syndrome; the identification of loss of-function apolipoprotein C3 gene changes as a potential

therapy for cutting heart disease risk; the use of nanoparticles to cut atherosclerotic plaque inflammation; and cells from human induced pluripotent stem cells to fix damaged heart tissue. Sustained funding will allow the NHLBI to implement its bold strategic vision.

*Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)*

An estimated 795,000 Americans will suffer a stroke this year and nearly 129,000 will die from one. Many of the 7 million survivors deal with grave physical, mental, and emotional distress. In addition, stroke costs an estimated $34 billion in medical expenses and lost productivity each year and a recent study projects that direct costs of stroke will triple between 2010 and 2030.

Stable and sustained NINDS funding is vital to building on stroke advances, including research showing that a stent system removes clots in large blood vessels to stop stroke damage. More resources could also help improve stroke recovery; boost NIH Stroke Trials Network; hasten translation of preclinical animal models into clinical studies; prevent vascular cognitive damage; expedite comparative effectiveness research trials; develop imaging biomarkers; refine clot-busting treatments; achieve robust brain protection; and promote the use of neural interface devices. Additional funding is also needed to support the BRAIN Initiative.

*American Heart Association Advocates*.—We recommend that NHLBI be funded at $3.3 billion and NINDS at $1.8 billion.

*Increase Funding for the Centers for Disease Control and Prevention (CDC)*

Prevention is the best way to protect us from the physical and fiscal ravages of heart disease and stroke. Yet, proven efforts are not fully executed due to scarce funds. We thank Congress for retaining in Public Law 113–203 the needed boost for the Division for Heart Disease and Stroke Prevention. In addition to funding research and evaluation and developing a surveillance system, the DHDSP directs Sodium Reduction in Communities and the Paul Coverdell National Acute Stroke Registry. DHDSP and the Centers for Medicare and Medicaid Services are promoting the Million Hearts™ initiative aimed at stopping 1 million heart attacks and strokes by 2017. DHDSP runs WISEWOMAN, serving uninsured and under-insured, low-income women ages 40 to 64. It helps them from becoming heart disease and stroke statistics through preventive health services, referrals to local healthcare, and tailored lifestyle plans to foster lasting behavioral change.

*American Heart Association Advocates*.—We join the CDC Coalition in asking for $7.8 billion for CDC's program level. AHA requests $130.037 million for the DHDSP to intensify work on the State Public Health Actions and on the State and Local Public Health Actions To Prevent Obesity, Diabetes, Heart Disease, and Stroke; and $37 million for WISEWOMAN. We ask for $5 million for Million Hearts™ to better control blood pressure—a "silent killer" of Americans.

*Restore Funding for Rural and Community Access to Emergency Devices (AED) Program*

About 90 percent of cardiac arrest victims die outside of a hospital. Yet, early CPR and use of an AED can more than double survival. Communities with full AED programs have survival rates near 40 percent. HRSA's Rural and Community AED Program awards competitive grants to States to buy AEDs, tactically place them, and train lay rescuers and first responders in their use. As a result of this program, nearly 800 patients were saved from August 1, 2009 to July 31, 2010. But scarce resources allow only 19 percent of approved applicants in 6 States to receive funds in fiscal year 2014.

*American Heart Association Advocates*.—We advocate for an $8.927 million appropriation for PHS Act sections 413 and 313, returning the program to fiscal year 2005 levels with 47 funded States.

CONCLUSION

Cardiovascular disease, including stroke, still inflict a staggering physical and economic toll on the American people. Our recommendations for NIH, CDC, and HRSA will save lives and reduce healthcare costs. We respectfully ask the Committee to endorse our recommendations that are a wise investment for our great Nation and the well-being of this and future generations.

[This statement was submitted by Elliott Antman, M.D., President, American Heart Association.]

## PREPARED STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION

On behalf of our nearly 5,000 member hospitals, health systems and other healthcare organizations, and our 43,000 individual members, the American Hospital Association (AHA) appreciates the opportunity to submit a statement regarding actions Congress can take to ensure accessible, affordable healthcare services are available in rural areas. We applaud the subcommittee for holding this hearing.

Approximately 51 million Americans live in rural areas and depend upon the hospital as an important—and often only source of healthcare in their community. Remote geographic location, small size, limited workforce, physician shortages and often constrained financial resources pose a unique set of challenges for rural hospitals. Additionally, burdensome, duplicative, and often outdated Federal regulations and policies present consistent strain on the ability for rural hospitals to keep their doors open and provide needed healthcare services.

The AHA recommends Congress take action on the issues discussed below to provide relief from harmful Federal regulations and policies and protect important programs.

### 96-HOUR RULE

The Centers for Medicare & Medicaid Services (CMS) has published guidance, in relation to its two-midnight admissions policy that implies that the agency will begin enforcing a condition of payment for critical access hospitals (CAHs) that requires a physician to certify that a beneficiary may reasonably be expected to be discharged or transferred to another hospital within 96 hours of admission. While CAHs must maintain an annual average length of stay of 96 hours, they offer some critical medical services that have standard lengths of stay greater than 96 hours. Enforcing the condition of payment will force CAHs to eliminate these "96-hour plus" services. The resulting financial pressure will severely affect their ability to operate and, therefore, threaten access to care for beneficiaries in rural communities.

The AHA supports the Critical Access Hospital Relief Act (S. 258/H.R. 169), which would remove the 96-hour condition of payment. CAHs would still be required to satisfy the condition of participation requiring a 96-hour annual average length of stay.

### DIRECT SUPERVISION

CMS recently removed its moratorium on Medicare contractors enforcing its policies related to its "direct supervision" requirement of outpatient therapeutic services furnished in CAHs and small rural hospitals with 100 or fewer beds. Therefore, for 2015 and beyond, the agency requires a minimum of direct supervision for all outpatient therapeutic services furnished in hospitals and CAHs, unless the service is on the list of services that may be furnished under general supervision or is designated as a nonsurgical extended duration therapeutic service. The AHA is deeply disappointed that CMS did not heed the concerns voiced by CAHs and small rural hospitals that imposing this policy is not only unnecessary, but also will result in reduced access to care.

The AHA supports the Protecting Access to Rural Therapy Services Act (S. 257/H.R. 1611), which, among other things, would adopt a default standard of "general supervision" for these outpatient therapeutic services.

### RECOVERY AUDIT CONTRACTORS (RACS)

Overzealous RACs are wasting resources by inundating hospitals with requests for records, requiring specialized staff to handle the heavy workload, and flooding the government appeals process with denials that are overturned more than two-thirds of the time. Rural hospitals are often particularly affected by overly aggressive RAC audits, because they may lack the human and financial resources to respond to ongoing records requests and to appeal perpetually inaccurate claims denials.

The AHA supports bipartisan legislation introduced in the U.S. House of Representatives, the Medicare Audit Improvement Act (H.R. 2156), which makes common-sense, fundamental changes to improve the program's efficiency and fairness, including changing how RAC contractors are paid. Rather than the current 9–12.5 percent contingency fee RACs receive for each denied claim, the AHA recommends RACS be paid a flat fee, just as all other Medicare contractors.

According to AHA survey data, hospitals appeal 49 percent of their RAC denials and win 72 percent of the time at the third level of appeal, according to the Health and Human Services' Office of Inspector General. But the appeals process also is

heavily backlogged, taking up to 3 years for a claim to work its way through the system. Yet hospitals are allowed only 1 year to rebill any claim.

RURAL COMMUNITY HOSPITAL (RCH) DEMONSTRATION

The Medicare RCH Demonstration Program was established under the Medicare Prescription Drug, Improvement and Modernization Act, and further extended in 2010 under the Affordable Care Act (ACA). The demonstration allows 30 rural community hospitals to test the feasibility of cost-based reimbursement for small rural hospitals that are too large to be CAHs. Currently, 23 hospitals participate in the demonstration.

The AHA supports the bipartisan Rural Community Hospital Demonstration Extension Act (S. 332/H.R. 663), which extends the program, in its current form, for 5 years. By extending the demonstration for five more years, this legislation will ensure that these hospitals may continue to provide services rural communities need.

EXTENDERS

The AHA applauds Congress for passing the Medicare Access and Chip Reauthorization Act of 2015 (MACRA), which temporarily extended several important programs for rural hospitals, including the:

—Medicare-Dependent Hospital program (extended until October 1, 2017);
—Enhanced adjustment for certain low-volume hospitals (extended until October 1, 2017);
—Ambulance add-on payments for ground ambulance services and super-rural areas (extended until January 1, 2018);
—Therapy cap exceptions process until (extended until January 1, 2018); and
—Medicare home health rural add-on until January 1, 2018.

The MACRA, which is now current law, provided short-term certainty for several important programs; however, more needs to be done. AHA-supported, bipartisan, bicameral legislation has been introduced this Congress to make each of these extensions permanent.

*Medicare-Dependent Hospital (MDH) Program*

The network of providers that serves rural Americans is fragile and more dependent on Medicare revenue because of the high percentage of Medicare beneficiaries who live in rural areas. Additionally, rural residents on average tend to be older, have lower incomes and suffer from higher rates of chronic illness than their urban counterparts. This greater dependence on Medicare may make certain rural hospitals more financially vulnerable to prospective payment.

To reduce this risk and support small rural hospitals for which Medicare patients make up a significant percentage of inpatient days or discharges, Congress established the MDH program in 1987. The approximately 200 MDHs are paid for inpatient services the sum of their prospective payment system (PPS) rate plus three-quarters of the amount by which their cost per discharge exceeds the PPS rate. These payments allow MDHs greater financial stability and leave them better able to serve their communities. The MDH program will expire on October 1, 2017.

The AHA strongly encourages Congress to pass the Rural Hospital Access Act (S. 332/H.R. 663), bipartisan legislation to permanently extend the enhanced low-volume adjustment payment and the MDH program.

*Low-Volume Adjustment*

The ACA improved the then low-volume adjustment for fiscal years (FY) 2011 and 2012. For these years, a low-volume hospital was defined as one that was more than 15 road miles (rather than 35 miles) from another comparable hospital and had up to 1,600 Medicare discharges (rather than 800 total discharges). An add-on payment was given to qualifying hospitals, ranging from 25 percent for hospitals with fewer than 200 Medicare discharges to no adjustment for hospitals with more than 1,600 Medicare discharges.

This enhanced low-volume adjustment was extended by Congress in several subsequent years. Over 500 hospitals received the low-volume adjustment in fiscal year 2013.

Medicare seeks to pay efficient providers their costs of furnishing services. However, certain factors beyond providers' control can affect these costs. Patient volume is one such factor and is particularly relevant in small and isolated communities where providers frequently cannot achieve the economies of scale possible for their larger counterparts. Although a low-volume adjustment had existed in the inpatient PPS prior to fiscal year 2011, CMS had defined the eligibility criteria so narrowly that only two to three hospitals qualified each year.

The improved low-volume adjustment in the ACA better accounts for the relationship between cost and volume, helps level the playing field for low-volume providers, and sustains and improves access to care in rural areas. This program expires October 1, 2017.

The AHA strongly encourages Congress to pass the Rural Hospital Access Act (S. 332/H.R. 663), bipartisan legislation to permanently extend the enhanced low-volume adjustment payment and the MDH program.

*Ambulance Add-On Payments*

Small patient volumes and long distances put tremendous financial strain on ambulance providers in rural areas. To help alleviate this situation and ensure access to ambulances for patients in rural areas, the Medicare Prescription Drug, Improvement, and Modernization Act increased payments by 2 percent for rural ground ambulance services and included a super rural payment for counties are in the lowest 25 percent in population density. Congress, in the Medicare Improvements for Patients and Providers Act (MIPPA), raised this adjustment to 3 percent for rural ambulance providers. Most recently, Congress extended these adjustments until January 1, 2018.

Congress appropriately decided that these additional rural payments were necessary and important because rural ambulance providers incur higher per-trip costs because of longer travel distances and fewer transports of patients. These provisions ensure that ambulance services are more appropriately reimbursed and that beneficiaries in rural and super rural areas will have access to emergency transport services.

The AHA supports the bipartisan Medicare Ambulance Access, Fraud Prevention and Reform Act (S. 377/H.R. 745), which would permanently extend the ambulance add-on payment adjustment.

TELEHEALTH

Telehealth increasingly is vital to our healthcare delivery system, enabling healthcare providers to connect with patients and consulting practitioners across vast distances. Hospitals are embracing the use of telehealth technologies because they offer benefits such as virtual consultations with distant specialists, the ability to perform high-tech monitoring without requiring patients to leave their homes, and less expensive and more convenient care options for patients. According to AHA survey data, in 2013, 52 percent of hospitals used telehealth and another 10 percent were beginning the process of implementing telehealth services.[1]

Approximately 20 percent of Americans live in rural areas where many do not have easy access to primary care or specialist services. The availability of telehealth services to these areas facilitates greater access to care by eliminating the need to travel long distances to see a qualified healthcare provider. Telehealth also can fill gaps in subspecialist care. Telepharmacy is another way to offer patients the convenience of remote drug therapy monitoring, authorizing for prescriptions, patient counseling and monitoring patients' compliance with prescriptions. With a nationwide shortage of psychiatrists, telepsychiatry can assist patients in need of behavioral health services who may otherwise have to drive hours to see mental health providers. Telepsychiatry services allow psychiatrists to speak to and evaluate patients in need of mental health services through videoconferencing.

Rural and critical access hospitals are often in need of critical care clinicians to diagnose, manage, stabilize and make transfer decisions concerning their most complex patients. Tele-ICU programs can help hospitals supplement clinician staffing of their ICU beds. In addition to improving access, patients are increasingly expecting levels of convenience in healthcare similar to what is available in the retail and banking sectors.[2] Telehealth, regardless of geographic location, can foster a patient's ability to connect with a primary care physician or health system on a more flexible basis and often without an in-person visit. Patients are able to receive services at a distance by using secure online video services or through secure email, often with the added benefit of reducing travel to healthcare facilities. The AHA urges to committee to provide funding to expand these types of telehealth opportunities.

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[2] Carnevale, A.P., Rose, J. and Cheah, B. (2011). The College Payoff. Washington, D.C.: Georgetown Center on Education and the Workforce.

[3] Baum, S., Ma, J., and Payea, K. (2013) Education Pays 2013: The Benefits of Higher Education for Individuals and Society. Washington, D.C.: The College Board.

[1] AHA Annual Survey, Health Information Technology Supplement (2013).

FUNDING FOR RURAL PROGRAMS

As the committee deliberates on funding for programs within the Departments of Labor, Health and Human Services (HHS), Education and Related Agencies for fiscal year 2016, the AHA urges you to consider the potential effect your committee's decisions will have on rural hospitals' ability to meet the many challenges facing them—such as workforce shortages, maintaining emergency readiness, coordinating care for the chronically ill and facilitating information technology to improve safety and quality of care.

While we recognize the fiscal constraints imposed upon the committee, we ask you to give strong and favorable funding consideration to the following rural healthcare programs, which have proven successful in improving access to quality healthcare. They have served to greatly improve the health of our citizens and we ask that you make funding these programs a priority in your fiscal year 2016 appropriations measure

—*Health Professions Programs*. An adequate, diverse and well-distributed supply of healthcare professionals, including allied healthcare workers, is indispensable to our Nation's healthcare infrastructure. Health professions programs help address problems associated with maintaining primary care providers in rural areas. These programs also support recruitment of individuals into allied health professions. Our Nation must maintain a vibrant workforce in the educational pipeline. Without decisive intervention, workforce shortages threaten hospitals' ability to care for patients and communities.

—*National Health Service Corps (NHSC)*. The NHSC awards scholarships to health professions students and assists graduates of health professions programs with loan repayment in return for an obligation to provide healthcare services in underserved rural and urban areas. The AHA supports maintaining investments in the NHSC.

—*Rural Health Programs*. Rural Health Programs, such as the Medicare Rural Hospital Flexibility Grant Program, Rural Health Outreach and Network Development, State Offices of Rural Health, Rural Telehealth, Rural Policy Development, and other healthcare programs are vital to ensuring that needed services remain available in America's rural communities. The president's fiscal year 2016 budget proposes to cut rural health programs by $20 million to rural programs. The AHA urges the subcommittee to reject efforts to cut funding below current levels for these programs.

CONCLUSION

The Nation's nearly 2,000 rural community hospitals frequently serve as an anchor for their region's health-related services, providing the structural and financial backbone for physician practice groups, health clinics and post-acute and long-term care services. In addition, these hospitals often provide essential, related services such as social work and other types of community outreach. Rural hospitals face additional challenges due to their often remote geographic location, small size, limited workforce and constrained financial resources.

The AHA urges the subcommittee to take action on the aforementioned issues to ensure access to healthcare services in rural communities.

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PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

This statement includes the fiscal year 2016 requests of the Nation's Tribal Colleges and Universities (TCUs), covering three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

DEPARTMENT OF EDUCATION

*I. Higher Education Act Programs*

—*Strengthening Developing Institutions*. Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. The TCUs, which by any definition are truly developing institutions, are funded under Title III–A Sec. 316 and provide quality higher education opportunities to some of the most rural/isolated, impoverished, and historically underserved areas of the country. The goal of HEA-Titles III/V programs is "to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation." The TCU

Title III–A program is specifically designed to address the critical, unmet needs of American Indian/Alaska Native (AI/AN) students and their communities, in order to effectively prepare them to succeed in a globally competitive workforce. Yet, in fiscal year 2011 this critical program was cut by over 11 percent, by another 4 percent in fiscal year 2012, and hit by sequestration—on the lowered baseline—in fiscal year 2013. Although sequestration was not imposed in fiscal year 2014 or fiscal year 2015, the TCUs are still feeling the impact of the earlier cuts to this vitally important program. The TCUs urge the Subcommittee to restore the discretionary funding for HEA Title III–A, Sec. 316 to $30,000,000 in fiscal year 2016.

Additionally, we ask that language be included clarifying that funds awarded under Title III, Sec. 316 shall remain available for an additional 5 years beyond the initial grant period, as is the case for grants awarded under the historically Black colleges and Universities (HBCUs) program; the other Title III grants that are awarded by formula. The language requested is as follows:

"The committee directs the U.S. Department of Education to allow any funds paid to an institution and not expended or used for the purposes for which the funds were paid during the 5-year period following the date of the initial grant award, may be carried over and expended during the succeeding 5-year period, if such funds were obligated for a purpose for which the funds were paid during the 5-year period following the date of the initial grant award."

The Department of Education has recently decided that it does not have the authority to extend the time that TCU-Title III grant funds must be formally obligated or encumbered beyond the initial 5-year grant period. According to the Department, a TCU may not request even a routine 1 year, no-cost extension on a Title III award, without forfeiting the chance to receive a new 5-year grant during that year. Most of the initial 5-year grants awarded by formula will close at the end of this current fiscal year. Many of the colleges are addressing long-term issues of inadequate facilities and insufficient infrastructure on their campuses using part of their Title III grant. Because these projects are long-term, while the funds are intended for these projects, not all of the funds have been expended or formally obligated. As it stands now, funds remaining in the initial grant that are not spent or formally obligated by September 30, 2015 will revert to the U.S. Treasury and be lost to the program. Therefore, colleges will have to abandon their carefully crafted strategic plans for the funds and find other ways to use them by September 30, or lose them altogether. We do not believe this to be a wise or effective way of administering this critically needed grants program. AIHEC is working with the Department to get this apparent misinterpretation of current law fixed. The language that we are seeking is the same as that included in the Title III program for HBCUs, which as noted earlier, is the other formula-funded Title III program. By adding this same language to the TCUs program, the Department will be afforded the authority and direction needs to allow the extension of time to expend TCU Title III grant funds intended for long-term projects that for many reasons may require additional time to complete.

—*TRIO*. Retention and support services are vital to achieving the national goal of having the highest proportion of college graduates in the world by 2020. TRIO programs, such as Student Support Services and Upward Bound, were created out of recognition that college access is not enough to ensure advancement and that multiple factors work to prevent the successful completion of postsecondary programs for many low-income and first-generation students and students with disabilities. Therefore, in addition to providing the maximum Pell Grant award level, it is critical that Congress also sustain student assistance programs, such as Student Support Services and Upward Bound so that low-income and minority students have the Federal support necessary to allow them to remain enrolled in and ultimately complete their higher education degrees.

*Pell Grants*.—The importance of Pell Grants to TCU students cannot be overstated. More than 70 percent of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other sources of financial aid than students at State-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. However, the Department of Education changed its regulations to limit Pell eligibility from 18 to 12 full-time semesters, without any consideration of those already in the process of attaining a postsecondary degree. This change in policy impeded some TCU students from completing a postsecondary degree, which is widely recognized as being critical for access to, and advancement in, today's highly technical workforce.

TCUs are open enrollment institutions. Recent placement tests administered at TCUs to first-time entering students indicated that 70 percent required remedial math, 53 percent required remedial reading, and 60 percent required remedial writing. These results clearly illustrate just how serious this new Pell Grant eligibility limit is to the success of TCU students in completing a postsecondary degree. Students requiring remediation can use as much as a full year of eligibility enhancing their math, and/or reading/writing skills, thereby hampering their future postsecondary degree plans. A prior national goal was to provide access to quality higher education opportunities for all students regardless of economic means, at which TCUs have been extremely successful. While the new national goal intends to produce graduates with postsecondary degrees by 2020, this change in policy does not advance that objective. On the contrary, the change in the regulations will cause many low-income students to once again abandon their dream of a postsecondary degree, as they will simply not have the means to continue to pursue it. This new policy evokes the adage "penny wise—pound foolish" and could indeed compromise the laudable goal of producing a well-trained technically savvy workforce. The TCUs urge the Subcommittee to continue to fund this essential program at the highest possible level, and to direct the Secretary of Education to implement a process to waive the impractical 12 semester Pell Grant eligibility for TCU students, to allow them to catch-up and excel.

*II. Perkins Career and Technical Education Programs*

—Tribally-Controlled Postsecondary Career and Technical Institutions: Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. AIHEC requests $8,200,000 to fund grants under Sec. 117 of the Perkins Act.

—Native American Career and Technical Education Program (NACTEP): NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. The TCUs strongly urge the Subcommittee to continue to support NACTEP, which is vital to the continuation of career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.

*III. American Indian Adult and Basic Education (Office of Vocational and Adult Education)*

This program supports adult basic education programs for American Indians offered by State and local education agencies, Indian tribes, agencies, and TCUs. Despite the absence of dedicated funding, TCUs must find a way, often using already insufficient institutional operating funds, to continue to provide adult basic education classes for those American Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. The new GED exam, which was instituted in January 2014, is more focused on mathematics. As noted earlier, placement tests for TCU-entering students reveal an enormous need for math remediation. Additionally, the new GED test is fully computerized. While younger GED seekers may be well-versed and comfortable with computer-based testing, older and poorer citizens may not be. These factors indicate a further and growing need for adult basic educational programs and GED preparation on Indian reservations. TCUs must have sufficient and stable funding to continue to provide these essential services and to ensure their respective reservation community residents have the same chances to succeed that others throughout the country have. In fiscal year 2015, Congress appropriated approximately $569,000,000 million for Adult Education State grants. TCUs request the Subcommittee to direct that $8,000,000 of the funds appropriated in fiscal year 2016 for Adult Education State Grants be made available to make competitive awards to TCUs to help meet the growing demand for adult basic education and remediation program services on their respective Indian reservations.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAM

*Tribal Colleges and Universities Head Start Partnership Program (DHHS–ACF).*—Tribal Colleges and Universities are ideal partners to help achieve the goals of Head Start in Indian Country. The TCUs are instrumental in meeting the mandate that Head Start teachers earn degrees in Early Childhood Development or a related discipline. In fiscal year 1999 Health and Human Services-Administration for Children and Families established the TCU-Head Start Partnership program. By 2004, TCUs had awarded more than 400 certificate and degrees. The 2007 reauthorization of the Head Start Act included mandates on education for Head Start workers and teach-

ers, and specifically authorized the TCU–HS Partnership. Ironically, that was the last year of funding for the program. Today, 71 percent of teachers nationally, have required degrees and credentials. By contrast, in Indian Country (Region 11) only 36 percent of the teachers meet the requirements set forth in the Head Start Act reauthorization. Clearly, the need for proper training is high in Indian Country, and the TCUs are perfectly situated to help address this inexcusable gap in training the tribal Head Start workforce. The TCUs request that of the over $10,000,000,000 proposed for making payments under the Head Start Act $5,000,000 be designated for the TCU-Head Start Partnership program, as reauthorized in PL 110–134, to ensure that TCUs can continue to provide high quality, culturally appropriate training for those working in reservation Head Start programs.

We respectfully request that the Members of the Subcommittee continue and expand the Federal investment in the Nation's Tribal Colleges and Universities and carefully consider our fiscal year 2016 appropriations needs and requests.

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## PREPARED STATEMENT OF THE AMERICAN LIVER FOUNDATION

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—$32 Billion for the National Institutes of Health (NIH) at an increase of $1 billion over fiscal year 2015. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.

—Support the NIH Portfolio on Viral Hepatitis and Other Liver Diseases and Liver Cancers within NIDDK'S Liver Disease Research Branch.

—$62.82 Million for the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis.

Chairman Blunt, Ranking Member Murray, and esteemed members of the Subcommittee, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1976, the American Liver Foundation (ALF) is the Nation's leading nonprofit health organization for people living with liver disease. ALF is a nationwide network of staff and volunteers that provides awareness, outreach, education and patient support services to educate the public about liver health and to improve the lives of individuals and their families affected by liver disease.

ALF's mission is to facilitate, advocate and promote education, support and research for the prevention, treatment and cure of liver disease, including focusing on hepatitis C, which untreated leads to liver disease.

ALF makes measurable difference in the fight against liver disease by providing resources for medical research, educating patients, families, caregivers, and healthcare professionals, advocating for patients and their families, and creating public awareness campaigns about liver wellness and disease prevention.

### FACTS

The liver is one of the body's largest organs, performing hundreds of functions daily including, removal of harmful substances from the blood, digestion of fat, and storing of energy. Non-alcoholic fatty liver disease (NAFLD), hepatitis C, and heavy alcohol consumption are the most common causes of chronic liver disease or cirrhosis (severe liver damage) in the U.S. Approximately 30 percent of adults and 3–10 percent of children have excessive fat in the liver or NAFLD which can lead to a severe liver disease called non-alcoholic steatohepatitis (NASH). Approximately 4.4 million Americans are living with Hep. B or C but most do not know they are infected. More than 2 million Americans are living with alcohol related liver disease. Approximately 5.5 million Americans are living with chronic liver disease or cirrhosis. Vaccinations for hepatitis A and B and treatments for hepatitis C are helping to change the course of this chronic life altering disease for the patient community.

ALF would like to thank the Subcommittee for its past support of liver disease and viral hepatitis research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically ALF recommends:

—32 billion for the NIH

—$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK) with support for the Liver Diseases Research Branch

—$62.82 million for CDC's Division of Viral Hepatitis

We at the ALF respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the ALF would like to highlight the current advancements being made.

VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH

ALF applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. ALF urges that funding be focused on expanding the capability of State health departments, particularly to enhance resources available to the hepatitis State coordinators. ALF also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

ALF supports $62.82 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. ALF also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

DIGESTIVE DISEASE COMMISSION

In 1976, Congress enacted Public Law 94–562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the State of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

ALF recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address liver diseases, cancers, and the epidemic of Viral Hepatitis.

CONCLUSION

ALF understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC.

Millions of Americans are pinning their hopes for a better life, or even life itself, on liver disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of the millions of liver disease and viral hepatitis patients, we appreciate your consideration of the views of the American Liver Foundation. We look forward to working with you and your staff.

[This statement was submitted by Navin VIJ, MD, Patient Advocate, American Liver Foundation.]

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## PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

The American Lung Association is pleased to present our recommendations for fiscal year 2016 to the Labor, Health and Human Services, and Education Appropriations Subcommittee. The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans. Founded in 1904 to fight tuberculosis, the American Lung Association is the oldest voluntary health organization in the United States. The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research.

A SUSTAINED INVESTMENT IS NECESSARY

Mr. Chairman, investments in prevention and wellness pay near- and long-term dividends for the health of the American people. In order to save healthcare costs in the long-term, investments must be made in proven public health interventions including tobacco control, asthma programs and tuberculosis programs. Our Nation must also continue its historic investments in biomedical research for better cures, treatments, diagnostics and detections for lung diseases.

*Lung Disease*

Each year, more than 400,000 Americans die of lung disease. It is America's number three killer, responsible for one in every six deaths. More than 33 million Americans suffer from a chronic lung disease and it costs the economy an estimated $173 billion each year. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease (COPD), tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

*Improving Public Health and Maintaining Our Investment in Medical Research*

The American Lung Association strongly supports increasing overall Centers for Disease Control and Prevention (CDC) funding to $7.8 billion in order for CDC to carry out its prevention mission and to assure an adequate translation of new research into effective State and local programs.

The U.S. must also maintain its commitment to medical research. While our focus is on lung disease research, we support increasing the investment in research across the entire NIH with particular emphasis on the National Cancer Institute, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Environmental Health Sciences, the National Institute of Nursing Research, the National Institute on Minority Health & Health Disparities and the Fogarty International Center.

*The Prevention and Public Health Fund*

The American Lung Association strongly supports the Prevention and Public Health Fund established in the Affordable Care Act and asks the Committee to oppose any attempts to divert or use the Fund for any purposes other than what it was originally intended. The Prevention Fund provides funding to critical public health initiatives, like community programs that help people quit smoking, support groups for lung cancer patients, and classes that teach people how to avoid asthma attacks. Money from the Prevention Fund has also been used to pay for the CDC's media campaign "Tips from Former Smokers." The Tips campaign has resulted in hundreds of thousands of Americans quitting smoking and has been demonstrated to have an incredible return on investment. A commonly accepted threshold for cost-effective public health interventions is $50,000. The 2012 Tips campaign spent $480 per smoker who quit and $393 per year of life saved.

*Tobacco Use*

Tobacco use is the leading preventable cause of death in the United States, killing close to half a million people every year. Over 46 million adults and 3.6 million youth in the U.S. smoke. Annual healthcare and lost productivity costs total $289 billion in the U.S. each year.

Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented, the CDC Office on Smoking and Health (OSH) should be much larger and better funded. Public health interventions, including but not limited to the Tips campaign, have been scientifically proven to reduce tobacco use, the leading cause of preventable death in the United States. The American Lung Association urges that $220 million be appropriated to OSH for fiscal year 2016.

*Lung Cancer*

More than 402,000 Americans alive today have ever been diagnosed with lung cancer. During 2015, approximately 221,000 new cases of lung cancer will be diagnosed, and over 158,000 Americans will die from lung cancer. Survival rates for lung cancer tend to be much lower than those of leading cancers. African Americans are more likely to develop and die from lung cancer than persons of any other racial group.

Lung cancer receives far too little attention and focus. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to lung cancer so that there can be better cures, treatments and early detection for lung cancer. Recognizing that personalized therapies may offer the best hope to people with lung cancer, the Lung Association supports the $215 million precision medicine proposal included in the President's fiscal year 2016 budget. We support a funding level of $5.265 billion for the National Cancer Institute and urge more attention and focus on lung cancer.

*Asthma*

Asthma is highly prevalent and expensive. More than 25 million Americans currently have asthma, of whom close to 7 million are children. Asthma prevalence rates are over 45 percent higher among African Americans than whites. Asthma

costs our healthcare system over $50.1 billion annually and indirect costs from lost productivity add another $5.9 billion, for a total of $56 billion dollars annually.

The American Lung Association asks this Committee to appropriate $30.596 million to the CDC's National Asthma Control Program (NACP) in fiscal year 2016. The NACP tracks asthma prevalence, promotes asthma control and prevention and builds capacity in State programs. This program has been highly effective: the rate of asthma has increased, yet asthma mortality and morbidity rates have decreased. However, at present only 23 States receive funding—leaving a nationwide public health void that can lead to unnecessary asthma-related attacks and healthcare costs.

In addition, we recommend that the National Heart, Lung and Blood Institute receive $3.188 billion and the National Institute of Allergy and Infectious Diseases receive $4.635 billion, and that both agencies continue their investments in asthma research in pursuit of treatments and cures.

*Chronic Obstructive Pulmonary Disease (COPD)*

COPD is the third leading cause of death in the U.S. It has been estimated that 11.5 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2012, 139,958 people in the U.S. died of COPD. The annual cost to the Nation for COPD in 2010 was projected to be $49.9 billion. We strongly support funding the National Heart, Lung and Blood Institute and its lifesaving lung disease research program at $3.188 billion. The American Lung Association also asks the Committee to continue its support of the National Heart, Lung and Blood Institute working with the CDC and other appropriate agencies to act on its national action plan to address COPD, which should include public awareness and surveillance activities.

*Influenza*

Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the U.S. To prepare for a potential pandemic, the American Lung Association supports funding the Federal CDC Influenza efforts at $187.558 million.

*Tuberculosis (TB)*

There are an estimated 10 million to 15 million Americans who carry latent TB infection, and it is estimated that 10 percent of these individuals will develop active TB disease. In 2014, there were 9,412 cases of active TB reported in the U.S. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB and totally-drug resistant TB also poses a significant public health threat. We request that Congress increase funding for tuberculosis programs at CDC to $243 million for fiscal year 2016.

IMPACT OF CLIMATE CHANGE ON LUNG HEALTH

Climate change is one of the greatest threats to public health. CDC's Climate and Health Program is the only HHS program devoted to identifying the risks and develop effective responses to the health impacts of climate change, including worsening air pollution; diseases that emerge in new areas; stronger and longer heat waves; more frequent and severe droughts, and provides guidance to States in adaptation. Pilot projects in 16 State and two city health departments States use CDC's Building Resilience Against Climate Effects (BRACE) framework to develop and implement health adaptation plans and address gaps in critical public health functions and services. As climate-related challenges intensify, CDC must have increased resources to support States and cities in meeting the challenge. The Lung Association supports the President's Budget Request of $18.613 million for the Center for Disease Control and Prevention's Climate and Health Program.

*Additional Priorities*

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. We support an appropriations level of $35 million for the Environment and Health Outcome Tracking Network. This program supports investments in communities to identify and improve policies and environmental factors influencing health and reduce the burden of chronic diseases.

*Conclusion*

Mr. Chairman, lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in six deaths. Progress against lung disease is not keeping pace with progress against other major causes of death and more must be done. The level of support this committee ap-

proves for lung disease programs should reflect the urgency illustrated by the impact of lung disease.

[This statement was submitted by Harold Wimmer, National President and CEO, American Lung Association.]

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## PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS

Chairman Roy Blunt, Ranking Member Patty Murray, and Members of the Subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization (WHO), and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative. In 2013, all WHO regions established measles elimination goals by 2020. The Measles & Rubella Initiative is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved impressive results by supporting the vaccination of more than 1.8 billion children since 2001. Largely due to the Measles & Rubella Initiative, global measles mortality dropped 75 percent, from an estimated 548,000 deaths in 2000 to 145,700 in 2013 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 88 percent. About 400 children still die from measles each day from a virus that can be countered with a safe, effective and inexpensive vaccine. Measles is among the most contagious diseases ever known, and a top killer of children in low-income countries where children have little or no access to medical treatment and are often malnourished. Measles spreads much more easily than the flu or the Ebola virus. In fact, one person infected with measles can infect up to 18 others if he has not been vaccinated. In addition, each year more than 100,000 children are born with congenital rubella syndrome (CRS). CRS can cause severe birth defects, including blindness, deafness, heart defects and mental retardation. CRS treatment is very costly to treat, yet very inexpensive to prevent.

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than $1.3 billion and provided technical support in more than 88 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2013, an estimated 15.6 million measles deaths were averted as a result of these accelerated measles control activities, making measles mortality reduction one of the most cost-effective public health interventions.

The majority of measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and "integrating" the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. Doses of oral polio vaccines are frequently distributed during measles campaigns in polio endemic and high risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children's health from a single campaign.

The extraordinary reduction in global measles deaths greatly contributed to reducing under-five child mortality. However, large outbreaks in several African, European and Asian countries from 2011 to 2014 have compromised 2015 measles elimination goals. These outbreaks highlight the fragility of the last decade of progress. If mass immunization campaigns are not continued, measles deaths will rapidly increase.

To achieve 2020 elimination goals and avoid a resurgence of measles, the following actions are required:

—Fully implementing activities, both campaigns and strengthening routine measles coverage, in India since it is the greatest contributor to the global burden of measles and congenital rubella syndrome though surveillance is weak in recording the latter.
—Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90 percent of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
—Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from Gavi, the Vaccine Alliance.
—Securing sufficient funding for measles and rubella-control activities both globally and nationally. The Measles & Rubella Initiative faces a funding shortfall of an estimated U.S. $368.8 million for 2015–2020. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. adults and children are also being protected from the diseases. Measles can cause severe complications such as pneumonia, encephalitis, and even death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened, and endemic transmission of measles cases have been eliminated here since 2000 and rubella in 2002. However, importations of measles cases into this country continue to occur each year. Since 2000, the annual number of people reported to have measles ranged from a low of 37 in 2004 to a high of 664 people across 27 States in 2014; the greatest number of cases reported in the U.S. since measles was declared eliminated in 2000. The country is currently experiencing a large, multi-State outbreak of measles with 178 cases reported by the CDC to March 27. The financial impact of these cases and outbreaks are substantial, both in terms of the costs to public health departments to conduct contact tracing and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between $100,000 and $200,000 to control.

THE ROLE OF CDC IN GLOBAL MEASLES MORTALITY REDUCTION

Since fiscal year 2001 and until 2015, Congress has provided funding for the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 88 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

—Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
—Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
—Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Congress—was essential in helping achieve the sharp reduction in measles deaths in just 13 years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate to have a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organi-

zations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2014 and fiscal year 2015, Congress appropriated $49.8 million each year to fund CDC for global measles control activities. In fiscal year 2016, the American Red Cross and the United Nations Foundation request sustained funding at the level requested by the President, $49.8 million for CDC's measles and rubella control activities to protect the investment of the last decade and prevent a global resurgence of measles.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

[This statement was submitted by Harold Brooks, Senior Vice President of International Operations, American National Red Cross.]

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## PREPARED STATEMENT OF THE AMERICAN PHYSIOLOGICAL SOCIETY

The American Physiological Society (APS) thanks the subcommittee for its ongoing support of the National Institutes of Health (NIH). Research carried out by the NIH contributes to our understanding of health and disease, which allows all Americans to look forward to a healthier future. The APS urges you to make every effort to provide the NIH with at least $32 billion in fiscal year 2016. This is necessary to prevent further erosion of research capacity.

Federal investment in research is critically important because breakthroughs in basic and translational research are the foundation for new drugs and therapies that help patients, fuel our economy, and provide jobs. The Federal Government is the primary funding source for discovery research through competitive grants awarded by the NIH. Although the private sector partners with academic researchers to develop research findings into new treatments, industry relies upon federally funded research to identify where innovation opportunities can be found. This system of public-private partnership has been critical to U.S. leadership in the biomedical sciences. However, this position of leadership is at risk as other nations, including China, increase their investments in research and development while the United States investment has lagged in recent years.

Federal research dollars also have a significant impact at the local level: more than 80 percent of the NIH budget is awarded throughout the country to researchers who use grant funds to pay research and administrative staff, purchase supplies and equipment, and cover other costs associated with their research.

*Challenges facing the scientific community*

Twenty years ago leaders in Congress undertook the grand challenge of doubling the budget of the NIH with a vision of moving biomedical science forward and improving quality of life for people around the world. The investment that Americans made between 1995 and 2003 allowed the biomedical research enterprise to grow in many ways: more research was funded, new investigators were trained, and the infrastructure required to support the science expanded to fit the need.

Unfortunately, the NIH budget has declined in constant dollars each year since 2004, causing a slow erosion of research capacity. Between fiscal year 2003 and 2015, NIH's capacity to support research declined by 22.9 percent. This was further exacerbated by the spending caps put in place by the Budget Act of 2011, which caused significant cuts for the agency in fiscal year 2013. One analysis showed that NIH supported approximately 1000 fewer investigators in fiscal year 2013 as a result of budget cuts.[1] Researchers who lose their funding face an uncertain future as there are few options to sustain their research without Federal grants. Losing Federal support puts at risk the investment that it took to build those programs over many years. It also means that talented individuals working in those labs will have to look elsewhere for increasingly scarce jobs. As a result of stagnant funding for NIH, scientists at all stages of their careers struggle to maintain their research programs.

Fundamental changes are needed to ensure long-term sustainability for the scientific enterprise and many groups have undertaken efforts to maximize the amount of research that can be carried out with the resources available. However, the reality is that scientists are approaching the point where they can no longer "do more with less" and as a result, less research will be accomplished. We urge Congress to

[1] Http://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/.

make every effort to provide NIH with the resources necessary to sustain the scientific enterprise and move research forward. The APS joins the Federation of American Societies for Experimental Biology (FASEB) in urging that NIH be provided with at least $32 billion in fiscal year 2016.

*The promise of research*

This year the NIH has announced plans to advance scientific priorities including:

—Continued investment in the Brain Research through Advancing Innovative Neurotechnologies ("BRAIN") initiative. The BRAIN initiative brings together researchers from diverse disciplines to tackle major gaps in current knowledge about the brain and brain diseases.

—A new Precision Medicine initiative would invest heavily in cancer genomics, and develop a national research cohort of 1 million participants.

—Resources would also be devoted to a multi-agency Antimicrobial Resistance initiative to address the growing public health crisis represented by the rise of multiple drug resistant pathogenic bacteria.

These important projects require significant resources, and at a time of constrained budgets, that will further diminish funding for investigator-initiated grants that focus on major disease areas including cancer and cardiovascular disease, the major killers of American citizens. The NIH system of allowing investigators to develop and propose ideas, which are then evaluated by their peers and selected for funding based on their merit has fostered a research enterprise that is second to none and has been the source of most every major new discovery in medicine. Increasing the NIH budget to $32 billion would provide funding for priority projects as described above, while also providing resources for individual scientists to pursue creative new avenues of research.

The NIH also uses the Institutional Development Award (IDeA) Program to broaden the geographic distribution of NIH funds by providing support to researchers and institutions in areas that have not previously received significant NIH funding. IDeA builds research capacity and improves competitiveness in those States by developing shared resources, infrastructure and expertise. Networks established through this program expand research opportunities for students and faculty at predominantly undergraduate institutions and enhance the level of science and technology knowledge of the workforce in IDeA States. The program currently serves institutions and researchers in 23 States and Puerto Rico. The APS believes this program is an important way to broaden participation in the scientific workforce.

The APS is a professional society dedicated to fostering research and education as well as the dissemination of scientific knowledge concerning how the organs and systems of the body work. The Society was founded in 1887 and now has more than 10,000 member physiologists. APS members conduct NIH-supported research at colleges, universities, medical schools, and other public and private research institutions across the U.S.

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## PREPARED STATEMENT OF THE AMERICAN PSYCHIATRIC ASSOCIATION

### INTRODUCTION & BACKGROUND

The American Psychiatric Association (APA), the national medical specialty society representing over 36,000 psychiatric physicians, is pleased to present its recommendations regarding fiscal year 2016 appropriations for Graduate Medical Education (GME), the National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and Indian Health Services.

APA recognizes that the Subcommittee faces difficult decisions in a constrained budget environment. However, a continued commitment to critical programs supporting physician workforce development should remain a high priority. Strong, sustained funding of mental health and substance use disorder services is necessary to ensure the overall health of Americans and the Nation's economic prosperity. Federal investment is also vital for the National Institutes of Health (NIH) to sustain its mission of improving health through medical science breakthroughs and maintaining international leadership in science and biomedical research.

*Impact of Budget Cuts on America's Health*

Continued austerity will have a tremendous impact on the Nation's medical schools and teaching hospitals and the patients they serve. Deficit reduction proposals to cut Medicare GME support, including decreases in Indirect Medical Education (IME) payments, threaten access to critical services and reduce physician

training at a time when patient needs are increasing. Between 2010 and 2050, the United States population ages 65 and older will nearly double, the population ages 80 and older will nearly triple. The Nation's elderly and disabled Medicare beneficiaries must have access to treatment of psychiatric and substance use disorders.

The Nation's supply of pediatricians and pediatric specialists depend on physician training programs at the Nation's children's hospitals. Training programs are supported by the Children's Graduate Medical Education program (CHGME). Reductions to CHGME jeopardize the supply of pediatricians and pediatric specialists that all children need. APA opposes Administration's proposed 38 percent cut to $100 million for CHGME, from fiscal year 2015's $265 million funding level.

IMPORTANCE OF FEDERAL INVESTMENTS IN BIOMEDICAL RESEARCH

APA strongly advocates for Federal investments to discover and develop treatments for mental illnesses and substance use disorders. The National Institute of Mental Health (NIMH) conservatively estimates the total costs associated with serious mental illnesses, disorders that are severely debilitating and affect about 6 percent of the adult population, to be in excess of $300 billion per year ($193 billion loss of earnings, $100 billion heath care expenditures and $24.3 billion disability benefits). The costs associated with mental illnesses stem from both the direct expenditures for mental health services and treatment (direct costs), and from expenditures and losses related to the disability caused by these disorders (indirect costs). Indirect costs include public expenditures for disability support, lost earnings among people with serious mental illness, and burden on families. More specific diagnostic tools, earlier treatment, developing medications with fewer side effects, and the potential of genomic-sensitive treatments are important priorities for NIMH. Gender and ethnic differences exist in the development, clinical course, and outcomes of bipolar disorder and schizophrenia. We need to understand the reasons for these disparities and develop methods of addressing them. Investment in the NIH and the Brain Research through Advancing Innovative Neurotechnologies Initiative (BRAIN) will advance this knowledge.

Drug abuse and addiction have serious consequences for individuals, families and for society. Estimates of the total overall costs of substance abuse in the United States, including productivity and health- and crime-related costs, exceed $600 billion annually. This includes approximately $181 billion for illicit drugs, $193 billion for tobacco, and $235 billion for alcohol. As staggering as these numbers are, they do not fully describe the breadth of destructive public health and safety implications of substance use and addiction, such as family disintegration, loss of employment, failure in school, domestic violence, and child abuse. The National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) are tasked with developing and implementing new treatments for addiction and identifying the causes and contributors of addiction. The need has never been greater for support of research on opiate addiction, prevention of prescription drug abuse, and the impact of alcohol on liver disease.

IMPORTANCE OF FEDERAL INVESTMENTS IN SERVICES

Seventy 5 percent of States reported a substantial increase in demand for community-based mental healthcare services. This higher demand comes at a time when States are closing psychiatric hospitals and clinics and reducing support for community-based mental health services. SAMHSA's Center for Mental Health Services (CMHS) funds important programs including: State block grants, suicide prevention, homelessness prevention, jail diversion for people with mental illness, and services for children and the elderly. Due to the economic downturn, States have been forced to cut mental healthcare funding by a total of nearly $4.6 billion since 2008. SAMHSA's Center for Substance Abuse Treatment (CSAT) and Center for Substance Abuse Prevention (CSAP) provides millions to States in block grants for flexibility in responding to the particular needs in each State. The APA would like to draw the Committee's attention to SAMHSA's Minority Fellowship Training program which underpins training for psychiatrists and other mental healthcare providers in underserved areas of the United States. The successful Minority Fellowship Training program promotes ethnic diversity and supports access to care for vulnerable populations.

*APA Requests*

APA requests that NIH receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in medical research. While the Consolidated Appropriations Act of 2014 included an increase for the National Institutes of Health (NIH), this increase did not reinstate all of the funds cut

by sequestration in fiscal year 2013 nor did it restore inflation's erosion of purchasing power over the past decade. We hope fiscal year 2016 represents a first step toward re-establishing sustained, predicable funding to restore our Nation's preeminence in medical research.

For the Center for Mental Health Services (CMHS) under SAMSHA, APA supports an appropriation of $10 million for CMHS' successful Minority Fellowship Training program to respond to workforce needs. As Congress considers funding of the "Now is the Time Initiative" within CMHS, APA requests that a variety of early detection programs be allowed to enter a competitive grant program for these funds. CMHS' fiscal year 2015 Omnibus Appropriations measure included a 5 percent setaside in the Mental Health Block Grant for the promulgation of evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders. APA supports this CMHS-NIMH collaboration. The APA remains concerned over the rise in addiction and abuse of opioid medications. APA strongly encourages the further training of physicians, including psychiatrists, for opioid-dependence treatment including the use of Suboxone and Buprenorphine. These medications act as "opioid antagonists" and can assist in the patient's supervised withdrawal from opioids. As a partner organization in two clinical mentoring and education initiatives funded by SAMHSA (Physicians Clinical Support System-Buprenorphine and the Prescribers' Clinical Support System- Opioid Therapies), APA is advancing clinical expertise in this area. APA has produced a series of webinars focused on the use of opioid therapies for treatment of opioid dependence and the safe use of opioids in the treatment of chronic pain. These free webinars are available for psychiatrists, other physicians, residents, and other interested clinicians at www.pcssb.org/educational-and-training-resources/special-topics.

Finally, APA supports a 10 percent ($420 million) increase in clinical services funding for the Indian Health Service in fiscal year 2016 in keeping with the recommendation from the Friends of Indian Health Coalition. Native American youth have a suicide rate that is 1.7 times higher than the rest of the population of the United States. Increasing access to services will get needed medical care to at-risk teenagers before acute psychiatric episodes present.

Congress needs to accelerate and increase its investment in medical research, the physician workforce, and care for those with mental health and substance use disorders and their families in order to continue to improve our Nation's health and economic well-being. American Psychiatric Association appreciates the opportunity to submit its statement on fiscal year 2016 funding priorities to the Subcommittee.

Thank you.

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## PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the U.S.: its membership includes nearly 130,000 researchers, educators, clinicians, consultants and students. APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives. Many programs in the Labor-HHS-Education bill impact science, education, and the populations served by clinical psychologists.

*National Institutes of Health*.—Sub-inflationary spending increases have eroded NIH's purchasing power and left many innovative research projects unfunded during the last 10 years. As a member of the Ad Hoc Group for Medical Research, APA recommends that NIH receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in health research. APA also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the threatened cuts to health research that squander invaluable scientific opportunities, discourage young scientists, threaten or slow improvements in our Nation's health, and jeopardize our economic future.

Psychological scientists are supported by research grants or training programs in almost all of NIH's 27 institutes and centers. They are working with animal models or human participants to improve diagnosis and treatment of Alzheimer's disease and diabetes, to understand the mechanisms underlying adoption of healthy behaviors, and to help prevent transmission of HIV and unhealthy behaviors such as substance abuse. Behavioral research is critical to NIH's mission: the Institute of Medicine recently reaffirmed that over 50 percent of premature mortality in the U.S. is due to behaviors such as smoking, sedentary lifestyle, and alcohol and other drug consumption.

APA is a strong supporter of the OppNet initiative, which has stimulated over $71.5 million worth of basic behavioral and social sciences research in 167 projects

that might not have otherwise been supported. The 5-year funding allotment for the initiative ended in fiscal year 2014. APA urges the Committee to examine the NIH's evaluation of the program when it is completed, and to encourage NIH not only to support the now-voluntary program but to seed new collaborative efforts to support basic behavioral and social science research that may be applied to advance the missions of many of the different NIH institutes.

APA endorses the National Institute of Child Development's continued focus on basic and applied research to advance our understanding of attachment in mother-infant relationships and its impact on development. Early life experiences can have profound effects on a range of behavioral and health outcomes later in life, including mental health outcomes, but often require specific experimental controls to pinpoint the impacts of various factors. NICHD supports human and animal studies identifying and describing the complex interaction of behavioral, social, environmental, and genetic factors on health outcomes with the ultimate goal of improved understanding of and interventions for mental illnesses such as depression, addiction, and autism.

Because there remains a disturbing paucity of scientific evidence about the effects of sporadic vs. regular use of marijuana, alcohol, nicotine and other substances on the developing brain, APA strongly supports the launch of the Adolescent Behavioral and Cognitive Development (ABCD) study under the auspices of NIH's Collaborative Research on Addictions (CRAN) initiative. Unique in its scope and duration, the ABCD will recruit 10,000 youth before they begin using alcohol, marijuana, nicotine and other drugs, and follow them over 10 years into early adulthood to assess how substance use affects the trajectory of the developing brain. The ABCD study design will use advanced brain imaging as well as psychological and behavioral research tools to evaluate brain structure and function and track substance use, academic achievement, IQ, cognitive skills, and mental health over time.

*Centers for Disease Control and Prevention*.—As a member of the CDC Coalition, APA supports an appropriation of at least $7.8 billion for core programs in fiscal year 2016. APA strongly supports the President's request for increased funding for the National Injury Prevention and Control Center, including $25 million for the National Violent Death Reporting System, to allow for its expansion to all 50 States and DC, and $10 million research into the causes and prevention of gun violence. As a member of the Friends of the National Center for Health Statistics, APA recommends a program level of $172 million for fiscal year 2016—$160 million in budget authority and $12 million in mandatory Prevention and Public Health Fund obligations.

The greatest number of new HIV infections in this country are among young people under 25 and specifically among Black young men who have sex with men (MSM). APA encourages the Committee to maintain the President's $6 million increase for the Division of HIV/AIDS Prevention (DHAP) to expand youth HIV prevention efforts in schools and non-school settings and ensure coordination of these efforts within the agency.

*Substance Abuse and Mental Health Services Administration—APA strongly supports:*

—The National Child Traumatic Stress Network (NCTSN) program. APA recommends increased support for the Network's efforts on behalf of the recovery of children, families, and communities affected by physical and sexual abuse, school and community violence, natural disasters, sudden death of a loved one, war's impact on military families, and other trauma.

—Garrett Lee Smith Memorial Act programs—Campus Suicide Prevention, State and Tribal Youth Suicide Prevention and the Suicide Prevention Resource Center. These effective national programs help meet the mental and behavioral health needs of youth and young adults through access to prevention, education, and outreach services to reduce suicide risk in these populations. First authorized in 2004, the Garrett Lee Smith Memorial Act has supported 370 youth suicide prevention grants in 50 States, 46 Tribes or Tribal organizations, and 175 institutions of higher education.

—Minority Fellowship Program—APA remains concerned that while minorities represent 30 percent of the U.S. population and are projected to increase to 40 percent by 2025, only 23 percent of recent doctorates in psychology, social work and nursing were awarded to minorities. In addition, disparities in research on minority mental health continues to be a challenge for the mental health workforce. We encourage the Committee to support level funding of the Minority Fellowship Program as requested in the fiscal year 2016 budget proposal. Maintaining the current funding level will assist in growing the pool of culturally

competent mental health professionals while expanding areas of research into minority mental health.

—Mental Health Care Provider Education in HIV/AIDS Program in CMHS- Continuing education for mental health providers in these clinical issues remains a high priority. APA urges Congress to maintain level funding in CMHS for the training of psychologists, social workers, and psychiatrists in vital substance abuse and mental health services to people with HIV/AIDS.

—SAMHSA's Safe Schools/Healthy Students program that expands access to mental and behavioral health services in schools and reduces violence through prevention and early intervention supports.

*Health Resources and Services Administration*.—APA strongly recommends funding services to individuals with perinatal depression. Postpartum depression (PPD) and perinatal depression are commonly undiagnosed conditions associated with childbirth. In the U.S., approximately one in five women suffers from PPD each year. Under the current USPSTF guidelines, depression screening is available as an Essential Health Benefit to all non-pregnant adults, yet excludes the vulnerable population of pregnant women. APA supports funding for PPD research and treatment under Section 512 of the Social Security Act, to incorporate screening and linkages to behavioral health treatment for women suffering from this condition. APA encourages the Committee to support incorporation of PPD screening into the Title V programs administered by HRSA as well as Healthy Start. APA also encourages the Committee to urge the Secretary to prioritize the issue of PPD by raising awareness, expanding research, and establishing grants for the operation and coordination of cost-effective services to afflicted women and their families.

APA recommends continued investments in the mental and behavioral health workforce, including $9.9 million for the Graduate Psychology Education program to increase the number of health service psychologists (including doctoral-level clinical, counseling, and school psychologists) trained to provide integrated services to high-need underserved populations in both urban and rural communities. This program supports the training of doctoral psychology students, interns and postdoctoral residents with other health professionals while they provide supervised mental and behavioral health services to underserved and vulnerable populations, including: children, older adults, veterans and their families, individuals with chronic illnesses, and victims of abuse and trauma. In 2013–2014 alone, the GPE program supported the training of over 2,500 graduate psychology students. APA encourages HRSA to build on recent efforts to expand training to increase mental and behavioral health services for returning service members, veterans and their families, with a strong emphasis on veterans reintegrating into rural civilian communities. Recognizing the growing need for highly trained mental and behavioral health professionals to deliver evidence-based services to the rapidly aging population, APA encourages HRSA to invest in geropsychology training programs and to help integrate health service psychology trainees at federally Qualified Health Centers.

*HHS programs on aging*.—Given that approximately 20–25 percent of older adults have a mental or behavioral health problem, and older white males (age 85 and over) currently have the highest rates of suicide of any group in the U.S. APA supports an expanded effort to address the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the Older Americans Act Amendments of 2006, grants to States for the delivery of mental health screening and treatment services for older individuals and programs to increase public awareness and reduce the stigma associated with mental disorders in older individuals.

APA also recommends continued support of the HHS's Lifespan Respite Program. Respite care can provide family caregivers with relief necessary to maintain their own health, bolster family stability and well-being, and avoid or delay more costly nursing home or foster care placements.

*Department of Education*.—APA supports strengthening our Federal investment in gifted and talented education and encourages Congress to fund the Javits Gifted and Talented Education Program in fiscal year 2016, funded last year at $10 million.

During this time of far reaching change in education, never has the need been greater for effective policies and practices based upon sound research. As a member of the Friends of the Institute of Education Sciences, APA urges you to build upon the President's request of $675.8 million and restore, at a minimum, $11.2 million to the Regional Education Laboratories program and $16.6 million to the National Center for Special Education Research, matching the 2008 funding level. This would provide a total of $703.6 million for the education sciences in fiscal year 2016. This would support critical investments to provide evidence-based information on effec-

tive educational practices to parents, teachers and schools, and new research to fill gaps in knowledge.

Thank you for the opportunity to submit testimony for the record in support of critical program areas funded by the Labor-Health and Human Services-Education appropriations bill.

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## PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

The American Public Health Association is a diverse community of public health professionals who champion the health of all people and communities. We are pleased to submit our request to fund the Centers for Disease Control and Prevention at $7.8 billion and the Health Resources and Services Administration at $7.48 billion in fiscal year 2016. We urge you to take our recommendations into consideration as you move forward with writing the fiscal year 2016 Labor-HHS-Education Appropriations bill.

### CENTERS FOR DISEASE CONTROL AND PREVENTION

APHA believes Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, we urge a funding level of $7.8 billion for CDC's programs in fiscal year 2016. We are pleased President Obama's fiscal year 2016 budget request would increase CDC's program level by $141 million over fiscal year 2015. The president's budget provides additional funding for several important new and existing programs and initiatives such as combating antibiotic resistance, preventing prescription drug overdose, viral hepatitis, the National Healthcare Safety Network, domestic HIV/AIDS, global disease prevention, violence prevention and surveillance, climate change and other important programs. Unfortunately, the president's budget also cuts or completely eliminates other important programs such as the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations, environmental health tracking and others. These cuts will reduce the ability of CDC and its State and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards and we urge you to restore this important funding. We are pleased that the president's budget would fully allocate the Prevention and Public Health Fund for public health and prevention activities. In fiscal years 2014 and 2015, Congress fully allocated the fund in both omnibus spending bills and we urge you to once again ensure the fund is fully allocated for public health programs to reduce chronic diseases and help restrain the rate of growth in private and public healthcare costs.

By translating research findings into effective intervention efforts, CDC is a critical source of funding for many of our State and local programs that aim to improve the health of communities. Perhaps more importantly, Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems. It is notable that more than 70 percent of CDC's budget supports public health and prevention activities by State and local health organizations and agencies, national public health partners and academic institutions.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for State and local capacity grants. Unfortunately, this is not a threat that is going away.

CDC serves as the command center for the Nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the prevention and control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating the ongoing multi-State measles outbreak to pandemic flu preparedness, CDC is the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

Programs under the National Center for Chronic Disease Prevention and Health Promotion address chronic diseases such as heart disease, stroke, cancer, diabetes and arthritis that continue to be the leading causes of death and disability in the United States. These diseases, many of which are preventable, are also among the most costly to our health system. The center provides critical funding for State programs to prevent chronic disease, conducts surveillance to collect data on disease prevalence, monitors intervention efforts and translates scientific findings into public health practice in our communities. We urge you to ensure these programs are adequately funded.

The National Center for Environmental Health works to protect public health by helping to control asthma, protecting our communities from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support adequate funding for NCEH. We urge you to support the president's request for increased funding for the Climate and Health Program and to restore the proposed cuts to the Environmental and Health Outcome Tracking Network.

Prescription drug overdose is an ongoing public health problem in the U.S. killing more than 145,000 over the past decade. We urge you to support the president's request for increased funding that would allow all 50 States to participate in the PDO Prevention for States program to undertake efforts to prevent and reduce prescription drug and heroin overdose deaths.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to support the president's request for the CDC Antibiotic Resistance Initiative which would build prevention programs in all 50 States and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA operates programs in every State and U.S. territory and is a national leader in improving the health of Americans through the delivery of quality health services and supporting a well-prepared workforce of sufficient size. The agency serves the health needs of people who are medically vulnerable, low-income and geographically isolated. The Nation faces a shortage of health professionals and continues to experience an ever growing, aging and increasingly diverse population, alongside health professionals that are nearing retirement age. We are deeply concerned that since fiscal year 2010, HRSA's discretionary budget authority has been cut by 18 percent in nominal dollars and 24 percent when adjusted for inflation. Funding for HRSA is far too low to address the present health needs of the U.S. and keeping austerity measures in place will threaten the agency's ability to adequately respond to the growing and changing health demands. To respond to the needs of our Nation, APHA recommends restoring funding to the fiscal year 2010 level of $7.48 billion for discretionary HRSA programs in fiscal year 2016.

HRSA programs have a strong history of providing quality care to keep people healthy and improve the health of those living outside of the economic and medical mainstream. HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health. HIV/AIDS programs administered by HRSA provide access to regular care and ensure adherence to antiretroviral treatment for people living with HIV, which reduces HIV transmission by 96 percent and greatly contributes to the prevention of new HIV infections. The Title X Family Planning Program has greatly contributed to decreasing unintended pregnancy—helping to prevent an estimated 870,000 unintended pregnancies in 2013. A committed investment from Congress is required to continue achieving the health improvements HRSA has made and to pave the way for new achievements.

Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs, including:

—Health Workforce supports the education and training of a broad range of health professionals. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce. The programs are responsive to the changing delivery systems, models of care and healthcare needs, and encourage collaboration between disciplines to provide coordinated care that is effective and efficient.

—Primary Care more than 9,000 health center sites in every State and U.S. territory, improving access to care for more than 21 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
—Maternal and Child Health including the Title V Maternal and Child Health Block Grant, Healthy Start and others support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare for more than 42 million women and children, including children with special healthcare needs.
—HIV/AIDS provides assistance to States and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for about half of the total population—1.2 million people—living with HIV/AIDS in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
—Family Planning Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for more than 4.5 million low-income women, men and adolescents. This program helps improve maternal and child health outcomes, promotes healthy families and reduce unintended pregnancies, infertility and related morbidity.
—Rural Health improves access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of healthcare services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

CONCLUSION

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up less than 1 percent of Federal spending and continued austerity measures that cut funding for public health and prevention programs will not balance our budget and will only lead to increased costs to our healthcare system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone. Without a robust and sustained investment in our public health agencies, we will fail to meet the mounting health challenges facing our Nation.

[This statement was submitted by Georges C. Benjamin, MD, Executive Director, American Public Health Association.]

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) recommends that Congress approve the Administration's fiscal year 2016 proposed budget for the Centers for Disease Control and Prevention (CDC). The $7 billion request increases the fiscal year 2015 level by $110 million to strengthen crucial capabilities of the Nation's principal health protection Agency. The ASM urges Congress to support CDC's unique surveillance and prevention networks, medical R&D activities and rapid response preparedness. The fiscal year 2016 budget will help sustain CDC field operations and laboratories, as well as the Agency's contributions to national and international health initiatives like the Administration's new National Strategy for Combating Antibiotic Resistant Bacteria (CARB) and the international push to eradicate polio.

PROTECTING PEOPLE FROM INFECTIOUS DISEASES

Microbial pathogens accounted for seven of CDC's ten most important public health challenges in 2014: the Ebola epidemic, antibiotic resistance and healthcare associated infections, a national outbreak of enterovirus D68 (EV–D68) in children, MERS–CoV (Middle East Respiratory Syndrome), the HIV/AIDS pandemic and the global battle against polio.

To combat the infectious diseases that persistently threaten public health, a large portion of the fiscal year 2016 CDC budget ($2.6 billion) is distributed among three CDC national centers: Immunization and Respiratory Diseases (NCIRD, $748 million); Emerging and Zoonotic Infectious Diseases (NCEZID, $699 million) and HIV/

AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP, $1.2 billion). The budget also increases funding for several CDC programs that protect against both global and domestic threats: the Strategic National Stockpile, Global Public Health Capacity, Polio Eradication and the Select Agent Program.

The 2015 priority areas targeted by NCEZID illustrate the depth and breadth of the agency's strategy against diverse infectious threats: detect, prevent and control antibiotic resistance in support of the national CARB initiative; continue actions against Ebola in West Africa; eliminate healthcare associated infections (HAIs); update foodborne illness surveillance systems and continue expanding the CDC's Advanced Molecular Detection (AMD) program to compile a large catalog of pathogens' genomic fingerprints.

Last year, NCEZID led more than 37 outbreak investigations and awarded approximately $134.2 million to health departments across the Nation. Nearly 300 NCEZID personnel have been deployed to West Africa since early spring 2014, assisting the fight against Ebola with surveillance, contact tracing, data management, lab testing and health education. NCEZID staff also worked the CDC Emergency Operations Center in Atlanta to provide Ebola logistics, technical expertise, communications and more.

The ASM supports the fiscal year 2016 budget increase of $264 million for the Antibiotic Resistance Solutions Initiative, CDC's contribution to the new interagency CARB strategy. International and U.S. health agencies are increasingly alarmed by spreading drug resistance among pathogens and by the shortages of new antimicrobials in development. This is a challenge to public health that the U.S. must neither ignore nor fail to overcome. The CDC priority areas include expanded disease tracking with additional local partners, improved drug prescribing in healthcare settings and studies on how antibiotics affect the human microbiome and its ability to protect the body. The Antibiotic Resistance initiative anticipates significant 5 year reductions in multiple targeted threats, like hospital onset methicillin resistant Staphylococcus aureus (MRSA) and carbapenem resistant Enterobacteriaceae (CRE).

The ASM supports the fiscal year 2016 budget request of $748 million to support CDC immunization programs, including ongoing influenza planning and response. The less than expected protection from this year's seasonal influenza vaccine, due to viral genetic shift post vaccine design, shows the complexities of vaccine R&D and the importance of a consistently excellent CDC vaccine program. As a prevention tool, immunization has been the principal strategy in some of public health's most dramatic successes. In the United States, vaccines were instrumental in stopping once deadly outbreaks of killers like diphtheria, polio and smallpox. CDC currently recommends vaccination to prevent 17 diseases across a lifespan. Staff routinely design vaccination education campaigns, collaborate with local officials, and update immunization protocols.

The current measles outbreak is just the latest reminder of how critical immunizations are to preserving public health, particularly since children under 12 months are too young to be vaccinated and thus highly vulnerable. In 1994, CDC launched the Vaccines for Children program (VFC), responding to that year's measles resurgence causing tens of thousands of cases. A 2014 CDC report estimated that vaccination of children born between 1994 and 2013 ultimately will prevent 322 million illnesses, more than 21 million hospitalizations, and 732,000 deaths, saving nearly $1.4 trillion in estimated societal costs. CDC also is the scientific lead in global prevention efforts that include vaccines as key cost effective strategies, the global eradication of polio, for example, could save an estimated $50 billion.

Another CDC surveillance report last August concluded that annual U.S. infant vaccination rates had increased or remained stable for all routinely recommended childhood vaccines, over 90 percent for measles, mumps and rubella (MMR), poliovirus, hepatitis B and varicella (with an increase for rotavirus, from 69 percent in 2012 to 73 percent in 2013). CDC warned, however, that vaccination coverage varied by State and community, leaving some areas vulnerable. Another 2014 report, released prior to the most recent measles outbreak, noted that U.S. measles cases in January—May were the largest number in the first 5 months of any year since 1994, nearly all associated with international travel by unvaccinated people.

Results from programs like those against HIV/AIDS and healthcare associated infections point to both progress made and opportunities to improve. A cross section of these statistics exposes CDC's enormous responsibility, for example:

—An estimated 3 million Americans are infected with hepatitis C, plus another 1.4 million with hepatitis B, but at least half do not know they are infected. New hepatitis C infections, which frequently lead to fatal complications, increased by 75 percent between 2010 and 2012, mainly among young people.

—One in 25 hospitalized patients develops healthcare associated infections, too often caused by drug resistant bacteria.
—Each year, about 80,000 refugees and 500,000 immigrants arrive from around the world, while infectious diseases continue to devastate the world's populations.
—Despite vaccine availability, there were nearly 29,000 reported U.S. cases of pertussis (whooping cough) in 2014.
—Seventy percent of the 1.2 million Americans with HIV do not have the virus under control, despite available therapeutics that improve outcomes and greatly reduce the likelihood of transmission (based on 2013 figures).

More than 250 pathogens and toxins are known to cause foodborne illness, accounting for an estimated 48 million U.S. cases each year. In 2014, the agency's annual report on its food safety efforts showed that Salmonella infections decreased by about 9 percent in 2013 compared with the previous 3 years, but campylobacter infections had risen 13 percent since 2008. About 20 million Americans still get sick from norovirus each year. Salmonella infections cause another 1.2 million illnesses, with the most deaths of any foodborne bacteria. More disturbing are the multi-drug resistant Salmonella types now causing about 100,000 of those cases.

### RESPONDING TO PUBLIC HEALTH THREATS

In January, CDC's yearly update on the Nation's public health preparedness noted that the agency's Office of Public Health Preparedness and Response processes more than 20,000 calls annually from public health agencies, clinicians and researchers, and the public. Agency experts investigate hundreds of disease reports each year; in the last 2 years, the agency deployed staff to more than 750 sites to examine health threats. In 2014, outbreak investigations included measles linked to a California amusement park; Listeria monocytogenes contaminated cheese, sprouts, and caramel apples; and cases of the intestinal illness cyclosporiasis in at least 20 States, some linked to cilantro. Last July, when the first locally acquired case of chikungunya fever was reported in Florida, CDC had already been actively preparing for its arrival since 2006.

To accommodate this massive workload, CDC partners with U.S. and international health agencies and distributes grants to strengthen community based responses. For example, CDC funds are allocated to local health departments through the Epidemiology and Laboratory Capacity for Infectious Diseases Cooperative Agreement ($97.2 million last year to all States, six largest local health departments and U.S. territories) and the Emerging Infections Program ($37 million to 10 State departments). In November, it added $2.7 million in personal protective equipment to the Strategic National Stockpile, for rapid deployment response kits ready to send to hospitals with Ebola patients.

To sustain CDC's high quality technical capability, the fiscal year 2016 budget request includes increased support for laboratory safety. In 2014, CDC reviewed its laboratory practices and policies in response to several incidents involving pathogens in Agency laboratories. As a result, changes are underway, including more stringent general enforcement of laboratory safety and quality protocols. Specific recommendations to improve personnel training for fiscal year 2016 include hands on training and expanded distance learning.

### CDC'S ADVANCED MOLECULAR DETECTION PROGRAM

Leveraging cutting edge technologies, CDC began its Advanced Molecular Detection (AMD) program with an initial investment in fiscal year 2014. It combines expertise in bioinformatics, epidemiology and genetic sequencing to boost health departments' speed and accuracy in identifying pathogens. AMD projects are underway at CDC facilities, as well as State and local partner laboratories. They are exploring AMD utility for specific diseases or pathogens that include anthrax, brucellosis, bunyaviruses, malaria, filovirus, influenza, gonorrhea, legionellosis, Listeria, melioidosis, and meningococcal disease.

AMD projects focused on healthcare associated infections are investigating how specific genes in pathogens change over time, initially for the two high threat bacteria Clostridium difficile and carbapenem resistant Enterobacteriaceae. AMD data will also be posted to CDC's online database, MicrobeNet, for use by other researchers and health departments to better identify disease outbreaks, track new and emerging pathogens, and find new ways to prevent illness. Recent examples of AMD enabled research are:

—Identified two new human pathogens from ticks; the Bourbon virus and the Heartland virus. AMD sequencing tools confirmed the two viruses were different.

—Detected enterovirus D68 (EV–D68) in children with severe respiratory illness hospitalized in two States in August 2014, and subsequently recognized the virus causing infections in almost every State; AMD enabled sequencing of the viral genome, contributing to development of a "real time" laboratory test.
—Produced the first whole genomic sequence of Liberian Ebola virus within 72 hours of sample collection from two American patients. The data showed the 2014 virus is 97 percent similar to the Ebola virus that first emerged in 1976.
—Utilized whole genome sequencing to match Salmonella in patient samples with that in a peanut butter production plant, quickly initiating a food recall after only four cases of foodborne illness (each case in a different State).

It is impossible to overstate how crucial CDC activities are to protect the health of all Americans and many millions living in other nations. The ASM strongly recommends that Congress increase the CDC's fiscal year 2016 budget.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) welcomes the fiscal year 2016 budget request of $31.3 billion for the National Institutes of Health (NIH) as a first step to increase NIH funding which has been flat since 2003, with a loss of 25 percent in purchasing power. Much of the proposed increased funding would be allocated to addressing specific public health issues that require biomedical expertise and research capabilities, including antimicrobial resistance, precision medicine and the human brain initiative.

In view of the ongoing and emerging health problems confronting the Nation and other countries worldwide, and the unprecedented scientific opportunities on the horizon, we recommend that the budget for NIH be increased to at least $32 billion in fiscal year 2016. This level of funding would enable NIH to take advantage of the many undifferentiated research project grants that lead to scientific discoveries and contribute to medical innovation. There is an urgent need to increase the NIH budget in view of the decade long attrition in Federal funding for biomedical research and the real danger of losing significant numbers of the current and next generation of scientists in the United States. We look forward to working with Congress to enhance NIH's ability to support cutting edge research and training of the scientific workforce.

INVESTING IN BIOMEDICAL RESEARCH AND SPURRING INNOVATION IN SCIENCE

For over a century, NIH funding has led to new knowledge and advances in medicine. Each year, NIH distributes much of its budget extramurally through more than 50,000 competitive grants, supporting 300,000 plus researchers at more than 2,500 universities, medical schools and other institutions. Intramural programs employ another 6,000 scientists at NIH's own laboratories.

NIH is the Nation's leader in funding biomedical research. Its 27 institutes and centers support studies focused on particular diseases and conditions or on targeted research areas. Last year, NIH reported funding for 235 research areas, conditions and disease categories. Sixty percent of the fiscal year 2016 NIH budget will be distributed extramurally as research project grants and 19 percent through R&D contracts. Intramural research at NIH's own laboratories accounts for another 12 percent of the proposed funding.

The ASM stresses the importance of sustaining adequate NIH funding for long term research efforts. Rising biomedical R&D price indices and flat budgets over the last decade have undercut NIH spending capabilities. This erosion in Federal support has had noticeable negative impacts on biomedical research in the United States.

A clear example is the shrinking number of submitted NIH grant proposals that are successfully funded: From 1 in 3 for all types of grants at the start of the 21st century to 1 in 5 by 2014. Decreasing success rates in part reflect rising numbers of submitted requests, but more importantly they are evidence of missed scientific opportunities. In 2014, NIH reviewed more than 51,000 applications for research projects grants (RPGs), selecting 9,241 for funding (an 18 percent success rate, slightly above 16.8 percent the previous year). The Administration's fiscal year 2016 budget would help boost the number of new and competing research grants by approximately 1,200.

The United States has been steadily reducing its biomedical R&D spending while other countries are accelerating their investments. During 2007–2012, the U.S. share of global expenditures slipped from 51 to 45 percent (once 80 percent). The high returns on biomedical R&D investment in improved public health and in science and technology innovation and marketplace economics are well documented.

Examples are victories over diseases like smallpox and polio, or the numerous NIH funded recipients of the prestigious Nobel and Lasker awards. Another is Federal investment in the Human Genome Project, which has thus far yielded an estimated 178-fold return of nearly $1 trillion in economic growth.

SCIENCE DISCOVERIES TO PROTECT PUBLIC HEALTH

Recent outbreaks of Ebola in West Africa and measles in the United States are compelling reminders of the importance of NIH research to addressing health threats. The NIH mission is to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life and reduce illness and disability.

Past Federal investments have made NIH the world leader in biomedical research leading to cures, preventives and therapies, whether against old nemeses like tuberculosis and malaria or emerging viral threats like the recent Ebola epidemic or highly virulent influenza strains. ASM supports the funding within the fiscal year 2016 budget for the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of General Medical Sciences (NIGMS), both of which have significantly advanced medical microbiology and related fields like genetics, systems biology and bioinformatics. In the fiscal year 2016 proposal, NIAID would receive a modest 4.5 percent increase over fiscal year 2015 levels, while NIGMS receives 2.6 percent.

NIAID funded studies regularly produce new knowledge and products like vaccines, diagnostic tests, therapeutics and other technologies that safeguard human health and stimulate economic development. Over the decades, NIH supported programs have literally changed the discussion surrounding a disease or condition. A striking example is HIV/AIDS. Once an early death sentence, HIV diagnosis has morphed into chronic illness with science based hope of possible cures and vaccines. NIAID efforts have contributed immeasurably to promising therapies for HIV infected newborns, successes with early anti HIV drug regimens and advances in vaccine development.

Evolving research emphasis centers on other infectious diseases as medical science advances, for example, influenza, which persists as a heavy burden on the U.S. healthcare system. The 2014 seasonal vaccine's inability to provide effective protection against an important virus strain, due to viral genetic drift after the current vaccine was designed is a strong argument for a universal influenza vaccine, an ultimate goal of NIAID vaccine projects. Scientists recently reported discovery of a new class of antibodies that can neutralize a wide range of influenza A viruses, with potential as a broadly effective, long lasting vaccine. Studies are underway on several other NIAID supported universal vaccine candidates.

FIGHTING ANTIMICROBIAL RESISTANT INFECTIONS

The ASM supports global health initiatives, such as the Administration's newly launched National Strategy for Combating Antibiotic Resistant Bacteria. The multiagency offensive against antimicrobial resistant (AR) pathogens receives targeted funding in the proposed fiscal year 2016 budget, nearly doubling the amount of Federal AR support to more than $1.2 billion. NIH would receive additional funding for its exploration of new drugs, rapid diagnostics, and biological mechanisms of microbial drug resistance.

Microbial pathogens that acquire resistance to drugs have emerged as one of today's most serious public health challenges. Each year antibiotic resistant infections in this country cause at least two million illnesses and an estimated 23,000 deaths. Associated economic losses total at least $20 billion annually in excess direct healthcare and up to $35 billion in lost productivity. The fiscal year 2016 budget would increase NIAID funding for AR research by $100 million, to expand its clinical trial capacity to evaluate new antibacterial products, develop a national genome sequence database of AR bacteria and underwrite an original competition to incentivize development of diagnostic devices.

NIAID has battled emerging drug resistance for years, aware that naturally evolving resistance will always occur. In 2014, an updated report on its AR related programs refocused efforts toward specific challenges like cataloguing entire genomes of specific microbes, developing vaccines against resistant Staphylococcus aureus and Neisseria gonorrhoeae, using healthy bacteria in the human body to combat infection and more. The AR portfolio also includes the search for new broad spectrum therapeutics, more judicious medical and agricultural use of antibiotics, surveillance of spreading AR patterns and research on pathogen biology to determine the mechanisms that lead to resistance.

Over the past year, NIAID solicited new grant proposals from industry to develop rapid diagnostics for five principal causes of resistant infections in hospital settings (Klebsiella pneumoniae, Acinetobacter baumannii, Pseudomonas aeruginosa, Enterobacter species, and pathogenic Escherichia coli). It began an early stage clinical trial for an oral antibiotic to treat infections of Clostridium difficile, an increasingly drug resistant pathogen responsible for about 250,000 U.S. hospitalizations and at least 14,000 deaths each year.

Relentless appearance of resistant pathogens reinforce how crucial it is to intensify investigations of novel drug classes and supply a more robust drug pipeline. NIAID supported scientists recently reported a new class of antimicrobial drug discovered while screening soil bacteria. Teixobactin, a toxin produced by the newly identified proteobacteria species Eleftheria terrae, is the first new antibiotic in more than 25 years. Excitement over the discovery stems from the apparent decreased risk of acquired resistance, as well as the innovative method for growing recalcitrant soil bacteria in the laboratory.

RESPONDING TO EMERGING INFECTIOUS DISEASES

When the largest Ebola epidemic in history ignited last year, NIAID accelerated its ongoing research on Ebola treatments and vaccines. That response illuminates the NIH capacity to respond quickly to emerging threats. The ASM applauds NIAID efforts against the Ebola virus and asks Congress to ensure funding for NIH programs that make possible this type of scientific agility against infectious threats.

NIAID supports basic and applied research on Ebola that includes pathogenesis studies using molecular technologies and animal models. Others are characterizing viral transmission patterns using genomic sequencing or examining virus host interactions. NIAID staff deployed to West Africa focused on diagnostics and training local personnel and collected hundreds of Ebola samples for genomic sequencing. NIAID is aggressively seeking therapeutics and vaccines that can stop Ebola's spread, with several candidate drugs in the pipeline and some undergoing early clinical trials. Three Ebola vaccine candidates are currently in various stages of NIH clinical testing, one developed earlier with NIAID funding in partnership with a biotech firm using chimpanzee virus to deliver an Ebola glycoprotein gene that elicits patient immunity.

Other emerging infectious diseases in the NIH portfolio include infections of chikungunya virus and coronavirus MERS–CoV (Middle East Respiratory Syndrome). In May 2014, when the first U.S. case of MERS was confirmed, NIH supported research was well underway. Scientists had identified dozens of compounds that inhibited the MERS virus in the laboratory, as others established a new monkey model to study the severe MERS pneumonia. Last September, NIAID reported that animal studies confirmed dromedary camels as the primary carrier of the virus, which kills about one third of its human victims. Like MERS, there is no specific therapeutic or vaccine for mosquito borne chikungunya virus, first detected in the Western Hemisphere in late 2013. In August 2014, NIAID reported its experimental chikungunya virus vaccine had induced antibodies in an early human clinical trial, just weeks after officials had confirmed the first locally acquired cases in the United States.

The ASM appreciates the opportunity to provide a statement in support of NIH funding and looks forward to working with Congress to provide significant, new funding for biomedical research.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairman Blunt and Ranking Member Murray: Thank you for the opportunity to provide testimony regarding fiscal year 2016 appropriations. The American Society for Nutrition (ASN) respectfully requests $31.3 billion dollars for the National Institutes of Health (NIH) and $172 million dollars for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS), consistent with the President's budget requests, in fiscal year 2016. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition, and has more than 5,000 members working throughout academia, clinical practice, government, and industry.

*National Institutes of Health (NIH)*

The NIH is the Nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent of federally-funded basic and clinical nutrition research. Although nutrition and obesity research makes up less than 8 percent of the NIH budget, some of the most promising nutrition-related re-

search discoveries have been made possible by NIH support. NIH nutrition-related discoveries have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. For example, U.S. death rates from heart disease and stroke have decreased by more than 60 percent, and the proportion of older adults with chronic disabilities has dropped by one-third. With additional support for NIH, additional breakthroughs and discoveries to improve the health of all Americans will be made possible.

Investment in biomedical research generates new knowledge, improved health, and leads to innovation and long-term economic growth. A decade of flat-funding, followed by sequestration cuts, has taken a significant toll on NIH's ability to support research. Such economic stagnation is disruptive to training, careers, long-range projects and ultimately to progress. Increasing the NIH budget to $31.3 billion dollars would help to restore the funding that was lost to sequestration and support additional competing research project grants. ASN recommends $31.3 billion dollars for NIH in fiscal year 2016, consistent with the President's budget request and asks that Congress direct the use of some of these funds for both intra- and extramural human nutrition research. NIH needs sustainable and predictable budget growth in order to fulfill the full potential of biomedical research, including nutrition research, and to improve the health of all Americans.

*Centers for Disease Control and Prevention National Center for Health Statistics (CDC NCHS)*

The National Center for Health Statistics, housed within the Centers for Disease Control and Prevention, is the Nation's principal health statistics agency. ASN recommends a fiscal year 2016 funding level of $172 million dollars for NCHS, consistent with the President's budget request, to help ensure uninterrupted collection of vital health and nutrition statistics, and help cover the costs needed for technology and information security maintenance and upgrades that are necessary to replace aging survey infrastructure. This request would provide $160 million in budget authority and $12 million in mandatory Prevention and Public Health Fund.

The NCHS provides critical data on all aspects of our healthcare system, and it is responsible for monitoring the Nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our Nation's children.

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the Nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in the area of health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

To continue support for the agency and its important mission, ASN recommends an fiscal year 2016 funding level of $172 million for NCHS. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding fiscal year 2016 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics. Please contact John E. Courtney, Ph.D., Executive Officer, if ASN

may provide further assistance. He can be reached at 9650 Rockville Pike, Bethesda, Maryland.

[This statement was submitted by Simin Nikbin Meydani, D.V.M., Ph.D., President, American Society for Nutrition.]

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PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR PHARMACOLOGY & EXPERIMENTAL THERAPEUTICS

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) fiscal year 2016 budget. ASPET recommends a fiscal year 2016 NIH budget of at least $32 billion.

Steady and sustained investment in the NIH is critical to improving human health, stimulating State and local economies, and improving the Nation's global competitiveness. We call upon Congress to ensure that the NIH remains a national priority. ASPET appreciates Congressional action in providing NIH-needed increases in the fiscal year 2014 and fiscal year 2015 omnibus appropriations bills. However, these increases did not restore the purchasing power lost to sequestration in fiscal year 2013. From 2003–2013, the NIH budget failed to keep pace with inflation in research costs leading to nearly a 25 percent reduction in the agency's purchasing power and a 34 percent reduction in the primary grant mechanism for supporting investigator-initiated research. A fiscal year 2016 budget of $32 billion would enable the NIH to fund 465 more research grants and help restore the agency's lost purchasing power that has occurred over the past decade.

Additionally, if funding for the next 10 years is similar to that of the past decade, the Nation will lose a generation of young scientists. Increasingly, these individuals, seeing no prospects for careers in biomedical research, will leave the research enterprise or look for employment in foreign countries. Not only are jobs increasingly limited in the academic sector, but the health industry too is under significant stress. The "brain drain" of young scientific talent jeopardizes the Nation's leadership in biomedical research. A 2013 survey of ASPET's own graduate students and post-doctoral researchers revealed that 45 percent of post-doctoral trainees and 25 percent of graduate students say they are no longer considering a career in biomedical research due to the restrictive funding environment; 50 percent of graduate students and 29 percent of post-doctoral trainees say they are willing to consider leaving the United States to pursue a career in biomedical research.

A $32 billion budget for the NIH in fiscal year 2016 is an important start to help restore NIH's biomedical research capacity. Currently, the NIH only can fund one in six grant applications, the lowest rate in the agency's history. Many highly innovative proposals that have important implications for human health go unfunded as a consequence of limited NIH funding.

A budget of at least $32 billion in fiscal year 2016 will help the agency manage its research portfolio more effectively without having to withhold funding for existing grants to researchers throughout the country. Only through steady, sustained and predictable funding increases can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country.

There is no substitute for a steady, sustained Federal investment in biomedical research. Industry, venture capital, and private philanthropy can supplement some elements of health research but they cannot replace the investment in basic, fundamental biomedical research provided by NIH. Neither the private sector nor industry will be able to fill a void for NIH-funded basic biomedical research. Much of the research undertaken by industry builds upon the discoveries generated from NIH-funded projects. The majority of the investment in basic biomedical research that NIH provides is broad and long-term, providing a continuous development platform for industry, which would not typically invest in research that may be of higher risk and require several years to fully mature. In addition to this long-term view, NIH also has mechanisms in place to rapidly build upon key technologies and discoveries that have the ability to have significant impact on the health and well being of our citizens.

Many of the basic science initiatives supported by NIH have led to totally unexpected discoveries and insight that have transformed our mechanistic understanding of and our ability to treat a wide range of diseases.

*Diminished Support for NIH will Negatively Impact Human Health*

Additional cuts or limited growth in the NIH budget will further reduce NIH's purchasing power and accelerate the loss of scientific opportunities to discover new

therapeutic targets. Without a steady, sustained Federal investment in fundamental biomedical research, scientific progress will be slower and potentially helpful diagnostic methods, therapies or cures will not be developed. For example, more research is needed on Parkinson's disease to help identify the causes of the disease and help develop better therapies. As another example, discovery of gene variations in age-related macular degeneration could result in new screening tests and preventive therapies. More basic research is needed to focus on new molecular targets to improve treatment for Alzheimer's disease. As yet another example, diminished support for NIH will prevent new and ongoing investigations into rare diseases that the Food and Drug Administration estimates almost 90 percent are serious or life-threatening.

Historically, our past investment in basic biological research has led to many innovative medicines. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector. The significant past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenomics and a reduction in adverse drug reactions that currently represent a major worldwide health concern. NIH is the world leader in efforts to prevent and treat HIV–AIDS. Several completed human genome sequence analyses have pinpointed disease-causing variants that have led to improved therapy and cures, but further advances and improvements in technology will be delayed with diminished NIH funding. The evolution of patient care into what has been termed "personalized medicine" or precision medicine and its application to a wide range of clinical disorders requires research to identify and test optimal diagnostic and therapeutic approaches for each individual. Our past support for NIH has revealed new frontiers of immunopharmacology and regenerative medicine which are producing cost savings by reducing in-patient hospital care for debilitative autoimmune diseases like rheumatoid arthritis and restoring movement and function through regenerative interventions. Furthermore, NIH must continue its support of research to prevent and treat infectious diseases.

*Investing in NIH Helps America Compete Economically*

A $32 billion budget in fiscal year 2016 will also help the NIH train the next generation of scientists and provide a platform for broader workforce development that is so critical to our Nation's growth. While most NIH trainees follow a career path in research, many individuals trained in the sciences through NIH support become educators in high schools and colleges. These individuals also enter into other areas of technology development and evaluation in the public and private sectors further enriching the community and accelerating economic development.

NIH research funding catalyzes private sector growth. More than 83 percent of NIH funding is awarded to over 3,000 universities, medical schools, teaching hospitals and other research institutions in every State. One national study by an economic consulting firm found that Federal (and State) funded research at the Nation's medical schools and hospitals supported almost 300,000 jobs and added nearly $45 billion to the U.S. economy. NIH funding also provides the most significant scientific innovations of the pharmaceutical and biotechnology industries.

Thus, this investment will help to create jobs and promote economic growth. A stagnating NIH budget will mean forfeiting future discoveries and jobs to other countries.

It is a sobering fact that the U.S. share of global research and development investment from 1999–2009 was only 31 percent, representing a decline of 18 percent. In contrast, other nations continue to invest aggressively in science. China has grown its science portfolio with annual increases to the research and development budget averaging over 20 percent annually since 2000. Russia plans to increase support for research substantially over the next decade. The European Union, despite great economic distress among its member nations, has proposed to increase spending on research and innovation by 45 percent between 2014 and 2020. All of these nations recognize the long-term economic value of scientific research and prioritize their budgets accordingly.

*Conclusion*

ASPET appreciates the many competing and important spending decisions the Subcommittee must make. However, the NIH's contribution to the Nation's economic well-being and to the health of our citizens should make it one of the Nation's top priorities. Lawmakers must replace sequestration in 2016 and beyond with a bipartisan, balanced approach to deficit reduction so that vital investments can be made in the best interests of the Nation. With enhanced and sustained funding, NIH can begin to reverse its decline and help achieve its potential to address many

of the more promising scientific opportunities that currently challenge medicine and affect healthcare in our country. A budget of at least $32 billion in fiscal year 2016 will be a good first step in allowing the agency to begin moving forward to full program capacity, exploiting more scientific opportunities for investigation, and increasing investigators' chances of discoveries that prevent, diagnose and treat disease. NIH should be restored to its place as a national treasure, one that attracts and retains the best and brightest to biomedical research and provides hope to millions of individuals afflicted with illness and disease.

ASPET is a 5,100 member professional society, whose members conduct basic, translational, and clinical pharmacological research within the academic, industrial and government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases, as well as increase our knowledge regarding how therapeutics can be used to improve human health.

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## PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) thanks the Subcommittee for the opportunity to submit written testimony on the fiscal year 2016 Departments of Labor, Health and Human Services, and Education Appropriations bill.

ASH represents more than 15,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene- and immunotherapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

### FUNDING FOR HEMATOLOGY RESEARCH: AN INVESTMENT IN THE NATION'S HEALTH

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries. This research would not have been possible without support from the National Institutes of Health (NIH).

Funding for hematology research has been an important component of this investment in the Nation's health. Most of the research that produced cures and treatments for hematologic diseases has been funded by the NIH. The study of blood and its disorders is a trans-NIH issue involving many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Even modest investments in hematology research have yielded large dividends for other disciplines. Basic research on blood has aided physicians who treat patients with heart disease, strokes, end-stage renal disease, cancer, and AIDS. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs.

*Future Promise*

The era of precision medicine has arrived. The field of hematology has experienced a recent surge in progress thanks to novel technologies, mechanistic insights, and cutting-edge therapeutic strategies that have driven significant and meaningful advances in the quality of care. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. These foundational insights are reframing modern research with the continued goal of improving outcomes and discovering cures for the most challenging hematologic diseases.

Translating these new discoveries and technologies into personalized patient care offers the possibility of better survival, less toxicity, disease prevention, improved quality of life, and lower health-care costs. Yet today, a number of specific and critically important research questions must be answered to gain the insights that will launch the field into the next generation of care for hematologic conditions. A wide variety of blood-related diseases—from malignancies such as lymphoma and leukemia, to non-malignant diseases including hemoglobinopathies—continue to be associated with significant morbidity and mortality and demand attention to reduce their burden and improve the quality of care worldwide.

SEQUESTRATION THREATENS SCIENTIFIC MOMENTUM

ASH is particularly concerned about the impact of continued cuts on biomedical research supported by the NIH. NIH's ability to continue current research capacity and encourage promising new areas of science is, and will be, significantly limited. At a time when we should be investing more in research to save lives, research funding remains in serious jeopardy. Trials to find new therapies and cures for millions of Americans with blood cancers, bleeding disorders, clotting problems, and genetic diseases are just a few of the important projects that could be delayed unless NIH continues to receive predictable and sustained funding.

Additionally, perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. The Society is especially concerned about the number of scientists who have abandoned research careers; continued cuts will exacerbate this exodus, forcing researchers to abandon potentially life-enhancing research.

FISCAL YEAR 2016 REQUESTS

*NIH Funding*

ASH appreciates the welcome and much needed funding increase for the NIH that Congress provided in the fiscal year 2015 Consolidated Appropriations Act. However, this increase did not give back all of the funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power lost over the past decade. ASH supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in medical research. ASH also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

*Centers for Disease Control and Prevention (CDC) Public Health Response for Blood Disorders*

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders. Blood disorders—such as sickle cell disease, anemia, blood clots, and hemophilia—are a serious public health problem and affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life-threatening.

CDC is uniquely positioned to reduce the public health burden resulting from blood disorders by contributing to a better understanding of these conditions and their complications; ensuring that prevention programs are developed, implemented, and evaluated; ensuring that information is accessible to consumers and healthcare providers; and encouraging action to improve the quality of life for people living with or affected by these conditions. The Society is concerned that the Division of Blood Disorders was cut by nearly $6 million in the Consolidated Appropriations Act of 2014 and only $500,000 was added back to the Division in fiscal year 2015. ASH respectfully requests that the Committee continue to restore funding for the Division of Blood Disorders to the fiscal year 2013 levels to ensure that the programs funded by the Division for hemophilia, thalassemia, sickle cell disease, and DVT/PE can be maintained. This funding will allow CDC to improve health outcomes and limit complications to those who are risk or currently have blood disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness of bleeding and clotting disorders such as such as hemophilia and thrombosis, and hemoglobinopathies, including sickle cell disease and thalassemia.

*Additional Activities*

In fiscal year 2016, ASH also urges the Subcommittee to recognize the following activities impacting hematology:

—Importance of Genome Editing and Gene Therapy for the Correction of Inherited Blood Disorders

Genome editing is currently at the forefront of genetic engineering. It has led to several transformative advances thanks to its simplicity, versatility, flexibility and ability to precisely manipulate cellular genomes and correct mutations. As an experimental tool, it has tremendous power to help researchers develop and manipulate experimental models designed to correct inherited genetic alternations in hematologic diseases such as sickle cell anemia, thalassemia and hemophilia. The correction of genetic defects that cause these disorders would allow for cure, rather than life-long palliation.

While gene editing represents a highly promising area for potential treatment of hematologic disorders, several critical questions still need to be addressed in order to establish appropriate processes that will guide the safe and effective transfer of its use into the clinic. NHLBI is encouraged to further its research efforts in genome editing and gene therapy by focusing on the following priority areas:

—Establishing strategies to determine the efficacy, safety, and toxicity of genome editing techniques. Basic science research and the development of proper clinical trial infrastructure is needed to further advance our understanding of the biology of genome editing. Preclinical research is essential to help determine the accuracy, safety and efficiency of this technology in order to help minimize off-target mutations and to reduce toxicity. Once the preclinical efficacy of this technology is established, its transfer into a well-established clinical trial structure will be critical in helping to understand its application in humans.

—Applying genome editing technology to correct hematologic disorders. Single nucleotide variants that result in hemoglobinopathies like thalassemias or sickle cell disease are ideal platforms for initial research programs; however, studies are still needed to determine which other disorders are amenable to genome editing correction, whether certain disorders can be characterized by more complex mutations, and which gene alterations should be targeted.

—Ensuring Coordination and Collaboration between Federal Agencies with an Interest in Sickle Cell Disease

Sickle cell disease (SCD) is the most common inherited red blood cell disorder in the United States, affecting 70,000–100,000 Americans (mostly, but not exclusively, of African ancestry). SCD causes the production of abnormal hemoglobin, a protein that attaches to oxygen in the lungs and carries it to all parts of the body. Healthy red blood cells are flexible so that they can move through the smallest blood vessels. In sickle cell anemia, the hemoglobin is abnormal, causing the red blood cells to be rigid and shaped like a "C" or sickle, the shape from which the disease takes its name. Sickle cells can get stuck and block blood flow, causing pain and infections. Complications of sickle cell anemia are a result of sickle cells blocking blood flow to specific organs, and include stroke, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, other disabilities, and in some cases premature death.

Although the molecular basis of SCD was established several decades ago, it has been challenging to translate this knowledge into the development of novel targeted therapies. New approaches in managing this disease have improved diagnosis and supportive care over the last few decades, but many patients still have severe complications to overcome. The future of care for SCD patients will be dependent on advanced and highly targeted approaches to research, discovery, and implementation of proven and new interventions.

To ensure that individuals with SCD receive state of the art care, it is important that key stakeholders, including Federal agencies, work together to invest in SCD-related research and initiatives that could truly move the field forward with the hope of curing SCD in the future. A multi-agency approach would deliver advances faster, more economically, and more efficiently to patients suffering from this debilitating disease in the United States and the world. The Department of Health and Human Services Interagency Working Group on SCD is essential to ensuring the coordination and collaboration between Federal agencies with an interest in SCD.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, if you have any questions or need further information concerning hematology research or ASH's fiscal year 2016 requests.

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PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

The American Society of Nephrology (ASN) is the world's largest kidney health professional organization—representing 15,000 scientists, nephrologists, and other kidney health providers—and committed to advancing research and treatment options for the more than 20 million children, adolescents, and adults with kidney disease in the United States today. The society requests at least $2.066 billion in funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH). The society also requests an additional $150 million per year over 10 years for NIDDK kidney research above the current funding level.

ASN believes these are crucial and necessary investments for preventing illness and maintaining fiscal responsibility. Investing in research to slow the progression of kidney disease and improve therapies for patients would yield significant saving to Medicare in the long run.

In 1972, Congress made a commitment to treat all Americans with kidney failure through the Medicare End-Stage Renal Disease (ESRD) Program—the only health condition Medicare automatically provides coverage for regardless of age or disability. At an annual cost of $35 billion—more than NIH's entire $30 billion budget—the ESRD Program represents nearly 7 percent of Medicare's budget even though ESRD patients represent less than 1 percent of the Medicare population. Despite the staggering burden of kidney disease, NIH investments in kidney research are less than 1 percent of total Medicare costs for patients with kidney disease ($585 million vs. $80 billion in 2014).

The vast majority of Federal research leading to advances in the care and treatment of patients with kidney disease is funded by NIDDK. Examples of critical discoveries arising from NIDDK-funded research are numerous.

For instance, investigative studies supported by NIDDK led to a groundbreaking discovery that helps explain racial and ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and better treatment. The finding that African Americans with two variants of the APOL1 gene are likely to progress to kidney failure faster than other ethnicities paves the way for future research to unlock better preventive therapies and gene-based cures.

Recent findings from NIDDK's Chronic Renal Insufficiency Cohort (CRIC) Study are helping uncover why patients with kidney disease are at greater risker for heart disease, the leading cause of death among patients with kidney failure. Further research exploring the mechanisms for this development could lead to new interventions for preventing heart disease.

Scientists supported by NIDDK have pursued cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment, the society firmly believes that funding NIDDK is a sound investment to create jobs, support the next generation of investigators, and ultimately provide quality care that is less expensive in order to improve the public health of Americans.

Medical research is a major force in the economic health of communities nationwide: every dollar invested in medical research generates $2–3 in economic activity. America must continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and remain the world leader in innovation and discovery—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIDDK's ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN urges Congress to uphold its longstanding legacy of bipartisan support for biomedical research. Should you have any questions or wish to discuss NIDDK or kidney research in more detail, please contact ASN Senior Policy and Government Affairs Associate Grant Olan at (202) 640–4657 or golan@asn-online.org.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's 15,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's Web site at www.asn-online.org.

## PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PLANT BIOLOGISTS

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the Subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research will be a critical step toward economic recovery and job creation in our Nation. ASPB supports the maximum fiscal year 2016 appropriation for NIH and asks that the Subcommittee Members encourage increased support for plant-related research within the agency; 25 percent of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of some 4,500 professional plant biology researchers, educators, students, and postdoctoral scientists with members across the Nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

### PLANT BIOLOGY RESEARCH AND AMERICA'S FUTURE

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutriceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

### PLANT BIOLOGY AND THE NATIONAL INSTITUTES OF HEALTH

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission to pursue "fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability." In general, plant research aims to improve the overall human condition—be it food, nutrition, medicine or agriculture—and the benefits of plant science research readily extend across disciplines. In fact, plants are often the ideal model systems to advance our "fundamental knowledge about the nature and behavior of living systems" as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and maintenance requirements that are less expensive than those required for the use of animal systems.

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

*Health and Nutrition*.—Plant biology research is also central to the application of basic knowledge to "extend healthy life and reduce the burdens of illness and disability." Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50 percent of child deaths under the age of five could be attributed to malnutrition's effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are working today to address the root cause of this problem by balancing the nutritional

content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast to developing countries, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

*Drug Discovery*.—Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60 percent of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants and support more funding opportunities similar to the "Genomes to Natural Products" which will hopefully pave the way for new plant-related medicinal research.

### CONCLUSION

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, ASPB asks the Subcommittee to provide the maximum appropriation and direction to NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.

Thank you for your consideration of ASPB's testimony. For more information about ASPB, please see www.aspb.org.

[This statement was submitted by Tyrone C. Spady, Ph.D., Director of Legislative and Public Affairs, American Society of Plant Biologists.]

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## PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

### SUMMARY: FUNDING RECOMMENDATIONS

(In millions $)

| | |
|---|---|
| National Institutes of Health | 32,000 |
| National Heart, Lung & Blood Institute | 3,214 |
| National Institute of Allergy & Infectious Disease | 4,701 |
| National Institute of Environmental Health Sciences | 717.7 |
| Fogarty International Center | 72.7 |
| National Institute of Nursing Research | 151 |
| Centers for Disease Control and Prevention | 7,800 |
| National Institute for Occupational Safety & Health | 292.3 |
| Asthma Programs | 30.5 |
| Div. of Tuberculosis Elimination | 243 |
| Office on Smoking and Health | 250 |
| National Sleep Awareness Roundtable (NSART) | 1 |

The ATS's 15,000 members help prevent and fight respiratory disease through research, education, patient care and advocacy.

### LUNG DISEASE IN AMERICA

Diseases of breathing constitute the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breath-

ing) system include chronic obstructive pulmonary disease (COPD), lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, asthma, and critical illness.

*National Institutes of Health*

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. Sequestration and a lack of inflationary adjustments over the past decade have significantly eroded the NIH research budget. Following the implementation of the sequestration funding cut in fiscal year 2013, NIH's spending power in inflation-adjusted dollars declined by over 22 percent since 2003. The number of grants supported by the NIH is now at the lowest level since 2001. The ATS is very concerned that due to reductions in Federal research funding, there is a lack of opportunities for young investigators who represent the future of scientific innovation. We ask the subcommittee to provide at least $32 billion in funding for the NIH in fiscal year 2016.

Despite the rising lung disease burden, lung disease research is underfunded. In fiscal year 2014, lung disease research represented just 20.1 percent of the National Heart Lung and Blood Institute's (NHLBI) budget. Although lung disease is the third leading cause of death in the U.S., research funding for the disease is a small fraction of the money invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

*Centers for Disease Control and Prevention*

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control and occupational safety and health research and training. The ATS recommends a funding level of $7.8 billion for the CDC in fiscal year 2016.

ANTIBIOTIC RESISTANCE

According to the Centers for Disease Control and Prevention's (CDC) 2013 report, Antibiotic Resistance Threats in the United States, as many as 23,000 deaths occur in the U.S. annually due to antibiotic resistant bacterial and fungal pathogens including drug resistant pneumonia and sepsis infections. The rise of antibiotic resistance demonstrates the need to increase efforts through the CDC, NIH and other Federal agencies to monitor and prevent antibiotic resistance and develop rapid new diagnostics and treatments. This includes the following recommendations for CDC programs:

—$264 million for the Antibiotic Resistance Solutions Initiative
—$32 million for the National Healthcare Safety Network (NHSN)
—$30 million for the Advanced Molecular Detection (AMD) Initiative

To address antibiotic resistance research needs, we urge a funding increase of $100 million for the National Institutes of Allergy and Infectious Disease (NIAID) to spur research into rapid new diagnostics, new treatments and other activities and an increase of $192 million for the Biomedical Advanced Research and Development Authority (BARDA) to support antimicrobial research and development.

COPD

Chronic Obstructive Pulmonary Disease (COPD) is the third leading cause of death in the United States and the third leading cause of death worldwide, yet the disease remains relatively unknown to most Americans. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the U.S. was $186 billion, including $117 billion in direct health expenditures and $69 billion in indirect morbidity and mortality costs.

The NHLBI is developing a national action plan on COPD, in coordination with the Centers for Disease Control and Prevention (CDC) to expand COPD surveillance, development of public health interventions and research on the disease and increase public awareness of the disease and we urge Congress to support it. We also urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES) and the National Health Information Survey (NHIS).

TOBACCO CONTROL

Cigarette smoking is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a key priority. The CDC's Office of Smoking and Health coordinates public health efforts to reduce tobacco use. In order to significantly reduce tobacco use within 5 years, as recommended by the subcommittee in fiscal year 2010, the ATS recommends a total funding level of $250 million for the Office of Smoking and Health in fiscal year 2016.

ASTHMA

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2010, 3,388 Americans died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. The disease costs our healthcare system over $50.1 billion per year. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. A study published in the American Journal of Respiratory Critical Care in 2012 found that for every dollar invested in asthma interventions, there was a $36 benefit. We ask that the subcommittee's appropriations request for fiscal year 2016 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least $30.596 million.

SLEEP

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. The ATS recommends a funding level of $1 million in fiscal year 2016 to support activities related to sleep and sleep disorders at the CDC, including surveillance activities and public educational activities. The ATS also recommends an increase in funding for research on sleep disorders at the Nation Center for Sleep Disordered Research (NCSDR) at the NHLBI.

TUBERCULOSIS

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.5 million lives each year. In the U.S., every State reports cases of TB annually. Drug resistant tuberculosis was identified as a serious public health threat to the U.S. in the CDC's 2013 report on antimicrobial resistance. Drug-resistant TB strains poses a particular challenge to domestic TB control due to the high costs of treatment, intensive healthcare resources and burden on patients. Treatment costs for multidrug-resistant (MDR) TB, which is up to 2 years in length, range from $100,000 to $300,000. The continued global pandemic of this airborne infectious disease and spread of drug resistant TB demand that the U.S. strengthen our investment in global and domestic TB control and research to develop new TB diagnostic, treatment and prevention tools.

The Comprehensive Tuberculosis Elimination Act (CTEA, Public Law 110–392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. The ATS, recommends a funding level of $243 million in fiscal year 2016 for CDC's Division of TB Elimination, as authorized under the CTEA, and urges the NIH to expand efforts to develop new tools to address TB. Additionally, in recognition of the unique public health threat posed by drug resistant TB, we urge BARDA to support research and development into new TB diagnostic, treatment and prevention tools.

PEDIATRIC LUNG DISEASE

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. In 2009, of the 10 leading causes of infant mortality, 4 were lung diseases or had a lung disease component. Many of the precursors of adult respiratory disease start in childhood. Many children with respiratory illness grow into adults with COPD. It is estimated that 7.1 million children suffer from asthma. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condi-

tion. The ATS encourages the NHLBI and NICHD to sustain and expand research efforts to study lung development and pediatric lung diseases.

CRITICAL ILLNESS

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be encouraged and funded to coordinate investigation in this area in order to meet this growing national imperative.

FOGARTY INTERNATIONAL CENTER

The Fogarty International Center (FIC) provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health professionals in TB treatment and research. The ATS recommends Congress provide $72.8 million for FIC in fiscal year 2016, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.

RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

As Congress considers funding priorities for fiscal year 2016, the ATS urges the subcommittee to provide at least level funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the Centers for Disease Control and Prevention (CDC), is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury.

The ATS appreciates the opportunity to submit this statement to the subcommittee.

[This statement was submitted by Thomas Ferkol, MD, President, American Thoracic Society.]

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PREPARED STATEMENT OF THERESA A ANDERSON

As a Parent, Guardian and member of VOR, I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization

and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

As a Parent & Guardian I am in the best position to understand my son, Matthew's wants & needs. Having an attorney or outside advocate make such decisions is unconscionable.

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

On behalf of the 52 million adults and 300,000 children living with doctor-diagnosed arthritis in the U.S., the Arthritis Foundation thanks Chairman Blunt and Vice Chairwoman Murray for the opportunity to provide written testimony to the Appropriation Subcommittee on Labor, Health and Human Services (HHS), and Education and Related Agencies for fiscal year 2016. Arthritis affects 1 in 5 Americans and is the leading cause of disability in the U.S., according to the Centers for Disease Control and Prevention (CDC). It results in 44 million outpatient visits, over a million hospitalizations, and over 9,000 deaths annually. It limits the daily activities of nearly 23 million Americans and causes work limitations for 40 percent of the people with the disease. This translates to $156 billion a year in direct and indirect costs from two forms of arthritis alone—osteoarthritis (OA) and rheumatoid arthritis (RA).

There is no cure for arthritis, and for some forms of arthritis like OA, there is no effective therapeutic treatment. Research is critical to build towards a cure, to develop better treatments with fewer severe side effects, and to identify biomarkers and therapies for types of arthritis for which none exist. A strong investment in public health research and programs is essential to making breakthroughs in treatments finding a cure for arthritis, and for delivering those breakthroughs to the 1 in 4 veterans suffering from the disease. This testimony will focus on the two HHS agencies and programs that are most essential for addressing arthritis: the National Institutes of Health and the Arthritis Program at the Centers for Disease Control and Prevention.

### NATIONAL INSTITUTES OF HEALTH (NIH)

As previously stated, there is no cure for arthritis, and for many types like OA, there are no effective therapeutic treatments. Even for auto-immune forms of the disease like RA, biologic medications—which have revolutionized treatment by halting the progress of disease in many patients—have severe side effects. There is also no "gold standard" diagnostic for many forms of arthritis. For example, there is no single test to diagnose RA. Instead, diagnose is usually made through a combination of clinical assessments, such as examination of the joints for inflammation, history of symptoms, blood tests and x-rays. Because of this, it can take a long time to diag-

nose RA, and Juvenile Arthritis in children. It is not uncommon for children to go months without an official diagnosis, which can delay the start of critical treatment. Research is the key to identifying better diagnostics and better treatments, so that patients have access to treatments early in their disease, ensuring a higher quality of life.

In the period from 2009–2013, NIH funding that went into the rheumatology community made up 1.79 percent of NIH funding, translating to 6,750 awards, totaling 1.52 percent of all NIH awards over that 5 year period. Arthritis is a diverse disease, and therefore arthritis research is supported at a number of NIH Institutes and Centers. For example, the National Institute of Allergy and Infectious Diseases (NIAID) supports much of the research on auto-immune forms of arthritis like rheumatoid arthritis; the National Institute on Aging (NIA) support research on arthritis in older Americans; and the National Institute of Child Health and Human Development (NICHD) supports research on arthritis in children.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is one of the primary NIH Institutes that supports arthritis research. There are a number of initiatives NIAMS has supported to better understand arthritis. The Osteoarthritis Initiative is a public-private, multi-center, longitudinal study of knee OA that was launched in 2002 with the goal of identifying biomarkers for OA as potential surrogate endpoints for onset and progression. The recently launched Accelerating Medicines Partnership is a public-private partnership that includes RA/lupus as one of three disease topics with the goal of accelerating drug development.

Research currently supported by NIAMS is addressing major questions necessary to unlocking the unknowns of arthritis, such as:

—How gene-environment interactions can help determine the relationship between RA and environmental and genetic factors that trigger onset.

—Which biological pathways are affected in people with RA and how drug development can target those pathways to expand the pool of drugs available to people with RA.

—How the immune system affects the initiation and progression of auto-immune forms of arthritis, to help identify potential therapies and interventions to strengthen the immune system in people with RA.

—How existing successful anti-rheumatic drugs may be used for other arthritis-related diseases.

Most recently, researchers have found the gene that confirms the existence of psoriatic arthritis. This is a breakthrough that has the potential to lead to targeted therapies for psoriatic arthritis, and even treatments that can prevent its onset. These types of research breakthroughs can have an enormous impact on the quality of life for people with arthritis, in addition to a generating a strong return on investment in reduced healthcare costs.

A strong overall NIH funding level is critical to maintaining the investment in research on arthritis in all its forms. Therefore, we urge you to fund NIH at a minimum of $32 billion in fiscal year 2016 to keep pace with the growing research needs in the arthritis community.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC) ARTHRITIS PROGRAM

The CDC Arthritis Program is the only Federal program dedicated solely to arthritis. It provides grants to 12 States to support public health programs, provide education services, perform public health research, and support data collection. Its goal is to connect all Americans with arthritis to resources to help them manage their disease. Evidence based programs like Enhance Fitness help keep older adults active, and has shown a 35 percent improvement in physical function, resulting in fewer hospitalizations and lower health costs compared to non-participants. Further, 1 in 4 veterans has doctor-diagnosed arthritis, and these evidence-based exercise programs are recommended by the CDC to help our veterans reduce the impact of arthritis on their lives.

Missouri is one of the 12 CDC-funded States, and with this Federal support, the State Arthritis and Osteoporosis Program and its partners have been able to develop and disseminate specific marketing material for arthritis programs, offer more programs in more communities and in more sites, involve more agencies and partners, and involve more referrals from doctor's offices. The impact to-date is a 50 percent increase in the number of self-management programs offered across the State in 2 years, a doubling of the offering of the Walk with Ease program, and an increase of 18 active partners in the Health Delivery System partnership.

Not only does the Arthritis Program provide resources to people with arthritis, it also supports data collection on the prevalence and severity of arthritis. Because of

this support, we know that 1 in 5 Americans has doctor-diagnosed arthritis, including 28 percent of people in Missouri and 25 percent of people in Washington, and 622,000 of those people in Missouri and 693,000 of those people in Washington are limited by their arthritis. Without the Arthritis Program, the robust level of data collection we have now would not exist. As you know, this data is critical for determining where to direct public health programs and how to set research priorities. For example, because of the data on the high number of people with arthritis who also have at least one other chronic disease like heart disease (24 percent) or diabetes (16 percent), we know that research on co-morbidities and coordinated chronic disease programs are important to reducing the overall impact of chronic disease on people with arthritis.

Given the high prevalence and severity of this disease, the Arthritis Program is woefully under-funded compared to the investment in other chronic diseases. Despite the low funding level of $13 million in fiscal year 2014, the program was slated for elimination in fiscal year 2015. While the program was preserved, the funding was cut by 25 percent, bringing the fiscal year 2015 total to $9.5 million. The Arthritis Program staff must now determine how to support the same level of programs in 12 States with 25 percent fewer resources.

In 2013 for the first time, data showed that arthritis affects at least 20 percent of the population in every State. All 50 States need funding from the Arthritis Program. While this is a long-term goal, a critical first step is to restore the program to its full funding level so it can continue its current level of operations in the 12 States is supports. Therefore, we urge you to restore the $3.5 million to the CDC Arthritis Program, bringing the total program level back to $13 million in fiscal year 2016.

We thank the Subcommittee for its commitment to public health. As you write the fiscal year 2016 Labor-HHS-Education appropriations bill, we urge you to fund NIH at a minimum of $32 billion and to restore the CDC Arthritis Program to its full funding level of $13 million in order to continue the investment in improving the lives of people with arthritis. Please contact Arthritis Foundation Director of Health Policy and Federal Affairs Anna Hyde at ahyde@arthritis.org with any questions.

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## PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges is a not-for-profit association representing all 141 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 148,000 faculty members, 83,000 medical students, and 115,000 resident physicians. The AAMC requests the following for Federal priorities essential in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: at least $32 billion for the National Institutes of Health (NIH); $375 million in budget authority for the Agency for Healthcare Research and Quality (AHRQ); $524 million for the Title VII health professions and Title VIII nursing workforce development programs at the Health Resources and Services Administration (HRSA)'s Bureau of Health Workforce; and continued support for student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the Subcommittee's longstanding, bipartisan efforts to strengthen these programs.

*National Institutes of Health*.—Congress's long-standing bipartisan support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments.

Nearly 84 percent of the NIH's budget is competitively awarded through more than 55,000 research and training grants to more than 300,000 researchers at over 2,500 universities and research institutions located in every State. At least half of this funding supports life-saving research at America's medical schools and teaching hospitals, where scientists, clinicians, fellows, residents, medical students, and trainees work side-by-side to improve the lives of Americans through research.

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and

translate this knowledge into the next generation of diagnostics, therapeutics, and other clinical innovations. This partnership not only lays the foundation for improved health and quality of life, but also strengthens the Nation's long-term economy.

While the AAMC is grateful for the increase provided to NIH in the current fiscal year, the NIH budget remains lower than it was in fiscal year 2012 in actual dollars, and since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation. This loss is significantly impacting the Nation's ability to sustain the scientific momentum that has contributed so greatly to our Nation's health and our economic vitality.

The AAMC supports the Ad Hoc Group for Medical Research recommendation that NIH receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in medical research. We look forward to working with Congress and the Administration to achieve this goal through the annual appropriations process.

The AAMC also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

Perhaps the most destructive and long-lasting impact of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce. Of particular concern is the challenge of maintaining a cadre of clinician-scientists to facilitate translation of basic research to human medicine. NIH supports many innovative training programs and funding mechanisms that foster scientific creativity and exploration.

Additional funding is needed if we are to strengthen our Nation's research capacity, ensure a biomedical research workforce that reflects the racial and gender diversity of our citizenry, and inspire a passion for science in current and future generations of researchers.

The AAMC thanks the Subcommittee for its efforts to retain the limit on salaries that can be drawn from NIH extramural awards at Executive Level II of the Federal Executive Pay Scale. Medical schools' and teaching hospitals' discretionary funds from clinical revenues and other sources have become increasingly constrained and less available to invest in research. If institutions and departments divert funds to compensate for a reduction in the salary limit, they have less funding for critical activities such as bridge funding to investigators between grants and start-up packages to young investigators to launch their research programs. A lower salary cap also will disproportionately affect physician investigators, who will be forced to make up salaries from clinical revenues, thus leaving less time for research. This may serve as a deterrent to their recruitment into research careers. The AAMC urges the Subcommittee to continue its efforts to retain the limit at Executive Level II.

*Agency for Healthcare Research and Quality*.—Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of healthcare, decrease healthcare costs, and provide access to essential healthcare services by translating research into measurable improvements in the healthcare system. The AAMC firmly believes in the value of health services research as the Nation continues to strive to provide high-quality, evidence-based, efficient, and cost-effective healthcare to all of its citizens. The AAMC joins the Friends of AHRQ in recommending $375 million in budget authority for the agency in fiscal year 2016.

As the only Federal agency with the sole purpose of generating evidence to make healthcare safer; higher quality; and more accessible, equitable, and affordable, AHRQ also works to ensure such evidence is available across the continuum of healthcare stakeholders, from patients to payers to providers. These research findings will better guide and enhance consumer and clinical decisionmaking, provide improved healthcare services, and promote efficiency in the organization of public and private systems of healthcare delivery.

*Health Professions Funding*.—HRSA's Title VII health professions and Title VIII nursing workforce development programs are the only Federal programs designed to improve the supply, distribution, and diversity of the Nation's primary care workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve and emphasizing interprofessional education and training, Title VII and VIII programs bring together knowledge and skills across disciplines to provide effective, efficient and coordinated care. Further, studies demonstrate that the programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

In addition to promoting educational innovations and preparing the workforce for changing delivery systems, the programs also support faculty development, curriculum development, and continuing education opportunities. These are all important components to ensure faculty and providers are equipped to meet the Nation's changing needs and train the next generation of health professionals.

The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending $524 million for these important workforce programs in fiscal year 2016. This funding level is necessary to ensure continuation of all existing Title VII and Title VIII programs while also supporting promising initiatives such as the Pediatric Subspecialty Loan Repayment program, the Clinical Training in Interprofessional Practice program, the Rural Physician Training Grants, and other efforts to bolster the workforce.

The AAMC objects to the Administration's proposal to eliminate the Title VII Area Health Education Centers (AHEC) program, which, in academic year 2013–2014 alone, trained more than 24,000 health professions students in over 10,000 sites across the country, including community-based and ambulatory care settings and CHCs. While we appreciate the Administration's proposal to enhance the focus on academic support and pre-professional engagement for students from disadvantaged backgrounds through the newly proposed Health Workforce Diversity Program, we are disappointed in the Administration's proposal to eliminate the Health Careers Opportunity Program (HCOP). Research shows that HCOP has helped students from disadvantaged backgrounds throughout the educational pipeline achieve higher grade point averages and matriculate into health professions programs. Continued support for these and the full spectrum of Title VII programs is essential to prepare our next generation of medical professionals to adapt to the changing healthcare needs of the Nation's aging and increasingly diverse population.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Workface also supports the Children's Hospitals Graduate Medical Education (CHGME) program. This program provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care and specialty care workforce for our Nation's children. At a time when the Nation faces a critical physician shortage, the AAMC has serious concerns about the substantial cuts to the CHGME program proposed in the president's budget. We strongly support full funding for the Children's Hospitals Graduate Medical Education program at $300 million in fiscal year 2016.

*Student Aid and the National Health Service Corps (NHSC).*—The AAMC urges the Subcommittee to sustain student loan and repayment programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently $180,000, and typical repayment can range from $328,000 to $483,000.

Along with more than 50 stakeholder organizations, the AAMC urges the Subcommittee to provide a discretionary appropriation for the National Health Service Corps (NHSC) in fiscal year 2016. As the Nation faces multiple health professional shortages, sustained investments in workforce programs are necessary to help care for our Nation's most vulnerable populations.

Recognizing that mandatory funding may be provided through other mechanisms, the appropriations committees retain primary responsibility for funding the administrative functions of the NHSC and for avoiding budgetary lapses in future years. We look forward to working with Congress to help ensure a long-term investment in the NHSC without sacrificing other Federal health professions training support.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee as it prepares its fiscal year 2016 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF ASSISTIVE TECHNOLOGY ACT PROGRAMS

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, I appreciate the opportunity to share the Association of Assistive Technology Act Programs' (ATAP) perspective on Federal investments in the Assistive Technology (AT) Act of 2004 (Public Law 108–364). ATAP is a national, member-based organization, comprised of 54 State Assistive Technology Act Programs funded under the Assistive Technology Act (AT Act). The AT Act receives a total of $31 million from the Federal Government, as part of Title II of the Labor, Health and Human Services, and related agencies appropriations bill. This level of funding provided $25.7 million for the State AT Grant Programs; $4.3 million for the Protection and Advocacy for Assistive Technology program; and $1.0 million for technical assistance required under the AT Act's National Activities authority.

ATAP was established in 1997 to provide support to State AT Program members to enhance the effectiveness of AT Programs on the State and local level, and promote the national network of AT Programs. ATAP facilitates the coordination of State AT Programs nationally and provides technical assistance and support to its members. ATAP represents the needs and interests of the State AT Programs and is the national voice of the AT Programs.

Funding for the AT Act supports State AT Grant programs that assure people with disabilities have access to and acquisition of the assistive technology services they need to live, work, and attend school in their communities.

State AT Grant Programs exist in every State and territory and support four State-level activities, required by the law: 1) device demonstration; 2) device loan; 3) device reutilization (reuse and exchange); 4) financial loan and other financing programs. State AT Grant programs also are required by law to provide technical assistance and training, and related assistive technology services. State AT Programs play a pivotal role in annually assisting thousands of individuals with disabilities to increase, maintain, or improve their functional capability through the use of appropriate AT. As a result, ATAP is advocating for full funding of the AT Act ($38 million) so that State AT Programs can help more individuals benefit from AT and meet the full demand at the State and local level. Full funding would provide the minimum authorized level for each State.

State AT Grant Programs yield significant savings to consumers and the Federal Government. Below is an outline of the return on investment yielded nationally by all four State-level activities:

—Demonstration Programs provide opportunities for people to learn about and become familiar with specific types of AT by comparing and contrasting the functions and features of devices through hands on exploration. Instruction is provided by knowledgeable AT professionals in a product neutral environment that does not favor one company or manufacturer. SAVINGS: 68,070 individuals participated in 39,916 device demonstrations conducted by State AT Programs in fiscal year 2014. Projecting a modest $100 savings realized by just half of the total demonstrations conducted results in national savings of approximately $2 million dollars.

—Device Loan/Borrowing Programs allow individuals to borrow—for a limited time period—devices for use at home, school, work etc. Device loans allow borrowers to try out devices in their own environments to determine if a device will meet their needs before a purchase is made. Device loans also can provide loaner AT while a device is being repaired, while a consumer is waiting for funding approvals, or to use for training or professional development purposes. SAVINGS: 35,243 device loans were made to individuals or agencies with 47,669 devices borrowed from short-term device loan programs operated through State AT Programs in fiscal year 2014. Using an average savings of $1,000 per loan with more than one device associated (at least one device was rejected as being a match and a second one was borrowed) results in national savings of well over $12 million. Projecting a minimum $10 per day rental fee for the average loan period of 35 days, results in national savings of almost $3 million for devices borrowed for accommodation (while a device is repaired or while waiting for funding) or for training since the device did not have to be rented for these purposes.

—Device Reutilization Programs support the reuse of assistive technology that is no longer needed or used by its original owner. Recipients usually obtain equipment at significantly lower cost or no cost. There are several options for reutilization including reassignment/reuse, device exchange (typically online) and long-term device loans where the borrower keeps the device as long as needed. SAVINGS: 43,713 recipients acquired 57,745 reutilized devices through State

AT Programs in fiscal year 2014. A total of $25,199,009 was saved by device recipients by purchasing/obtaining reutilized AT instead of new. In addition, close to 70 percent of the reuse device recipients indicated that they would not have been able to afford the AT if it were not for the reuse services of the State AT Program. The cost of those individuals being unable to work, learn or live in the community without the AT they need would be immeasurable.

—State Financing Activities help individuals purchase/obtain AT through a variety of initiatives. Financial loan programs provide consumers with affordable, flexible borrowing options. Other programs provide AT directly to consumers at no cost using dollars from non-AT Act sources or save consumers money when purchasing AT. SAVINGS: 631 borrowers obtained financial loans totaling $4,295,953 to buy 639 devices in fiscal year 2014. These loans were made at an average interest rate of 3.33 percent. Assuming most standard loans would be at a 7 percent or higher interest rate, consumers have saved considerable expense through access to this lower rate. 2,385 recipients acquired 2976 devices valued at $3,183,057 from other State financing programs that directly provide AT using external funding sources. 3,356 recipients acquired 5,557 AT devices with a savings of $897,808 from other State financing activities, such as cooperative buying programs and device lease programs. The vast majority (84 percent) of recipients indicated that if the State financing activity they used was not available they would not have been able to purchase/obtain the AT potentially resulting in individuals who are unable to successfully work, learn or live in the community.

*Overall, State AT Grant Programs, based on the fiscal year 2014 Federal investment of $25.7 million, yielded over $46 million in savings and benefits, leveraged over $13 million and provided direct services to nearly 700,000 people with disabilities.*

While it is clear State AT Programs provide cost effective services and supports that improve the lives of people with disabilities and warrant an ongoing Federal investment, still there are 11 State AT Act programs that do not receive the minimum grant authorized in the law in 2004 ($410,000). Due to the tremendous impact programs have on the lives of people with disabilities, and the sincere savings they yield both the government and the consumer, it would be valuable and cost-effective to provide an additional $7 million to such a successful Federal program. This level of funding would bring the AT Act to the full level of funding intended in the statute and benefit thousands more people who need assistive technology.

Thank you for the opportunity to provide testimony to the committee as you make decisions on the fiscal year 2016 budget.

[This statement was submitted by Linda Jaco, Chair, Association of Assistive Technology Act Programs.]

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## PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) thanks the Subcommittee for its long-standing and bipartisan leadership in support of the National Institutes of Health (NIH). We continue to believe that science and innovation are essential if we are to continue to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy.

The final fiscal year 2015 omnibus appropriations bill included a welcome and much needed increase for NIH. However, this increase did not make up for funds cut by sequestration in fiscal year 2013 nor did it restore the purchasing power NIH has lost over the past decade. In fact, despite budget increases in the each of the past two fiscal years, the NIH budget remains lower than it was in fiscal year 2012 in actual dollars, and since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation.

While the President's fiscal year 2016 budget request for NIH would provide a much needed next step by increasing NIH funding above biomedical inflation, AIRI believes that the ongoing and emerging health challenges confronting the United States and the world, and the unparalleled scientific opportunities to address these burdens demand a funding level of at least $32 billion in fiscal year 2016. AIRI also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander invaluable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

AIRI is a national organization of more than 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The partnership between NIH and America's scientists, research institutions, universities, and medical schools is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements that deliver more treatments and cures to patients. Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every State.

The Federal Government has an irreplaceable role in supporting medical research. No other public, corporate, or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge research necessary to yield new innovations and technologies of the future. NIH supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. Unfortunately, continued erosion of the national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability.

Additionally, AIRI member institutes have championed (and very frequently are called upon to lead) technologies and research centers to collaborate on biological research for all diseases. Using shared resources—specifically, advanced technology platforms or "cores,"—as well as genomics, next-generation sequencing, electron and light microscopy, high-throughput compound screening, bioinformatics, imaging, and other technologies, AIRI researchers advance therapeutics development and drug discovery.

AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall. In addition to concerns over funding, AIRI member institutes oppose legislative provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such prescriptive policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

AIRI members are located in 25 States, including many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

The biomedical research community depends upon a knowledgeable, skilled, and diverse workforce to address current and future critical health research questions.

While the primary function of AIRI member institutions is research, most are highly involved in training the next generation of biomedical researchers, ensuring that a pipeline of promising scientists is prepared to make significant and potentially transformative discoveries in a variety of areas. AIRI supports policies that promote the ability of the United States to maintain a competitive edge in biomedical science.

The NIH initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health. However, one of the most destructive and long-lasting impacts of the decline in the NIH budget is on the next generation of scientists, who see training funds slashed and the possibility of sustaining a career in research diminished. The continued success of the biomedical research enterprise relies heavily on the imagination and dedication of a diverse and talented scientific workforce.

In addition, strong support for NIH is critical to the Nation's competitiveness. This country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and the cuts of sequestration, which jeopardize our competitive edge in an increasingly innovation-based global marketplace. Other countries have recognized the critical role that biomedical science plays in innovation and economic growth and have significantly increased their investment in biomedical science.

This shift in funding raises the concern that talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To maintain our dominance, we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

AIRI thanks the Subcommittee for its important work dedicated to ensuring the health of the Nation, and we appreciate this opportunity to urge the Subcommittee to provide at least $32 billion for NIH in the fiscal year 2016 appropriations bill. AIRI also urges Congress and the Administration to work in a bipartisan manner to end sequestration and the continued cuts to medical research that squander valuable scientific opportunities, discourage young scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic future.

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## PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Chairman Blunt and Distinguished Subcommittee Members—I am grateful for this opportunity to submit written testimony on behalf of the Association of Maternal & Child Health Programs (AMCHP), our members, and the millions of women and children that are served by the Title V Maternal and Child Health (MCH) Services Block Grant. I am asking the Subcommittee to support an increase of $2 million in funding for the Title V MCH Services Block Grant for a total of $639 million for Federal fiscal year 2016.

These funds are needed to extend evidence-based services and strategies that further the program's statutory purpose to improve the health of all mothers and children by (1) ensuring access to quality maternal and child health services, (2) reducing infant mortality and preventable diseases and conditions, and (3) providing and promoting family centered, community-based, coordinated for children with special healthcare needs and facilitating the development of community-based systems of services for such children and their families.

I know you and your colleagues understand that this level of funding does not allow us to address all the health needs of our Nation's women, children, fathers and families. Despite recent progress, close to 24,000 babies tragically die each year. Many others are born too soon and cost our society upwards of $26 billion per year. Gaps in both private and public insurance create barriers for families needing services. Many pregnant women still smoke. The obesity epidemic continues to plague our country and the list goes on and on. In the face of these challenges, public health programs have already borne more than their fair share of deficit reduction with years of cuts and a budget cap that could cut funding even further. In total, more than 52,000 State and local public health jobs have been lost since 2008 due to the elimination of positions, hiring freezes, layoffs and furloughs. This represents a loss of 17 percent of the State and territorial public health workforce and a 22

percent loss of the local public health workforce, with serious consequences for our capacity to address leading MCH challenges.

However, we recognize that during these tough budgetary times any substantial increase in funding would come at the detriment of other public health programs. Therefore, we strongly urge you to support a small $2 million increase in funding for the Federal investment in the Title V MCH Services Block. Title V has proven to be a cost effective, accountable, and flexible funding source used to address the most critical, pressing and unique MCH needs of each State. States and jurisdictions use the Title V MCH Block Grant to design and implement a wide range of maternal and child health programs that respond to locally defined needs.

One of the most exciting developments with the Title V MCH Block Grant is a transformation that is happening right now under the leadership of Dr. Michael Lu, associate administrator of the Health Resources and Services Administration Maternal and Child Health Bureau. This transformation is focused on three main goals—to reduce burden, maintain flexibility and improve accountability. At its center is an effort to improve our performance measurement framework with a sharpened focus on national outcome measures, national performance measures and evidence-based strategy measures.

This transformation will ensure that investments made by the programs support evidence-based or informed strategies. Title V focuses on accountability and delivering results, and we are confident this transformation will build and strengthen that important focus so you can be assured that we are getting the best value for the taxpayer dollar while making real and measurable differences in the lives of our mothers and children. For more information on this effort, please contact me and my staff will help arrange further briefing and information on what this means for your State.

A key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of State Title V, Medicaid and the Children's Health Insurance Program (CHIP) by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home child care facilities.

One of the primary focus areas for States Title V programs is supporting systems of services for children and youth with special healthcare needs (CYSHCN). These systems serve a diverse group of children ranging from children with chronic conditions such as asthma or diabetes, to children with autism, to those with more medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. Overall, CYSHCN are defined as children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. In a recent national survey, children with a chronic condition birth to age 18 represented approximately 15 percent of the entire child population in the United States.

Creating a comprehensive, quality system of care for children and youth with special healthcare needs (CYSHCN) has been one of the most challenging areas for State health leaders and other stakeholders such as State Title V CYSHCN programs, health plans, private insurers, State Medicaid and CHIP agencies, pediatricians and family physicians, and families. By one critical measure, only 43 percent of all CYSHCN report receiving services via a recommended medical home. Medical homes are considered the gold standard because they promote care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Recently AMCHP—with the generous support of the Lucile Packard Foundation for Children's Health and a broad group of stakeholders—forged a project that we believe accelerates progress in this challenging area. For more than three decades, numerous national reports, initiatives, and research have described or called for frameworks, standards and various measures to advance a comprehensive system of care for CYSHCN and their families. These and other efforts have helped to establish important work in States, communities, health plans, provider practices, and other areas to build comprehensive systems of care for CYSHCN. However, until recently they have not resulted in an agreed on national set of standards that could be used and applied within healthcare and public health systems and other child-serving systems to improve healthcare quality and health outcomes for this population of children. It became clear to AMCHP and others that achieving consensus

on the necessary capacity and performance of systems serving CYSHCN is essential to comprehensive, quality systems of care for this population of children.

To pursue this vision, AMCHP recently led a National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs project to develop a core set of structure and process standards for systems of care for CYSHCN, based on the research and national consensus among a diverse group of stakeholders with expertise in their field. The resulting standards—available on our website—are intended for use by a range of national, State and local stakeholder groups including State Title V CYSHCN programs, health plans, State Medicaid and CHIP agencies, pediatric provider organizations, children's hospitals, insurers, health services researchers, families/consumers and others. These standards represent a major breakthrough that can help improve our system of care for all children—and this committee can help further accelerate progress by assessing the resources needed to make sure every State has the capacity to fully operationalize and implement them.

In our view, one of the biggest under-celebrated success stories of recent times are the contributions this committee makes in funding programs such as the Title V MCH Services Block Grant that contribute to substantial progress in reducing infant mortality. In fact, a few months ago President Obama responded to a question about priorities in media coverage by saying in an interview, "There's just not going to be a lot of interest in a headline story that we have cut infant mortality by really significant amounts over the last 20 years . . . " He noted that plane crashes and terrorism are more likely covered, and that other complex stories are harder for the media to report.

He's right, and yet those who take a closer look will find that in 2013, 23,440 babies in the United States died in their first year of life, which is equivalent to about 117 average sized passenger planes crashing every year. That's close to one every three days. The president also is right that we made tremendous progress in reducing that toll in recent decades—as mentioned, perhaps one of the greatest public health success stories rarely covered in the press.

For a long time, infant mortality rates have been one of the sentinel measures to gauge how well any society is doing to ensure the health of women, children and families. And here is the headline news: since we began collecting statistics in 1915, the overall infant mortality rate declined from nearly 100 of every 1,000 babies born in 1915 to nearly just 6 per 1,000 in 2011. That is a stunning 94 percent improvement and represents millions of lives saved.

Ensuring that babies are born in optimal health is all the more important considering the recent scientific advances in our understanding about how a baby's early years are critical to building a strong foundation for the rest of their life course. That is the good news—but there also are a few caveats and contradictions. First, there are persistent and unacceptable disparities among racial and ethnic groups that have existed since the data collection began. The black and Native American infant mortality rates are twice the rates of whites, and in some communities it is even three times higher.

The second caveat is that the political will to accelerate progress and eliminate disparities is inconsistent. Perhaps the biggest contradiction is that the United States spends more money on maternity care than any other nation on earth, yet still lags behind 26 other industrialized nations on the key outcome of infant mortality.

Part of the problem is that too often we spend more on high tech treatments—think elective C-sections and neonatal intensive care units—than on basic prevention programs to address risk factors that can lead to poor birth outcomes. For example, we know that breastfeeding, family planning, immunization, smoking cessation and safe sleep are effective in reducing infant mortality. However, funding levels for these key public health programs have never matched actual need, have slowly eroded over time, and are suffering further threats from budget caps and looming sequestration.

Additionally, in June 2012, then Secretary of Health and Human Services Kathleen Sebelius called for the first ever National Strategy to Reduce Infant Mortality. A federally appointed Secretary's Advisory Committee on Infant Mortality (SACIM) submitted detailed recommendations but, to date, no formal strategy has been adopted.

Congress of course has the power of the purse, but has not consistently delivered on its obligation to annually review programmatic funding levels for public health programs and match resources to national needs. Instead, it has allowed the slow erosion of critical programs like the Title V MCH Block Grant—which has a statutory purpose to reduce infant mortality—by imposing cuts of close to $100 million over the past decade.

Currently funded at $637 million, this preventive program represents less than one day's worth of the Nation's spending on the Medicaid program, which at $1.2 billion a day reached a total of $450 billion in 2013. This demonstrates once again that our health system spends plenty on healthcare but invests precious little in prevention and public health efforts. In terms of total potential cost savings to our health system, far too little attention is consistently given to health economics and the measurable financial impact of public health and the prevention of disease, illness and early death.

To move forward, we suggest four things: (1) your committee could ask the current leadership of the U.S. Department of Health and Human Services to take another look at the existing recommendations and deliver on the promise to create a national strategy to reduce infant mortality; (2) your committee could take a close look at that strategy, ask for briefings, assess where improvement is possible, and provide the resources and leadership needed to bring proven efforts to scale; (3) members of this committee and your colleagues can visit and highlight the communities where public health efforts are succeeding to help create the political will to accelerate those successes; and (4) you can support the small $2 million increase in funding for the Federal investment in the cost effective and accountable Title V MCH Block Grant. Taken together, this should generate some interest in headline stories and more importantly, help ensure that every baby that enters this world is born healthy and loved.

About AMCHP: The Association of Maternal & Child Health Programs is a national resource, partner and advocate for State public health leaders and others working to improve the health of women, children, youth and families, including those with special healthcare needs.

[This statement was submitted by Lori Tremmel Freeman, Chief Executive Officer, Association of Maternal & Child Health Programs.]

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## PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

Title VII Health Professions Training Programs
—$24.602 Million for the Minority Centers of Excellence.
—$22.133 Million for the Health Careers Opportunity Program.

$32 Billion for the National Institutes of Health
—$285 Million for the National Institute on Minority Health and Health Disparities.
—$100 Million for Research Centers for Minority Institutions.

$65 Million for the Department of Health and Human Services' Office of Minority Health.

$65 Million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.

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Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you. I am Dr. Anthony Wutoh, Chairman of the Board of Directors of the Association of Minority Health Professions Schools (AMHPS) and the Dean of the College of Pharmacy at Howard University in Washington, D.C. AMHPS, established in 1976, is the consortium of our Nation's twelve historically black medical, dental, pharmacy, and veterinary medicine schools. The members are two dental schools at Howard University and Meharry Medical College; four colleges of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one college of veterinary medicine at Tuskegee University.. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our

Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help AMHPS continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2016, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2016, I recommend a funding level of $25 million for COEs.

*Health Careers Opportunity Program (HCOP).*—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2016, I recommend a funding level of $14 million for HCOPs. Additionally, we have worked hard with the Obama Administration for them to understand this program. They have offered to "rebrand" HCOP. Until such time that the agency that administers the program, HRSA, and community agree on a path forward, we support the current funding of HCOP.

NATIONAL INSTITUTES OF HEALTH

National Institute on Minority Health and Health Disparities: The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan

for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through its Centers of Excellence program. For fiscal year 2016, I recommend $285 million for NIMHD.

Research Centers at Minority Institutions: The Research Centers at Minority Institutions program (RCMI) has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. For fiscal year 2016, I recommend $100 million for RCMI.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health: Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in healthcareers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities; however, that role will be greatly diminished if this agency does not retain its grantmaking authority. For fiscal year 2016, I recommend a funding level of $65 million for the OMH.

DEPARTMENT OF EDUCATION

*Strengthening Historically Black Graduate Institutions*.—The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2016, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS' member institutions and the Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. The Association seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman.

[This statement was submitted by Anthony Wutoh, Ph.D., Chairman, Board of Directors, Association of Minority Health Professions Schools.]

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## PREPARED STATEMENT OF THE ASSOCIATION OF SCIENCE-TECHNOLOGY CENTERS

### INTRODUCTION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to submit written testimony for the record. My name is Anthony (Bud) Rock, and I serve as the President and Chief Executive Officer of the Association of Science-Technology Centers (ASTC). My testimony today addresses the importance of science, technology, engineering, mathematics (STEM), and health education, and will focus specifically on the fiscal year 2016 budgets for four specific offerings at three Federal agencies over which your subcommittee has jurisdiction, including: (1) the Science Education Partnership Award (SEPA) program at the National Institutes of Health (NIH), which would receive $18.5 million under the President's fiscal year 2016 request; the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS), which would receive $33.6 million under the President's fiscal year 2016 request; and the 21st Century Community Learning Centers (21st CCLC) and Mathematics and Science Partnerships (MSP) programs at the Department of Education (ED), which would receive $1.15 billion and $202.7 million, respectively, under the President's fiscal year 2016 request.

OUR REQUEST

On behalf of ASTC and the nearly 400 science centers and museums we represent here in the United States, I urge the Subcommittee to continue its strong support for critical STEM and health education programs within NIH, IMLS, and ED as the Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill for fiscal year 2016 moves forward. Specifically, I ask you to:

—Provide $20 million for the SEPA program at NIH (fiscal year 2016 request is $18.5 million);

—Provide $38.6 million for the OMS at IMLS (fiscal year 2016 request is $33.6 million);

—Provide $1.15 billion for the 21st CCLC program (same as fiscal year 2016 request) and $202.7 million for the MSP program (same as fiscal year 2016 request) at ED; and

—Continue to thoroughly examine any proposals that would seek to consolidate and/or reorganize Federal STEM, health, and environmental education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Before providing more detail about ASTC and the science center and museum field, I want to first offer a brief snapshot of these Federal programs and why they are so vital to communities across the country.

NATIONAL INSTITUTES OF HEALTH

According to NIH, the goal of the Science Education Partnership Award program is to invest in educational activities that assist in workforce development to meet the Nation's biomedical, behavioral and clinical research needs. By supporting partnerships between researchers and teachers, schools, and institutions like science centers and museums, the SEPA program provides opportunities for students from underserved communities to consider careers in research, provides teachers with professional development in science- and health-related content and teaching skills, and improves community health literacy through exhibits and programming at science centers and museums.

In but one recent example, the Pacific Science Center in Seattle, Washington, received support for "Out of the Lab and Into the Spotlight," which was created to provide opportunities for the general public to increase their understanding of current health information and increase their awareness of cutting-edge research taking place in their own backyard. By engaging with research scientists in several venues, the public will be exposed to NIH funded research and health science careers. The President's fiscal year 2016 budget request includes $18.5 million—the same amount available for fiscal year 2015—for SEPA. Given the program's impact and importance, I ask the Committee to continue its strong support by providing $20 million for SEPA for fiscal year 2016.

INSTITUTE OF MUSEUM AND LIBRARY SERVICES

IMLS is driven by its mission to inspire libraries and museums to advance innovation, lifelong learning, and cultural and civic engagement by providing leadership through research, policy development, and grant making. The agency's Office of Museum Services offers and administers competitive grant programs that undergo a rigorous peer review process in an effort to identify well-designed projects. Just last fall, IMLS announced new grants for 211 museum projects through the Museums for America and National Leadership Grants for Museums programs. Recipients included the Mississippi Children's Museum (Jackson), which will use the funding towards the creation of a "Literacy Garden," an outdoor gallery that will promote early learning and development for underserved children in the first 7 years of life; the Clay Center for the Arts and Sciences of West Virginia (Charleston), which will enable it to create professional learning communities of teachers and after-school staff serving 7th grade students at seven partner schools using digital storytelling as a tool to explore energy-related topics impacting their communities; and the Oregon Museum of Science and Industry (Portland) for its "Museum Cafés: Integrating Food, Money, and Mission," program, which will develop replicable innovative educational experiences to teach food science, health, and the environment to the public.

The President's fiscal year 2016 budget request includes $33.6 million for the Office of Museum Services at the Institute of Museum and Library Services. ASTC asks the Subcommittee to provide $38.6 million—the congressionally authorized level of funding—for OMS programs for fiscal year 2016.

DEPARTMENT OF EDUCATION

For years, the 21st Century Community Learning Centers program has supported the creation of community learning centers that provide academic enrichment opportunities during non-school hours for children—particularly those students who attend high-poverty and low-performing schools. The 21st CCLC program helps students meet State and local student standards in core academic subjects, such as reading and math; offers students a broad array of enrichment activities that can complement their regular academic programs; and offers literacy and other educational services to the families of participating children. ASTC members across the country have utilized 21st CCLC funding to partner with local school districts in an effort to highlight STEM in afterschool. The agency's Math and Science Partnerships program was intended to increase the academic achievement of students in mathematics and science by enhancing the content knowledge and teaching skills of classroom teachers—an area in which science centers and museums excel. ASTC members, in partnership with local education agencies and institutions of higher education, have implemented MSP programs, and the Department's proposal to use new resources to strengthen the program and to develop and increase the use of evidence-based practices and provide students with opportunities for authentic STEM experiences in formal and informal settings is welcome.

The President's fiscal year 2016 budget request for the Department of Education includes $1.15 billion for the 21st Century Community Learning Centers program (the same amount available for the previous fiscal year) and $202.7 million for the Mathematics and Science Partnerships ($50 million more than the amount appropriated for fiscal year 2015). I encourage the Subcommittee to continue to support both programs by providing the requested funding levels.

STEM EDUCATION CONSOLIDATION AND REORGANIZATION

With regard to the Federal STEM education consolidation plan first released by the Administration for fiscal year 2014 and amended in each of the last two budget requests, I recognize the importance of creating efficiencies within the Federal Government whenever possible. Nevertheless, I continue to have serious concerns about a proposal that would eliminate effective programs that support informal STEM, health, and environmental learning. Integral Federal investments, including the SEPA program itself, have been slated for termination in previous fiscal years. While SEPA now enjoys the support of the Administration, programs at the National Aeronautics and Space Administration and the National Oceanic and Atmospheric Administration were not as fortunate and are, once again, on the chopping block. I sincerely appreciate the Subcommittee's thoughtful consideration of the harmful effect of the proposed terminations, and ask you to remain steadfast in your support of these programs.

ABOUT ASTC AND SCIENCE CENTERS

The Association of Science-Technology Centers is a global organization providing collective voice, professional support, and programming opportunities for science centers, museums, and related institutions, whose innovative approaches to science learning inspire people of all ages about the wonders and the meaning of science in their lives. Science centers are sites for informal learning, and are places to discover, explore, and test ideas about science, technology, engineering, mathematics, health, and the environment. They feature interactive exhibits, hands-on science experiences for children, professional development opportunities for teachers, and educational programs for adults. In science centers, visitors become adventurous explorers who together discover answers to the myriad questions of how the world works—and why. As Members of this Subcommittee know, it is imperative that we spark an interest in STEM fields at an early age—a key role for community-based science centers and museums, who often undertake this effort with the aforementioned support from NIH, IMLS, and ED, in addition to other Federal agencies.

ASTC works with science centers and museums to address critical societal issues, locally and globally, where understanding of and engagement with science are essential. As liaisons between the science community and the public, science centers are ideally positioned to heighten awareness of critical issues like agriculture, energy, the environment, infectious diseases, and space; increase understanding of—and exposure to—important and exciting new technologies; and promote meaningful exchange and debate between scientists and local communities.

ASTC now counts 636 members, including 489 operating or developing science centers and museums in 45 countries. Collectively, our institutions garner 95 million visits worldwide each year. Here in the United States alone, our guests—and

your constituents—pass through science center doors more than 73 million times to participate in intriguing educational science activities and explorations of scientific phenomena.

Our centers reach a wide audience, a significant portion of which are school groups. Here in the U.S., 94 percent of our members offer school field trips, and we estimate that more than 13 million children attend science centers and museums as part of those groups each year. Field trips, however, are truly just the beginning of what science centers and museums contribute to our country's educational infrastructure, as: 92 percent offer classes and demonstrations; 90 percent offer school outreach programs; 76 percent offer workshops or institutes for teachers; 74 percent offer programs for home-schoolers; 67 percent offer programs that target adult audiences; 65 percent offer curriculum materials; 50 percent offer after-school programs; 34 percent offer youth employment programs; and 22 percent offer citizen science projects.

CONCLUSION

With this in mind, and while I am fully aware of the significant budget challenges that face this Subcommittee, Congress, and the Nation, I hope you will continue to recognize the important educational offerings science centers and museums make available to students, families, and teachers, along with the essential Federal support they receive from NIH, IMLS, and ED.

Again, I respectfully request that you provide $20 million for the Science Education Partnership Awards program at the National Institutes of Health; $1.15 billion for the 21st Century Community Learning Centers program and $202.7 million for the Mathematics and Science Partnerships program at the Department of Education; and $38.6 million for the Office of Museum Services at the Institute of Museum and Library Services. In addition, please continue to closely examine any proposals that would seek to consolidate and/or reorganize Federal STEM education programs in an effort to ensure that stakeholder input has been sought and that proven, successful programs are maintained.

Thank you once again for your strong support for America's science centers and museums—and for the opportunity to present these views. My staff and I would be happy to respond to any questions or provide additional information as needed by the Subcommittee.

[This statement was submitted by Anthony F. (Bud) Rock, President and Chief Executive Officer, Association of Science-Technology Centers.]

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## PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY

On behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the ten Agricultural Centers for Disease and Injury Research, Education, and Prevention funded by the National Institute for Occupational Safety and Health (NIOSH), we respectfully request that the fiscal year 2016 Labor, Health and Human Services Appropriations bill include level funding of $27.5 million for the Education and Research Centers and $24 million for the Agriculture, Forestry and Fishing (AFF) Program within the NIOSH budget.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each year more than 3 million workers are seriously injured on the job, daily, 12 workers die from an injury suffered at work, and 145 workers die from work-related diseases. This burden costs industry and citizens an estimated $4.8 billion per week. This is an especially tragic situation because work-related fatalities, injuries and illnesses most often affect the most productive individuals in our society and are preventable with effective, professionally directed, health and safety programs.

NIOSH is the Federal agency responsible for supporting education, training, and research for the prevention of work-related injuries and illnesses in the United States. It does this in several ways. Some programs focus upon the most dangerous occupations in the US. Another NIOSH program aims to provide training to current health professionals while educating the next generation of professionals. These Education and Research Centers (ERCs) are regional and national resources for parties involved with occupational health and safety—industry, labor, government, academia, and the public. Collectively, the ERCs provide training and research re-

sources to every Public Health Region in the United States. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

—*Prevention Research*.—Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.

—*Professional Training*.—ERCs support 86 graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.

—*Research Training*.—Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.

—*Continuing Education*.—Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 18 ERCs, as well as through distance learning technologies.

—*Regional Outreach*.—Responding to specific requests from employers, healthcare professionals, and workers on issues related to occupational health and safety.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates increase at age 45, with rates for workers 65 years and older nearly three times greater than younger workers. In addition to changing demographics, the rapid development of new technologies (e.g., nanotechnology) poses many unanswered questions with regard to workplace health and safety that require urgent attention. Newly emerging risks, such as Ebola and other infectious disease outbreaks, require swift responses to the need for worker protection.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses. For example, NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers.

In response to risks posed by potential Ebola exposure, ERCs have delivered educational programs and provided expertise in developing protocols and policies to prevent worker exposure. In one case, a single webinar developed for this purpose reached more than 320 company, academic, and government organizations. Additionally, NIOSH is the Federal agency that is charged with certifying and approving the respirators that are required to protect U.S. workers.

We need manpower to address these challenges and it is the NIOSH ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life.

NIOSH also focuses upon the nation's most dangerous work. People who work in agriculture, forestry and fishing experience occupational fatality rates that are 6 times to more than 30 times higher than the average for American workers. The Agricultural Safety and Health Centers program was established by Congress in 1990 (Public Law 101–517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes nine regional Centers for Agricultural Disease and Injury Research, Education, and Prevention and one national center to address children's farm safety and health. The AFF program is the only substantive Federal effort to meet the obligation to ensure safe working conditions for workers in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78 percent employ fewer than 10 workers, and most rely on family members and/or immigrants, part-time, contract and seasonal labor. Many of these agricultural workers

are excluded from labor protections, including OSHA oversight, on the vast majority of American farms.

In 2012 the AFF sector had a work-related fatality rate of 22 per 100,000 workers, the highest of any sector in the nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on the most dangerous farms—those with fewer than 11 full-time employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the NIOSH AFF program is not replicated by any other agency:

—State and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the NIOSH AFF program.

—While committed to the well-being of farmers, the USDA has little expertise in the medical or public health sciences. USDA no longer funds, as it did historically, land grant university-based farm safety specialists.

—Staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts in order to learn about the cutting-edge research and new directions in this area.

*NIOSH Agricultural Center activities include:*

—AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 140 close calls with no injuries among farmers who had installed ROPS. 99 percent of program participants said they would recommend the program to other farmers. Similar programs are now offered to prevent serious injuries due to entanglement in other farm machinery.

—Working in partnership with producers and farm owners, the NIOSH AFF Centers have developed evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.

—Commercial Fishing had a reported annual fatality rate 58 times higher than the rate for all U.S. workers in 2009. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. A NIOSH AFF-funded team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the US Coast Guard's revision of regulations requiring commercial fishing vessel captains complete navigation training.

—The Centers have partnered with producers, employers, the Federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and healthcare providers about the best way to treat and prevent agricultural injury and illness.

—New tools and work processes have been introduced and widely adopted by agricultural producers because they reduce musculoskeletal injury and pain and at the same time improve productivity.

—In 2010, the logging industry had a reported fatality rate of 91.9 deaths per 100,000 workers (preliminary data), a rate more than 25 times higher than that of all US workers. NIOSH AFF Centers, including the Southeast and the Northwest, are uniquely positioned to ensure the safety of our nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and wellbeing of others in our communities.

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## PREPARED STATEMENT OF THE ASSOCIATION OF ZOOS AND AQUARIUMS

### INSTITUTE OF MUSEUM AND LIBRARY SERVICES

Thank you Chairman Blunt and Ranking Member Murray for allowing me to submit testimony on behalf of the Nation's 215 AZA-accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of $38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the fiscal year 2016 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501c(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. Accredited zoos and aquar-

iums annually see more than 180 million visitors, collectively generate more than $17 billion in annual economic activity, and support more than 165,000 jobs across the country. Over the last 5 years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with $160,000,000 annually in more than 100 countries. In the last 10 years, accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the "Museum and Library Services Act of 2003" (Public Law 108–81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and scientific heritages. Grants are awarded in several areas including educational programming, professional development, and collections management, among others.

As valued members of local communities, AZA-accredited zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services ensure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Despite this funding shortfall, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever. AZA-accredited zoos and aquariums are essential partners at the Federal, State, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the Nation's economic and cultural vitality. Therefore, I strongly encourage you to include $38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the fiscal year 2016 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you.

[This statement was submitted by Jim Maddy, President and CEO, Association of Zoos and Aquariums.]

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PREPARED STATEMENT OF THE ASSOCIATION FOR CAREER AND TECHNICAL EDUCATION

Chairman Blunt, Ranking Member Murray and members of the subcommittee, on behalf of the Association for Career and Technical Education (ACTE), the Nation's largest not-for-profit association committed to the advancement of education that prepares youth and adults for successful careers, I would like to urge you to help support career and technical education (CTE) through a strong Federal investment in the Carl D. Perkins Career and Technical Education Act (Perkins) for fiscal year 2016. The passage of the Bipartisan Budget Act and subsequent Consolidated Appropriations Act of 2014 helped to alleviate some of the harmful sequestration cuts that have impacted important career education and workforce training programs, but more needs to be done to support our high schools, technical centers, community colleges and millions of CTE students nationwide.

To ensure that students are equipped with the academic, technical and employability skills they need for success in the jobs that are available today, and the careers of tomorrow, I respectfully request that the subcommittee restore the Perkins Basic State Grant program (Title I) to the pre-sequestration level of $1.123 billion in the fiscal year 2016 Labor, Health and Human Services, and Education appropriations bill.

Perkins is the principal source of Federal support for CTE programs at secondary and postsecondary institutions across the county. This Federal investment is crucial to ensuring that students have the academic, technical and employability skills that are needed for careers in expanding fields like engineering, information technology, advanced manufacturing and healthcare. In a rapidly changing job market, CTE provides students with transferable skills that ensure they are college-and career-ready, while offering retraining opportunities to many adult or dislocated workers.

Perkins is the foundational support for CTE program improvement that is essential to moving our economy forward. However, funding has not kept pace with the demand for high-quality programs. In fiscal year 2015, Congress appropriated over $140 million less in Perkins grant funding to States than it did in fiscal year 2010.

From fiscal year 2007 through fiscal year 2014, total Perkins grant funding to States declined by 13 percent (a 23 percent decline when adjusted for inflation). A recent survey found that 9 out of 10 career and technical educators report that they rely on Perkins to support their CTE program, but more than half of CTE educators say their program budget has decreased in recent years. Perkins funding is an essential component in allowing education providers to build the capacity necessary to serve more than 12 million secondary, postsecondary and adult students nationwide.

The erosion of Perkins funds comes at a time when CTE programs are experiencing new attention and growth. States are using Perkins funding to achieve positive results—meeting or exceeding nearly every accountability target for student performance in areas such as attainment of academic and technical skills, and transition to further education or employment. The average high school graduation rate for students concentrating in CTE programs is 93 percent, compared to a national adjusted cohort graduation rate of 80 percent. This data is borne out on the ground where students involved in CTE programs are more engaged in their education, perform better academically, gain critical employability skills and earn industry-recognized credentials. Perkins provides a strong return on our Federal investment by fostering an educated and highly skilled workforce that delivers direct benefits to American employers, further strengthening the economy through productivity and innovation.

The Obama Administration's fiscal year 2016 budget request includes the addition of $200 million for a CTE Innovation Fund within the Basic State Grant, which would support the proposed American Technical Training Fund by providing competitive grants to support the development and operation of innovative, evidence-based job training programs in high-demand fields. The request for a $2 million increase for CTE National Programs would provide technical assistance and evaluation support for projects under the American Technical Training Fund proposal. However, the Administration's budget, once again, fails to provide any additional funding for the formula Perkins Basic State Grant program. It is the position of ACTE that limited resources for education and job training are better directed to proven, formula-driven programs, and we remain committed to expanding equitable access to high-quality CTE. Congress must fulfill its commitment to America's students, employers and educators by increasing its investment in CTE through Perkins.

A broad coalition of Senators has submitted a letter to this subcommittee expressing support for funding CTE. This letter echoes ACTE's request that Perkins Basic State Grant funding be restored to at least $1.123 billion in fiscal year 2016 Labor, Health and Human Services, and Education appropriations bill. ACTE strongly supports this effort and we reaffirm the message that CTE works to ensure that students have the academic and technical skills necessary for true college and career readiness—and that Perkins funding is a key component to student success.

Thank you for your continued leadership and for your thoughtful consideration during the appropriations process. We look forward to working with the subcommittee in a bipartisan fashion to make building our investment in CTE a top priority.

[This statement was submitted by Stephen DeWitt, Deputy Executive Director, Association for Career and Technical Education.]

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PREPARED STATEMENT OF THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY AND THE SOCIETY FOR HEALTHCARE EPIDEMIOLOGY OF AMERICA

The Association for Professionals in Infection Control and Epidemiology (APIC) and the Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on Federal efforts to detect dangerous infectious diseases, protect the American public from preventable healthcare-associated infections (HAIs) and address the rapidly growing threat of antibiotic resistance (AR). We ask that you support the following programs: First, under the Centers for Disease Control and Prevention (CDC) National Center for Emerging and Zoonotic Infectious Diseases: $501 million for Core Infectious Diseases including $264 million for the new Antibiotic Resistance Solutions initiative, $32 million for the National Healthcare Safety Network (NHSN), and $30 million for the Advanced Molecular Detection (AMD) Initiative. Additionally, we request $34 million for HAI research activity conducted by the Agency for Healthcare Research and Quality (AHRQ) and $4.6 billion for the National Institutes of Health/National Institute of Allergy and Infectious Diseases (NIAID).

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 25 hospitalized patients has an HAI, totaling approximately 722,000 infections and 75,000 deaths in 2011. Further, a growing number of infections are resistant to antibiotics causing an estimated two million illnesses and approximately 23,000 deaths annually. Antibiotics, created to save lives, are now contributing to patient deaths through misuse and overprescribing that promotes the emergence of highly resistant bacteria and leads to deadly adverse events. AR is one of the most critical public health and patient safety threats facing our Nation. The actions we take now will determine if we will return to an era where even a small cut could prove fatal.

*Centers for Disease Control and Prevention (CDC)*

We urge you to support the CDC Coalition's request for $7.8 billion in fiscal year 2016 for the CDC's "core programs." We are pleased that the President's fiscal year 2016 budget proposal would increase the CDC's budget authority by $141 million when compared with fiscal year 2015. We urge Congress to prioritize funding for all the activities and programs supported by CDC that are essential to protect the health of the American people and reduce healthcare costs.

We urge you to support $32 million for CDC's National Healthcare Safety Network (NHSN) and Prevention Epicenters Program. This request represents a $14 million increase over the fiscal year 2015 enacted level for the NHSN to support HAI prevention and reporting efforts to more than 17,000 healthcare facilities across the spectrum of care. This will enable CDC to conduct applied research on interventions for infection prevention and continue to provide data for national HAI elimination goals and targeted HAI prevention initiatives. This funding level will also allow for the extension and implementation of the NHSN Antimicrobial Use and Resistance Module to track antibiotic use in healthcare settings and provide real time data about antibiotic use and trends.

NHSN data and the Prevention Epicenters Program, a collaboration between CDC and academic medical centers that conduct innovative infection prevention and control research, serve as the foundation for the development of pioneering, evidence-based HAI prevention strategies. Consistent, scientifically sound data reported at the State and Federal level are necessary to ensure that accurate data are available to evaluate progress related to the National Action Plan to Prevent HAIs as well as to support transparency to the public, allowing for equitable comparisons between facilities.

Since 2008, the cumulative impact of CDC infection prevention resources, guidelines and programs has contributed to significant reductions of HAIs in healthcare settings, including a 44 percent reduction in central line-associated bloodstream infections, a 31 percent reduction in healthcare-associated invasive MRSA infections, and a 20 percent reduction in surgical site infections.

Despite these improvements to patient safety, the significant increase in facility users, and the importance of the system's contributions to reducing HAIs and combating AR, funding for NHSN and the Prevention Epicenters has been flat since fiscal year 2010.

APIC and SHEA request $501 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antibiotic Resistance, and Emerging Infections Program. The Emerging Infections Program (EIP) helps States, localities and territories in detecting and protecting the public from known infectious disease threats in their communities while maintaining our Nation's capacity to identify new threats as they emerge. Increased funding for Core Infectious Diseases will expand the number of EIP sites from 10 to 20. Beyond surveillance, prevention, and control of emerging infectious diseases, EIP provides sufficient flexibility for emergency response and addresses new problems as they arise; develops and evaluates public health interventions, and ultimately transfers what is learned to public health agencies and healthcare providers.

We support the $264 million request in the President's budget for the Antibiotic Resistance Solutions Initiative. This comprehensive initiative will establish State AR prevention programs in all 50 States and 10 large cities to protect patients and communities through the rapid identification of outbreaks. The initiative will improve response time to outbreaks of infectious disease threats by creating a network of AR regional labs that use cutting edge methods to track and mitigate disease spread. Pharmaceutical companies and researchers will be able to test their antibiotics against isolates maintained in an AR isolate bank established by the AR Solutions Initiative. The isolate bank will be able to provide a complete collection of current resistant threats and keep pace with mutations.

The AR Solutions Initiative will incorporate NHSN antibiotic use information to improve antibiotic prescribing practices, which contributes to the rise of resistant

pathogens. Moreover, we strongly support CDC's focus on the implementation of antibiotic stewardship programs in all healthcare settings. The initiative anticipates outcomes resulting in a reduction of carbapenem-resistant Enterobacteriaceae (CRE) and Clostridium difficile, two pathogen groups labeled as urgent threats by CDC in 2013, by 60 percent and 50 percent respectively. It is critical that Congress prioritize this rapidly growing threat to public health and patient safety in our Nation and around the world.

We urge your continued support of the President's $30 million request for the Advanced Molecular Detection (AMD) Initiative in bioinformatics and genomics, which allows CDC to more quickly determine where emerging diseases come from, whether microbes are resistant, and how microbes are moving through a population. This initiative is critical because it strengthens CDC's epidemiologic and laboratory expertise to effectively guide public health action.

*Agency for Healthcare Research and Quality (AHRQ)*

We request your support of the proposed investment of $34 million for AHRQ's HAI research activity. These grants ($17.8 million) and contracts ($16.2 million) will advance our knowledge about effective approaches to reducing HAIs while promoting the implementation of proven methods for preventing HAIs. In addition, contracts funded by the HAI budget will accelerate the nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP), an evidence-based safety framework for improvement in culture, teamwork, communication, and patient-care practices.

To date, widespread adoption of the CUSP approach in over 1,000 intensive care units has reduced the incidence of central line-associated bloodstream infections by 41 percent within those units, saving 500 lives and $36 million in excess costs. In spite of notable progress, there remains work to be done toward the goal of HAI elimination.

*National Institutes of Health (NIH)/National Institute of Allergy and Infectious Diseases (NIAID)*

APIC and SHEA support the $4.6 billion requested by the Administration for fiscal year 2016 for the National Institute of Allergy and Infectious Diseases (NIAID) within NIH. The emergence of diseases such as chickungunya, enterovirus-D68, and the re-emergence of Ebola illustrates the need for critical research that can lead to the discovery of new therapies, new diagnostic approaches, and new preventative strategies.

NIAID's long-standing basic and translational research on Ebola and other hemorrhagic fever viruses has yielded some of today's most promising therapeutic candidates. Additionally, NIAID is addressing the growing problem of antimicrobial resistance (AR) through basic research to understand how microbes acquire and transmit resistance genes and clinical efforts including studies to optimize the use of currently licensed drugs, combination therapies, and alternative, non-antibiotic treatment strategies. Severe economic disincentives have caused a mass exodus of private companies from the antibiotics market, making federally funded research in this area more critical than ever. We are pleased that the fiscal year 2016 budget request would provide adequate investment in emerging infectious diseases research.

We thank you for the opportunity to submit testimony and greatly appreciate your leadership in the effort to eliminate preventable HAIs, combat antibiotic resistance and improve patient safety and outcomes.

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PREPARED STATEMENT OF KOMALA BALAKRISHNAN

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-

licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF JILL R. BARKER

I am writing as the parent of two adult sons with profound physical and mental disabilities.

I urge the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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PREPARED STATEMENT OF MARY J. BECK

I am submitting this because I want you to understand that your constituency wants and needs your help in protecting some of the most vulnerable people in this country—people with intellectual disabilities. These people need the best care we can give them. Often, institutionalized care is the best alternative for our retarded citizens because it provides better care and ensures better accountability and more efficient use of resources than other alternatives.

I urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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PREPARED STATEMENT OF CANDICE BELL

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Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

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> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

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PREPARED STATEMENT OF DIANE BOOHER AND MARK BOOHER, PH.D.

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PREPARED STATEMENT OF KATHLEEN BORNIGER

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My brother died 1 year ago at the age of 65. He had been a resident at KNI since 1960 and had been in 2 other stated institutions prior to that, since the age of 6. I am a registered Nurse and seeing the care that Paul received gave great testament to the commitment and skill of his caregivers at KNI in Topeka. He would never have had the long life he had if he had been in a community based home. He lived with his community of caregivers and friends. It would be a tragedy of monumental proportion to place these precious, medically fragile souls in a small community-based home that lacked the ability to give 24 hour medical care and observation. Not only a tragedy but inhumane. Please do not let this happen.

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PREPARED STATEMENT OF SALLY BOYD

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PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to submit this written testimony with regard to the fiscal year 2016 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our network of State affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 2.5 million people sustain brain injuries from falls, car crashes, assaults, and contact sports. Males are more likely than females to sustain brain injuries. Children, teens, and seniors are at greatest risk. Currently, more than 5 million Americans live with a TBI-related disability.

Increasing numbers of service members returning from the conflicts in Iraq and Afghanistan with TBI and their families are seeking resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into their communities.

*Administration for Community Living*.—BIAA respectfully urges you to relocate the Federal Traumatic Brain Injury (TBI) State Grant Program and Protection and Advocacy Systems Grant Program from the Maternal and Child Health Program of the Health Resources and Services Administration to the Administration for Community Living (ACL) in fiscal year 2016 appropriations. The TBI Act Reauthorization, S. 2539, which was signed by President Obama on November 26, 2014, authorized appropriations for these critical TBI grant programs through 2019 and gave authority to the Secretary of the U.S. Department of Health and Human Services, with discretion on where to locate the TBI grant programs.

The TBI State Grant and Protection and Advocacy Grant Programs are designed to increase access to treatment and community-based services for individuals who are injured, protect the rights of those individuals, and to improve service system coordination within States and territories. Because people of all ages sustain TBIs and because the injury can negatively impact health and function across the lifespan, we believe it is in the best interests of individuals and families to move the TBI State Grant and Protection and Advocacy Systems Grant Programs to ACL.

As you know, several disability programs formerly housed in the U.S. Department of Education will move to ACL by July 2015 as a result of the Workforce Innovation and Opportunity Act of 2014. These programs include: the TBI Model Systems, the Research and Training Center on TBI Community Reintegration, the Independent Living Center program, and the Assistive Technology programs. Locating the TBI State Grant and Protection and Advocacy Grant Programs would only further enhance the existing collaboration and coordination among them. In addition, we believe placing the TBI State Grant and P&A Grant programs within ACL would help to:

—integrate TBI into the HHS community long-term services initiatives, including the single point of entry through Aging and Disability Resource Centers;
—promote collaboration with Administration on Aging (AoA) on falls-related TBIs among older adults and the lifespan respite care program;
—include TBI in the veterans initiatives between HHS and Department of Veterans Affairs to support Home and Community-Based Services (HCBS) for veterans and returning service members; and
—coordinate/enhance services for individuals with TBI who may also be eligible for services provided through State Intellectual/Developmental Disabilities systems and/or could benefit from Administration on Intellectual/Developmental Disabilities (AIDD) initiatives to improve education, employment outcomes, voting and self-advocacy.

*CDC—National Injury Center*.—$10 million (+$5 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness.

The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 2.5 million TBIs occur each year and 5.3 million Americans live with a life-long disability as a result of TBI. The TBI Act as amended in 2014 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds States for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays

a leading role in helping standardize evidence based guidelines for the management of TBI and $1 million of this request would go to fund CDC's work in this area.

In the President's fiscal year 2016 budget, a $5 million increase was included for the Centers for Disease Control and Prevention (CDC) Injury Prevention and Control Center to develop sports concussion surveillance to accurately determine the incidence of sports related concussions among youth ages 5–21.

*NIDILRR TBI Model Systems of Care*.—Funding for the TBI Model Systems in the Administration on Community Living is urgently needed to ensure that the Nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this program would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a "proving ground" for future researchers.

In order to make this program more comprehensive, Congress should increase funding in fiscal year 2016 for NIDILRR's TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive "line-item" status within the broader NIDILRR budget. Specifically, the Congressional Brain Injury Task Force requests increased funding by $13 million over the next 6 years to support the TBI Model Systems program:

—Increase funding for the National Data and Statistical Center by $100,000 annually to allow all participants to be followed; when re-competed, increase from $625,000 to $1 million annually;

—Increase funding for centers by $150,000 annually from the current average of $437,500;

—Increase the number of competitively funded centers from 16 to 18; and

—Increase the number of multicenter TBI Model Systems Collaborative Research projects from one to five, each with an annual budget of $1.5 million (current funding is $600,000 each).

We ask that you consider favorably these requests for the Administration for Community Living, the CDC, and the NIDILRR's TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist States in coordinating services, protect the rights of persons with TBI, and bolster vital research.

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PREPARED STATEMENT OF HELEN R. BURNS

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Sincerely,

Harris T. Capps
Parent of a son with significant Intellectual and Developmental Disabilities

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## PREPARED STATEMENT OF DONNA M. CARMICAL

Members of the subcommittee thank you for taking the time to consider public testimony regarding the National Institute of Health (NIH) 2016 budget request.

My name is Donna Carmical, I live in Fredericksburg, VA. On August 26, 2009, my son and his wife became the proud parents of beautiful twin boys. Six months later, on March 9, 2010 our lives were forever changed when the oldest of the twins, Declan Carmical, was diagnosed with a rare form of pediatric cancer called AT/RT (atypical teratoid/rhabdoid tumor). Hearing that your child/grandchild has cancer is devastating but hearing Doctor's say that there are no treatments, no cures, no hope is incomprehensible. Doctor's advised that we should take our beautiful Declan home, make him comfortable, and that he would be dead in a few weeks. There are no words to describe the shock of this moment and the days and weeks following. After a brave and courageous battle that included several brain surgeries, removal of his kidney, six weeks of proton radiation and many rounds of poisonous chemo, our sweet Declan lost his battle 8 days before his first birthday. If you have never watched a child die you are fortunate, I pray you never experience this horror, the torturous memories will be with me forever.

This testimony is not about Declan, but because of him and what we learned about the insidious world of pediatric cancer. What we learned about the treatments kids endure and the statistic no one talks about, that only about 20 percent of children survive pediatric cancer treatments without significant impact. Each decade we lose approximately 27,000 children to cancer in the U.S., decade after decade, and there is no reason to believe that this will change without significant investment of Federal research funding. Childhood cancer research is an area sadly neglected as budget decisions are made by the National Institute of Health (NIH). NIH continues to lamely defend their lack of investment by saying that research in adult cancers brings benefits to childhood cancers, there are insufficient resources to increase funding levels for childhood cancer research and a myriad of other excuses from the brilliant researchers that make agency budget decisions. It is hard to believe that NIH has a true reality of the torturous treatments kids endure, the side effects, the burden of this disease and that the thousands of kids that die each year are a negligible cost to society.

I myself lacked a reality about childhood cancer and its impacts. I gave to St. Jude's for over 30 years, with the belief that St. Jude's, other organizations and our Government were doing everything possible to bring the best possible treatments to kids with cancer. Like so many Americans, I was blissfully ignorant and I was dead wrong. Our children are paying the price for this ignorance and apathy. They have no voice, no lobby, no money, and although kids represent 26 percent of the U.S. population, they can't vote and it seems their needs fall to the bottom of the budget pile, especially where funding decisions are concerned. Our children deserve to be

a priority as Federal research dollars, taxpayer dollars, are distributed and decisions are made about how the billions of research dollars are allocated.

Childhood cancer is the #1 disease related killer of children in the U.S. The National Cancer Institute (NCI) says that childhood cancer is rare. They indicate that annually approximately 16,000 kids are diagnosed with pediatric cancer and that childhood cancer is on the rise. The fact that 1 in 285 children will be diagnosed with cancer is not acceptable statistic, especially in terms of deciding that this is an area that doesn't need real investment of research funding. Approximately 1 in 5 children diagnosed with cancer are terminal on diagnosis and 2 out of 3 children suffer life altering impacts as a result of treatments. In the U.S. alone, nearly 2,000 children die each year as a result of pediatric cancer.

According to NCI there are currently 380,000 survivors of childhood cancer in the U.S., they project this number will increase over time. Adult chemotherapy is proven to help cure cancer with many side effects. Even though these treatments are approved for children, many treatments are the same as those approved for adult cancers but provided at a lower dose for kids. As StandUp2Cancer reports on their webpage—"While childhood cancer research often yields discoveries that benefit adults with cancer, the opposite is less common. Children are not simply smaller versions of adults, and childhood cancers are very different from the cancers that strike adults."

Many children suffer life altering impacts of treatment. If they pass the 5 year survival rate—they are statistically considered cured; yet, many children suffer long term impacts, secondary cancers, heart problems, infertility, learning disabilities, stunted growth, hearing problems and more. The increase in survivors, burden of disease, growing number of survivors, as well as number of deaths each year are a great cost to society in so many ways. An investment in childhood cancer research could deliver big results—pediatric protocols that might result in cures, less invasive treatments, reduction in life altering impacts, etc. In addition, as some in the medical community have indicated, there is a belief that childhood cancer research has the potential to bring knowledge about adult cancer research.

Childhood cancer is not one disease, there are 16 major types of cancer and over 100 subtypes. Many of these childhood cancers, like DIPG, AT/RT, receive little to no funding for research. NCI indicates that survival rates for a few childhood cancers like acute lymphoblastic leukemia (ALL) have improved dramatically over the past decades, ironically this is due to the investment in research. NIH makes little mention of statistics regarding the deadly childhood cancers where for decades there has been little to no research. There are many other statistics related to childhood cancer; yet, despite compelling statistics, childhood cancer is vastly and consistently underfunded and virtually ignored in terms of Federal research funding.

Ironically many pediatric cancer organizations raising funds for childhood cancer research have been started by families who have lost a child to pediatric cancer. These families are trying to fund research because their eyes have been opened to the lack of childhood cancer research funding and the life changing consequences to society. Families desperately want other kids to have cures denied to their own children. The thing is that even the largest organizations are raising tens of millions of dollars, compared to Federal dollars, the little money that is raised by private organizations means that potential cures are probably decades into the future. Childhood cancer research needs a huge investment, an investment of billions that can only be accomplished by putting our tax dollars to work for kids.

Following the AIDS pandemonium in the 1980s, Congress provided billions for AIDs research. Dr. Collins has testified that success with HIV/AIDS research "may enable us to envision the first AIDS free generation since the virus emerged more than 30 years ago." This success would not have been possible without the substantial investment of dollars in AIDS research, an investment of tens of billions of taxpayer dollars over the last few decades. Since the turn of the century, approximately 30,000 children have lost their battle with childhood cancer. Today 10 percent of NIH funding, approximately $3 billion each year, is devoted to AIDS research, that's almost $100 billionillion since the 1980s. This is not to say that AIDS funding is wrong, no doubt there has been tremendous accomplishment in this area, but to illustrate the impact of significant investment. NIH has asked for additional investment for AIDS in 2016, while continuing to ignore childhood cancer research. I personally would like to see transparency, a cost-benefit analysis of this continued amount of funding, what kind of results are expected for this significant investment year after year.

Currently the NCI offers that it provides around $200 million of its $5 billion budget to childhood cancer research. Childhood cancer research is not a line item in the NIH/NCI budget and rarely mentioned. The $200 million level identified by NCI as benefitting childhood cancer research, is not actually dedicated to childhood

cancer research projects. As far as I can determine by looking at the public information, the $200 million is made up of percentages of grant projects that estimate impact on childhood cancer. For example, an Alzheimer grant for $100 thousand might say that 5 percent of the projected benefit might be for childhood cancer, so NCI indicates $5,000 goes towards childhood cancer research. Even though Congress has suggested that NCI increase this funding level over the past few years, NCI has chosen to mostly ignore this "suggestion." In his testimony, Dr. Varmus has offered that they could do more only if Congress provides more funding. It is unclear to me how decision-makers at NIH/NCI can ignore the fact that only Congress has the authority to decide what programs are funded and the funding levels. It would be interesting to see how much of the NIH funding over the past decade has been dedicated to childhood cancer research, their goals, objectives when it comes to childhood cancer research and results achieved.

As reported by The Atlantic in a January 2013 article, "there is not enough funding for childhood cancer, specifically. The National Cancer Institute, a government organization, provides funding for researchers, but only 10 percent of them can move forward with their findings due to budget cuts. Most of the financial support researchers receive is from philanthropists. In the meantime, research that could benefit children on an individual level stays in the lab, and doctors prescribe the same regimens that can be successful, but can also hurt the patient in several ways. Researchers say they are working hard to discover new theories and treatments, but they feel they are being held back." The article goes on to quote, Dr. William Carroll, researcher and director of the cancer institute at New York University saying, "Ninety-six percent of grants (sic childhood cancer) don't get funded . . . There's no doubt there's less funding available, and it's driving people out of the field."

NIH has requested a billion dollar increase for 2016. Their documents indicate that key investments are for Alzheimer's research, Precision Medicine Initiative, Antimicrobial Resistance, AIDS, the Brain initiative, etc. Changes from the 2015 enacted budget to the 2016 President's Budget request indicates this billion dollar investment provides on average a 3 percent increase for every institute/center across NIH. I think the American public would agree childhood cancer research deserves to be a priority in the budget. I would love to see Congress provide that $1 billion to NIH but legislate that these dollars would go to childhood cancer research. Even a negligible trim to every line item in the NIH budget with that amount going to childhood cancer research, could make significant funds available for childhood cancer research. This is not really about more money, this is about making childhood cancer research a priority.

With all due respect to the wonderful work that NIH does, the Director of NIH has spoken about the budget stressor put on scientific opportunities, the throwing away of "innovative, talented research proposals" and the "serious risk of losing the most important resource we have, which is this brain trust, the talent and creative energies of this generation of scientists." I would counter that many childhood cancer research proposals are thrown away due to the lack of Federal research funding and that we have no idea about the potential brain trust of the thousands of children lost and maimed each year because of the decision that childhood cancer research is not a priority. No parent should have to hear the words, there has been no research, there are no cures, treatments or protocols, take your child home, make him comfortable and in a few weeks your child will be dead. This happens every day. The diagnosis for AT/RT and other deadly pediatric cancers has not changed much in the past 30 years because this childhood cancer is not worthy of research. Our children deserve better.

I'm nobody special, just a mother and grandmother. I understand that I don't know much compared to the wonderful scientists at NIH. I understand that the budget process is hard work for the committees, and resources are limited. But my experience over the past 5 years compels me to fight for kids. I can't do anything to change what happened to our sweet Declan, but I believe research will result in more funding for those deadly childhood cancers. Much like the prognosis has changed for ALL over the past decades, I believe research could provide pediatric treatments and protocols that will offer cures to children like Declan in the future. We can't keep condemning these kids to death year after year and do nothing because of money.

I hope you will agree that at least some of what I'm saying has merit and consider there is a huge need to fund childhood cancer research. Making childhood cancer research a priority in the Federal budget process would be a tremendous legacy for Congress and has great potential to give children the cures and hope they deserve.

Thank you for the opportunity to offer my thoughts.

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation's prevention programs. We represent millions of public health workers, clinicians, researchers, educators and citizens served by CDC programs.

We believe Congress should support CDC as an agency, not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, public health emergencies, new and reemerging infectious diseases and other unmet public health needs, we urge a funding level of $7.8 billion for CDC's programs in the Senate's fiscal year 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We are pleased President Obama's fiscal year 2016 budget request would increase CDC's program level by $141 million over fiscal year 2015. The president's budget provides additional funding for several important new and existing programs and initiatives such as combating antibiotic resistance, preventing prescription drug overdose, viral hepatitis, the National Healthcare Safety Network, domestic HIV/AIDS, global disease prevention, violence prevention and surveillance, climate change and other important programs. Unfortunately, the president's budget also cuts or completely eliminates other important programs such as the REACH program, the Preventive Health and Health Services Block Grant, cancer prevention and control, immunizations, environmental health tracking and others. These cuts will reduce the ability of CDC and its State and local grantees to investigate and respond to public health emergencies, ensure adequate immunization rates and track environmental hazards. We are pleased that the president's budget would fully allocate the Prevention and Public Health Fund for public health and prevention activities. In fiscal years 2014 and 2015, Congress fully allocated the fund in both omnibus spending bills and we urge you to once again ensure the fund is fully allocated for public health programs to reduce chronic diseases and help restrain the rate of growth in private and public healthcare costs.

CDC is a key source of funding and technical assistance for State and local programs that aim to improve the health of communities. CDC funding provides the foundation for State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC serves as the command center for the Nation's public health defense system against emerging and reemerging infectious diseases. From aiding in the prevention and control of Ebola in West Africa and detecting and responding to cases in the U.S., to monitoring and investigating the ongoing multi-State measles outbreak to pandemic flu preparedness, CDC is the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. States, communities and the international community rely on CDC for accurate information and direction in a crisis or outbreak.

CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC's emergency preparedness and response activities.

The development of antimicrobial resistance is occurring at an alarming rate and far outpacing the struggling research and development of new antibiotics. We urge you to support the president's request for the CDC Antibiotic Resistance Initiative which would build prevention programs in all 50 States and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria.

Heart disease is the Nation's No. 1 killer. In 2013, over 611,000 people in the U.S. died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More males than females died of heart disease in 2013, while more females than males died of stroke that year. Stroke is the fifth leading cause of death and is a leading cause of disability. In 2013, nearly 129,000 people died of stroke, accounting for about one of every 20 deaths. CDC's Heart Disease and Stroke Prevention Program, WISEWOMAN, and Million Hearts work to improve cardiovascular health.

Cancer is the second most common cause of death in the U.S. More than1.6 million new cancer cases and 589,430 deaths from cancer are expected in 2015. In 2011 the direct medical costs of cancer in the U.S. were $88.7 billion. CDC's National Breast and Cervical Cancer Early Detection Program helps millions of low-income,

uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to all 50 States to develop comprehensive cancer control plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each State's particular needs. Unfortunately, the president's budget would cut or eliminate several important cancer prevention and control programs and we urge you to restore this critical funding.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's Office of Smoking and Health funds important programs and education campaigns such as the Tips From Former Smokers campaign that help to prevent tobacco addiction and provide resources to encourage smokers to quit. We must continue to support these vital programs to reduce the enormous health and economic costs of tobacco use in the U.S.

Of the 29.1 million Americans who have diabetes, more than 8 million cases are undiagnosed. In 2012, about 1.7 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, nontraumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were $245 billion in 2012. The Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Obesity prevalence in the U.S. remains high. While the obesity rates among children between the ages of 2–5 have significantly decreased over the past decade, more than one-third of adults are obese and 17 percent of children are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise and develop other habits of healthy nutrition and physical activity.

Arthritis is the most common cause of disability in the U.S., striking more than 52 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis and we urge you to support adequate funding for the program.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, including 14 percent who are undiagnosed. The number of people living with HIV is increasing as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed an estimated 658,507 in the U.S. and is devastating populations around the globe.

Sexually transmitted diseases continue to be a significant public health problem in the U.S. Nearly 20 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system almost $16 billion annually. An adequate investment in CDC's STD prevention programs could save millions in annual healthcare costs in the future.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey are an essential part of the Nation's statistical and public health infrastructure and must be adequately funded.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, $10.20 is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths are prevented each year through timely immunization. We urge you to restore the president's proposed cuts to the Section 317 immunization program.

Injuries are the leading causes of death for people ages 1–44. Unintentional injuries and violence, such as older adult falls, motor vehicle traffic accidents, prescription drug overdose, child maltreatment and sexual violence account for approximately 31 million emergency department visits each year. Annually, injury and vio-

lence cost the U.S. approximately $406 billion in direct and indirect medical costs. The National Center for Injury Prevention and Control works to prevent injuries and minimize their consequences by researching the problem, identifying the risk and protective factors, developing and testing interventions and ensuring widespread adoption of proven prevention strategies. We urge you to support the president's request for increased funding for initiatives that work to reduce injury and violence-related injury and death such as the National Violent Death Reporting System and gun violence prevention research.

Prescription drug overdose is an ongoing problem in the U.S. killing more than 145,000 over the past decade. We urge you to support the president's request for drug overdose prevention funding that would allow all 50 States to participate in CDC's PDO Prevention for States program to undertake efforts to prevent and reduce prescription drug and heroin overdose deaths.

Birth defects affect one in 33 babies and are a leading cause of infant death in the U.S. Children with birth defects who survive often experience lifelong physical and mental disabilities. Over 500,000 children are diagnosed with a developmental disability and it is estimated that up to 57 million people in the U.S. currently live with a disability. The National Center on Birth Defects and Developmental Disabilities conducts important programs to prevent birth defects and developmental disabilities and promote the health of people living with disabilities and blood disorders and we urge you to fund the center at the president's requested level.

The National Center for Environmental Health works to protect public health by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support adequate funding for NCEH. We urge you to support the president's request for increased funding for the Climate and Health Program and to restore the proposed cuts to the Environmental and Health Outcome Tracking Network.

We also urge you to restore the proposed elimination of the Preventive Health and Health Services Block Grant and the Racial and Ethnic Approaches to Community Health program in the president's budget. The REACH program plays a critical role in achieving health equity by closing the existing racial and ethnic gaps in health status. The PHHS Block Grant provides flexible resources to States to allow them to invest in public health and prevention activities that meet the unique needs of their communities.

In order to meet the many ongoing public health challenges outlined above, we urge you to support our fiscal year 2016 request of $7.8 billion for CDC's programs.

[This statement was submitted by Donald Hoppert, Director, Government Relations, American Public Health Association.]

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## PREPARED STATEMENT OF THE CHALKEY FAMILY

Good day Committee Members!

We are submitting this written testimony urging the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

We are the Chalkey family: Gary (father), Christine (mother) and three boys Cody, 24; Jacob, 20; and Blake 17. We reside in Streator, IL. What the few committee members are deciding today will have a dire consequence, impacting and affecting the lives of millions of American families. The American families affected will not only be those who are struggling to care for a family member with special needs but also the millions of tax payers who believe their hard-earned tax money is being spent justly and fairly to care for the most vulnerable and frail of all our society; those with Developmental and Physical Disabilities.

Our son, and brother, Jacob, has a very rare developmental disability. He is one of 18 in the world with what is called bi-lateral periventricular nodular heterotopias, hippocampal malformation and cerebellar hypoplasia syndrome.

Because of Jacob's severe brain malformation and life-threatening seizure disorder, which was diagnosed at 8 months, medical professionals predicted he may never walk, talk or live past age two.

Well, long story short, and 20 years later, Jacob did walk, talk, learn to read and write, and is now participating in high school track, bowling, cross country, singing in the school choir and continuing to amaze us all with what he accomplishes.

Jake is the oldest living survivor, and according to his research neurologist, Dr. William Dobyns from Seattle Children's Hospital, Washington, " Jacob is doing remarkably well and better than the others" with his rare disorder.

As you can see Jacob and others with DD have differing abilities, situations and circumstances that are all unique. An individual approach should be applied, and all residential choices preserved and offered, because even the best of medical professionals can never accurately predict an outcome or future.

Currently, Jacob lives at home with his family and actively participates in his community. But realistically, because of the severity of his epilepsy, each seizure can cause permanent damage or death. Each day, and each seizure, leaves us living in uncertainty, and not knowing what today or tomorrow may bring. We are living a real life limbo.

Although we are uncertain of Jacob medical condition and our future, we are certain of this—denying all choices out lined under the *Olmstead* Decision is creating a hell on earth for the many who need, these real-life options, and individualized level of medical and personal care provided in a state operated developmental center or (ICF–IID).

Additionally, IL, and many other states, holds a last place ranking for providing community services and supports for those with DD. In IL alone, we have over 24,000 children and adults on a state registry list waiting to get necessary services and help. Over 6,000 are classified in emergency situations in need of basics, like shelter, food and medical care.

What civilized society, and truly understanding and compassionate legislator or professional, would attempt to close state operated homes for the disabled and place them on a list or into the over-burdened, under-served community supports system? Realistically, we should not close one more SODC until we fix the problems and shortages of services and supports provided in these community programs.

To deny the reality my family faces, and those currently residing and needing the care provided in SODCs, is one of the greatest injustices, discriminations and sins against humanity.

We are asking you to uphold and support all the choices outlined in the *Olmstead* Decision. The fact is that no two people with DD are the same and an individualized approach to residency needs to be followed; whether it is 24-hour institutionalized nursing care (SODC, ICFs) or community residency and supports. And, more importantly those with DD, and their families and care takers, need be included in making the best and most appropriate of these life decisions.

We support VOR's testimony, and any other groups, upholding and preserving the *Olmstead* Decision and civil right to offer ALL residential choice it clearly defines, including SODC's.

To deny the fact that all people with DD are unique, and require an individualized and common-sense approach to living, is inhumane and committing an injustice against society.

We would like to close with a quote from great American Civil Rights leader Martin Luther King Jr. who eloquently stated that an "INJUSTICE TO MANKIND, ANYWHERE IS A THREAT TO JUSTICE EVERYWHERE." So please remember that funding all residential choices outlined under the *Olmstead* Decision is the only right, civil, moral and just way to serve all, especially the truly vulnerable and their family and caretakers.

Please feel free to contact us with any questions, concerns or feedback.

Respectfully submitted.

[This statement was submitted by the Chalkey Family, Christine, Gary, Cody, Jacob and Blake.]

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## PREPARED STATEMENT OF THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the clinical and translational research community as you work to craft the fiscal year 2016 L-HHS Appropriations Bill. The community would like to thank you for your past support of the full spectrum of medical research.

### ABOUT THE COALITION FOR CLINICAL AND TRANSLATIONAL SCIENCE

CCTS is the unified voice of the clinical and translational science research community. CCTS is a nationwide, grassroots network of dedicated individuals who work together to educate Congress and the Administration about the value and im-

portance of Federal clinical and translational research and research training and career development activities. The Coalition includes the Nation's leading health research institutions. CCTS's goals are to ensure that the full spectrum of medical research is adequately funded, the next generation of researchers is well-prepared, and the regulatory and public policy environment facilitates ongoing expansion and advancement of the field of clinical and translational science.

*Association for Clinical and Translational Science (ACTS)*

ACTS supports investigations that continually improve team science, integrating multiple disciplines across the full translational science spectrum: from population based and policy research, through patient oriented and human subject clinical research, to basic discovery. Our goal is to improve the efficiency with which health needs inform research and new therapies reach the public.

ACTS is the academic home for the disciplines of research education, training, and career development for the full spectrum of translational scientists. Through meetings, publications, and collaborative efforts, ACTS will provide a forum for members to develop, implement, and evaluate the impact of research education programs.

ACTS provides a strong voice to advocate for translational science, clinical research, patient oriented research, and research education support. We will engage at the local, State, and Federal levels and coordinate efforts with other professional organizations.

ACTS will promote investigations and dissemination of effective models for mentoring future generations of translational scientists. Through collaborative efforts, ACTS will provide a forum for members to share studies, promote best practices, and optimize professional relationships among trainees and mentors.

*The Clinical Research Forum (CRF)*

CRF was formed in 1996 to discuss unique and complex challenges to clinical research in academic health centers. Over the past decade, it has convened leaders in clinical research annually and has provided a forum for discussing common issues and interests in the full spectrum of research. Through its activities, the Forum has enabled sharing of best clinical practices and increasingly has played a national advocacy role in support of the boarder interests and needs of clinical research.

Governed by a Board of Directors constituted of clinical researchers from thirteen member institutions, CRF has grown to sixty members from academia, industry, and volunteer health organizations. CRF engages leaders in the clinical research enterprise including leaders from government, foundations, other not-for-profit organizations, and industry in addressing the challenges and opportunities facing the clinical research enterprise.

Parallel with our widening focus upon the broad needs of the entire national clinical research enterprise, CRF is committed to working in those areas where it is uniquely positioned to have a significant impact. Collaboration with other organizations with similar goals and synergizing with their efforts strengthens all approaches to the issues facing clinical research.

SEQUESTRATION

Thank you for providing sequestration relief in fiscal year 2014 and fiscal year 2015.

Federal medical research programs form the cornerstone of our Nation's biotech sector. In addition to undermining active and emerging research projects, across the board funding cuts create widespread disruption. Due to a number of factors, this disruption compounds significant challenges facing the clinical and translational research training and career development pipeline.

Recent years of near-level funding have curtailed NIH's ability to issue funding opportunities. As a result, the pay line at NIH has decreased substantially while the average age of an investigator receiving their first award has increased significantly. This dynamic creates a strong disincentive for young people to pursue a career in this field. Prior to sequestration, NIH would often discuss the decline in young investigators entering the research training and career development pipeline.

Beyond public health, our country needs to ensure that we are adequately preparing the next generation of medical investigators for reasons related to both the economy and national security. Recently, China announced a $300 billion 5-year investment in medical research; this amount is double the current NIH budget over the same period of time. With strong competition from foreign countries, we run the risk of a researcher brain-drain from the U.S. to other nations. Scientific breakthroughs and innovation will continue, but our loss in this area will mean gains for

other nations. Foreign economies will benefit from the significant return-on-investment that occurs through robust support of research.

Sequestration has the potential to severely exacerbate an already difficult task of recruiting and training the next generation of scientific investigators. In order to ensure that the U.S. maintains a strong research training and career development pipeline, please eliminate the threat of sequestration and further support key activities.

NATIONAL INSTITUTES OF HEALTH

This Nation has a proud history as a global leader in medical research and biotechnology. This leadership has provided our country with cutting-edge patient care, high-quality jobs, and meaningful economic growth. The Milliken Institute recently calculated that every dollar invested in NIH returns about a $1.70 in economic output in the short term and as much as $3.20 long-term. Crucially, through a robust external research program, NIH resources flow out to the States where the benefit of the funding infusion is felt on the local level.

NIH's impact on public health has been profound. Conditions once considered a death-sentence can now be managed, survival rates for patients with life-threatening diseases have increased dramatically, and additional innovative therapies and diagnostic tools come to market each year. NIH has been successful, but much more can be done. Please provide NIH with at least $32 billion in fiscal year 2016 so ongoing research projects can be adequately supported and new research activities can be initiated.

*Clinical and Translational Science Awards (CTSAs)*

NIH's CTSA Program, which is housed within the National Center for Advancing Translational Sciences (NCATS), is transforming the efficiency and effectiveness of clinical and translational research. Since its establishment with 12 centers in 2006, the CTSA program has expanded to 62 of the leading medical research institutions located across the country. These centers are linked together and work in concert to improve human health by energizing the research and training environment to innovate and enhance the quality of clinical and translational research.

Recently, based on a recommendation by your Committee, the Institute of Medicine (IOM) released a review of the CTSA program. The report entitled, The CTSA Program at NIH: Opportunities for Advancing Clinical and Translational Research, spoke favorably of the CTSA effort and made the following recommendations to improve the program:

> (1) Strengthen NCATS leadership of the CTSA program, (2) reconfigure and streamline the CTSA Consortium, (3) build on the strengths of individual CTSAs across the spectrum of clinical and translational research, (4) formalize and standardize evaluation processes for individual CTSAs and the CTSA Program, (5) advance innovation in education and training programs, (6) ensure community engagement in all phases of research, (7) strengthen clinical and translational research relevant to child health.

CCTS supports the recommendations of the IOM report and the organization is hopeful these changes will continue to be implemented quickly. Another emerging opportunity is to promote collaboration between CTSAs and all NIH Institutes and Centers. Further, when the CTSA program was authorized, Congress indicated that the consortium would be considered fully-funded when it received an annual appropriation of $750 million. For fiscal year 2016, as part of an overall funding increase for NIH, please provide CTSAs with at least $500 million to ensure the program can continue to grow and advance. Additionally, we hope you will continue working over the coming years to provide CTSAs with $750 million to fully fund the program and establish a robust home for clinical and translational research.

*Institutional Development Awards Program (IDeA)*

The IDeA program broadens the geographic distribution of NIH funding for biomedical research. The program fosters health-related research and enhances the competitiveness of investigators at institutions located in States in which the aggregate success rate for applications to NIH has historically been low. The program also serves unique populations—such as rural and medically underserved communities—in these States. The IDeA program increases the competitiveness of investigators by supporting faculty development and research infrastructure enhancement at institutions in 23 States and Puerto Rico. Through Centers of Biomedical Research Excellence and IDeA Networks for Biomedical Research Excellence, the IDeA program builds important infrastructure and works to advance the field of clinical and translational research.

In fiscal year 2016, please provide the IDeA program with a 5 percent increase to bring the total funding level up to around $250 million. Such an increase would facilitate important growth in the program.

FEDERAL RESEARCH TRAINING AND CAREER DEVELOPMENT PROGRAMS

As we discussed previously, the future of our Nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. The "T" and "K" series awards at NIH and AHRQ provide much-needed support for the career development of young investigators. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K and T awards would have a devastating impact on our pool of highly trained clinical researchers. CCTS urges you to support the ongoing commitment to research training through adequate funding for T and K series awards and a meaningful fiscal year 2016 funding increase for AHRQ.

Additionally, we are supportive of the overall effort being undertaken by the 21st Century Cures Initiative, but we find some of the recommendations and the lack of funding authorizations within the current discussion draft to be worrisome. In future proposals, we hope to see additional funding authorized to support any and all new activities.

Thank you for the opportunity to present the views and recommendations of the clinical and translational research and research training and career development community.

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PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to share with the Subcommittee on Labor, Health and Human Services, Education and Related agencies its views regarding the fiscal year 2016 appropriations for the Low-Income Home Energy Assistance Program (LIHEAP).

The CONEG Governors appreciate the Subcommittee's long-standing support for this vital program, and recognize the difficult budgetary decisions that face the Subcommittee. In these challenging economic times, the Nation's low-income households also face difficult budget choices as they struggle to afford the basic necessity of home energy.

The Governors urge the Subcommittee to fund the LIHEAP program in fiscal year 2016 at no less than $4.7 billion provided as block grants to the States. Adequate, predictable and timely Federal funding is essential for LIHEAP to provide a vital lifeline to those households faced with unaffordable home energy bills. The governors also urge the Subcommittee to provide these funds in a manner consistent with the LIHEAP statutory objective of addressing the energy burden: "assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs."

In the Northeast and across the Nation, LIHEAP assistance is targeted to households with the lowest income and high energy burden. The majority of LIHEAP recipients have incomes far below the eligibility criteria of 150 percent of the Federal poverty level ($23,595 for a two-person household in 2015). More than ninety percent of LIHEAP households have at least one vulnerable member—the elderly or disabled and young children—for whom temperature extremes could have serious health and safety consequences. These low-income households, particularly low-income senior households, spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. The American Association for Retired Persons (AARP) estimates that twenty-seven percent of older households have family incomes of less than $20,000.

The energy burden of keeping warm and safe is particularly challenging for low-income households in the Northeast which has some of the country's oldest homes and coldest climate. More than any other region of the country, Northeast households are dependent upon delivered fuels—heating oil, propane and kerosene. In the winter heating season that is just now coming to an end, senior households with incomes of less than $10,000 heating with fuel oil will spend 14 percent of their income on heating costs. Those heating with other fuels (natural gas, electricity, and propane) can expect to spend between six and 9 percent of household income on heating costs.

Although the price of many home heating fuels has remained relatively stable or declined this winter from recent peak prices, the need for the program remains strong. For example, due to this winter's brutal deadly temperatures, low-income families still incurred increased home energy bills. At the end of the heating season, home heating oil prices in the Northeast averaged $3.00 per gallon according to the Energy Information Administration (EIA). While the need remains great, average LIHEAP benefit levels nationwide have been reduced by almost $100 since 2010, and the number of households served has declined from 8.1 million in fiscal year 2010 to 6.6 million in fiscal year 2014.

Reducing home energy costs presents unique challenges to northeast States. Thirty percent of Northeast households rely upon delivered fuels which are also the most expensive and volatile in price. In addition, compared to homes heating with natural gas or electricity, these "delivered fuel" households are less likely to have the option of payment plans, access to utility assistance programs, and the protection of utility service shut-off moratoria during the heating season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

State LIHEAP programs continue to seek innovative and efficient ways to "do more with less" and stretch scarce LIHEAP dollars to ensure that meaningful assistance can be provided to those households with the greatest needs, and as such, benefit from flexibility in the use of block grant funds. State LIHEAP programs, often working with their Weatherization Assistance Programs, help low-income households take steps to reduce their energy use and lower their energy bills. Programs to provide repair or replace inefficient, unsafe and non-working home heating systems improve the safety and reduce the energy use of low-income households. LIHEAP funds are frequently leveraged by utility assistance programs for low-income households. States in the Northeast have worked with utilities to develop payment plans to reduce arrearages and lessen the prospect of utility shut-offs after the heating season ends. They have negotiated with fuel dealers to receive discounts on deliverable fuels, and have entered into agreements to purchase fuel in the summer when prices are lowest. States working to meet the heating and cooling needs of low income households need continued flexibility so that they may allocate limited LIHEAP funding in a manner that best suits their needs.

Even with these programs, many of the lowest income families that benefit from LIHEAP have limited options to reduce their energy bills. There is simply no room in their household budget for energy upgrades. Some older homes and many manufactured homes have structural issues that make them ineligible for weatherization assistance. Low-income families are more likely to rent than to own a home and therefore have less ability or incentive to make significant energy efficiency upgrades to their homes. For many of these households, switching to less expensive heating fuels is simply not possible. Homes in rural and metropolitan areas throughout the Northeast are not served by natural gas infrastructure. In addition, the New England Fuel Institute estimates that converting a complete home heating system from oil to natural gas can cost as much as $10,000.

In summary, LIHEAP is targeted to meet the immediate home heating needs of some of the Nation's most vulnerable households who face a high energy burden. It is one of the most efficiently run programs with low overhead costs. Even with significant cost-cutting steps, States have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels.

Therefore, the CONEG Governors appreciate the Subcommittee's continued support for LIHEAP, and urge you to fund the core block grant at the level of no less than $4.7 billion in fiscal year 2016.

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## PREPARED STATEMENT OF THE COLLEGE OF PHARMACY AND PHARMACEUTICAL SCIENCES, FLORIDA AGRICULTURAL AND MECHANICAL UNIVERSITY

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

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Title VII Health Professions Training Programs:
—$25 Million for the Minority Centers of Excellence.
—$14 Million for the Health Careers Opportunity Program.
—$285 Million for the National Institutes of Health's National Institute on Minority Health and Health Disparities.
—$100 Million for the Research Centers at Minority Institutions Program at NIMHD
—$65 Million for the Department of Health and Human Services' Office of Minority Health.

—$65 Million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.

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Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Michael Thompson, dean of the College of Pharmacy and Pharmaceutical Sciences at Florida Agricultural and Mechanical University (FAMU). The primary mission of the College of Pharmacy and Pharmaceutical Sciences, in concert with Florida A&M University, is to prepare students for life-long learning and careers in an evolving profession of pharmacy. The College reinforces its mission through an active role and responsibility in the delivery, outcome, and study of pharmaceutical care services it shares with other healthcare providers. The College is committed to the advancement of pharmaceutical knowledge through teaching, research, and service in a supportive and caring environment that enhances the attainment of educational excellence and the highest standards in professional and ethical practice. The College inculcates cultural sensitivity and diversity through its faculty, student body, and patient care.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help Tuskegee continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well-established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2016, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year

2016, I recommend a funding level of $25 million for COEs. Additionally, I encourage the Committee direct HRSA to re-evaluate the funding mechanism for the original four COEs, as it does not always lead to funding based on the merit of an institution's proposal.

*Health Careers Opportunity Program (HCOP)*.—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2016, I recommend a funding level of $14 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH

*National Institute on Minority Health and Health Disparities*.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through its Centers of Excellence program. For fiscal year 2016, I recommend funded increases proportional with the funding of the overall NIH, with increased FTEs.

*Research Centers at Minority Institutions*.—The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2016.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

*Office of Minority Health*.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in healthcareers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, but that role is only possible if this agency continues to keep its grant-making authority. For fiscal year 2016, I recommend a funding level of $65 million for the OMH.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions: The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to FAMU. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2016, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, FAMU , Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. FAMU seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

[This statement was submitted by Michael Thompson, Pharm.D., Dean, College of Pharmacy and Pharmaceutical Sciences, Florida Agricultural and Mechanical University.]

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PREPARED STATEMENT OF THE COLLEGE OF VETERINARY MEDICINE, NURSING & ALLIED HEALTH

SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—Title VII Health Professions Training Programs:
  —$25 Million for the Minority Centers of Excellence.
  —$14 Million for the Health Careers Opportunity Program.
—Increased Support for the National Institutes of Health's National Institute on Minority Health and Health Disparities.
—$32 Billion for the National Institutes of Health.
  —$285 Million for the National Institute on Minority Health and Health Disparities.
  —$100 Million for Research Centers for Minority Institutions
—$65 Million for the Department of Health and Human Services' Office of Minority Health.
—$65 Million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Ruby Perry, dean of the College of Veterinary Medicine, Nursing, and Allied Health at Tuskegee University. The mission (purpose) of Research and Advanced Studies at the College of Veterinary Medicine, Nursing & Allied Health (CVMNAH) is to transform trainees into ambassadors of the Tuskegee tradition to benefit Man and animals. Such a tradition is honed in the "one medicine-one health" concept that for decades has guided our academic mission, to expand biosciences and create bridges between veterinary medicine, agricultural and food sciences on one side and human health and welfare on the other.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help Tuskegee continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare work-

force in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2016, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2016, I recommend a funding level of $25 million for COEs. Additionally, I encourage the Committee direct HRSA to re-evaluate the funding mechanism for the original four COEs, as it does not always lead to funding based on the merit of an institution's proposal.

*Health Careers Opportunity Program (HCOP)*.—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2016, I recommend a funding level of $14 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH

*National Institute on Minority Health and Health Disparities*.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through its Centers of Excellence program. For fiscal year 2016, I recommend $285 million for NIMHD.

*Research Centers at Minority Institutions*.—The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, for fiscal year 2016 I recommend $100 million for the RCMI program.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

*Office of Minority Health*.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in healthcareers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, but that role is only possible if this agency continues to keep its grant-making authority. For fiscal year 2016, I recommend a funding level of $65 million for the OMH, and a continuation of their grant making authority.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions: The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to TU CVMNAH. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2016, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Tuskegee University's College of Veterinary Medicine, Nursing, and Allied Health , Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. CVMNAH seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman, and I welcome every opportunity to answer questions for your records.

[This statement was submitted by Ruby Perry, DVM, Dean, College of Veterinary Medicine, Nursing & Allied Health.]

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PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the research supported by the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 1000 members, has been in existence since 1929. It is the longest standing group of scholars in the United States addressing problems of drug dependence and abuse. The organization serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. CPDD also works in collaboration with the World Health Organization.

Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least $32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

*Marijuana Research*.—The committee recognizes that many States either have or are considering legalizing or making marijuana available for medical use without appropriate knowledge about its effects on human development, structure and function of their brains. Therefore the committee supports the Adolescent Behavioral Cognitive Development (ABCD) Study being initiated by NIDA and other institutes of NIH. The committee also recognizes that the study will take at least a decade to complete since it will be a comprehensive study of the effects of marijuana and other abused drugs throughout growth from 10 to 20 years of age. Further the committee recognizes the cost of this comprehensive study should not inhibit funding investigator initiated studies and a special appropriation for this study is necessary.

*Opiate Abuse and Addiction*.—The Committee is concerned about the escalating crisis of prescription drug abuse in the U.S. It is now estimated that 120 people die each day in this country from opioid overdose making it one of the highest causes of non-disease related causes of deaths for adolescents and young adults. The June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the Nation of $72,500,000,000. Further, the Committee is very concerned with the concomitant rise in heroin abuse, addiction and deaths as the cost of this illegal opioid is less than that for prescription opioids. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research to enhance the development of such medications; and 3) report on what we know regarding the transition from prescription opiate analgesics to heroin abuse and addiction within affected populations.

*Medications Development*.—The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that decrease the ability of specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations to affect the brain. The Committee is excited by this approach—if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.

*Research to Assist Military Personnel, Veterans, and Their Families*.—The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.

*Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.*.—The Committee is pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other healthcare professionals to increase especially those treating our youth to better recognize the signs that lead to drug abuse and addiction. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over $600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease —this new knowledge has helped to correctly emphasize the fact that drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalities due to heroine, as well as the continued abuse of prescription opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2016 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

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PREPARED STATEMENT OF COMMUNITY SERVINGS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White HIV/AIDS Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Community Servings is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. We provide over half a million medically tailored, home delivered meals to critically and chronically ill individuals, their dependent families, and caregivers in twenty cities and towns in Massachusetts annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White HIV/AIDS Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White HIV/AIDS Program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White HIV/AIDS Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

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[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

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[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]
—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by David B. Waters, CEO, Community Servings.]

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## PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

The Consortium of Social Science Associations (COSSA) appreciates the opportunity to comment on the fiscal year 2016 appropriations for the agencies under the Subcommittee's jurisdiction. COSSA recommends that the National Institutes of Health (NIH) receive at least $32 billion in fiscal year 2016 as the next step toward a multi-year increase in our Nation's investment in medical research, and urges the Subcommittee to appropriate $7.8 billion for the Centers for Disease Control and Prevention (CDC), $172 million for the National Center for Health Statistics (NCHS), $375 million for the Agency for Healthcare Research and Quality (AHRQ), and $703.6 million for the Institute of Education Sciences (IES).

COSSA serves as a united voice for a broad, diverse network of organizations, institutions, communities, and stakeholders who care about a successful and vibrant social science research enterprise. It represents the collective interests of all fields of social and behavioral science research, including but not limited to sociology, anthropology, political science, psychology, economics, statistics, language and linguistics, population studies, law, communications, educational research, criminology and criminal justice research, geography, history, and child development. We are appreciative of the Subcommittee's and the Congress' continued support of NIH, CDC, NCHS, AHRQ, and IES. Strong, sustained funding for these agencies is essential to the national priorities of better health and economic revitalization.

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*National Institutes of Health (at least $32 billion), U.S. Department of Health and Human Services*

Since 2003, NIH funding has declined by 23 percent after adjusting for biomedical inflation, despite recent budget increases provided by the Congress the past 2 fiscal years. The agency's budget remains lower than it was in fiscal year 2012 in actual dollars. The President's fiscal year 2016 budget request represents a much-needed next step by increasing NIH funding above biomedical inflation; however, there are ongoing and emerging health challenges confronting the United States and the world. To that end, COSSA believes that to address these challenges the NIH requires a funding level of at least $32 billion in fiscal year 2016.

As the Committee knows, the NIH mission is to support scientifically rigorous, peer/merit-reviewed, investigator-initiated research—including basic and applied behavioral and social science research—in fulfilling its mission: "Science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life and reduce illness and disability." COSSA, however, remains concerned about the recent criticism of the NIH's funding decisions and the accompanying mischaracterization of NIH-supported research. The ongoing targeting of specific grants produces a chilling effect across the scientific community.

The behavioral and social sciences regularly make important contributions to the well-being of this Nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous role behavior plays in our health. At a time when genetic control over disease is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the Nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness.

The fundamental understanding of how disease works, including the impact of social environment on these disease processes, underpins our ability to conquer devastating illnesses. Perhaps the grandest challenge we face is to understand the brain, behavior, and society—from responding to short-term pleasures to self-destructive behavior such as addiction, to lifestyle factors that determine the quality of life, infant mortality rate, and longevity. Congress' continued support of the BRAIN (Brain Research through Advancing Innovative Neurotechnologies) initiative is an important first step to begin to address these challenges.

And while Americans have achieved very high levels of health over the past century and are healthier than people in many other nations, according to the 2013 National Academies' report, U.S. Health in International Perspective: Shorter Lives, Poorer Health, "a growing body of research suggests that the health of the U.S. population is not keeping pace with the health of people in other economically advanced, high-income countries." Nearly 125 million Americans are living with one or more chronic conditions, including heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness, and Alzheimer's disease, according to the CDC. At the same time, healthcare spending in the United States is impacted by the aging of the U.S. population and the rapid rise in chronic diseases, many of which are caused or exacerbated by behavioral factors—including, obesity caused by sedentary behavior and poor diet, and addictions resulting from health problems caused by tobacco and other drug use, including prescription drug abuse by women. As the NAS report notes, "the United States is losing ground in the control of diseases, injuries, and other sources of morbidity."

As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

Among the important contributions stemming from NIH's support of behavioral and social science are:

—Economic research, specifically, research on the linkages between socioeconomic status and health outcomes in the elderly and achievement and health outcomes in children;

—Economic matching theory to develop a system that dramatically improves the ability of doctors to find compatible kidneys for patients on transplant lists;

—The translation of basic research to lifesaving interventions such infant massage, that enhance premature infants' weight gain and save lives;

—Resources for enhancing Alzheimer's caregiver health (REACH) program, which aims to help maintain the health of informal caregivers for the millions of American Alzheimer's patients who live at home;

—Research that led to understanding and improving ways that people communicate about health-related issues; and
—Research that increased our understanding adolescence peer pressure and smoking.

Finally, COSSA applauds the Administration's proposed Precision Medicine Initiative (PMI) and the NIH's involvement of its Office of Behavioral and Social Sciences Research (OBSSR) in the initial planning phase of this million-person cohort, including its commitment to including behavioral, physiological, and environmental measures. To this end, the recent advances in mobile and wireless sensor technologies, also known as mHealth, to assess these behavioral, physiological, and environmental parameters are an integral aspect of this initiative. This technology has great potential to transform medical research. OBSSR has led the NIH's efforts in using, understanding, and training scientists in the use of mHealth, which allows for more rapid and accurate assessment in modifying behavior, biological states, and contextual variables. Its support of the NIH mHealth Training Institutes is designed to attend to scientific silos by bringing together scientists from diverse fields to enhance the quality of mHealth research.

*Centers for Disease Control and Prevention ($7.8 billion) and National Center for Health Care Statistics ($172 million), U.S. Department of Health and Human Services*

COSSA urges the Subcommittee to appropriate $7.8 billion for the Centers for Disease Control and Prevention (CDC), including $172 million for the CDC's National Center for Health Statistics. As the country's leading health protection and surveillance agency, the CDC works with State, local, and international partners to protect Americans from infectious diseases; prevent the leading causes of disease, disability, and death; protect Americans from natural and bioterrorism threats; monitor health and ensure laboratory excellence; keep Americans safe from environmental and work-related hazard; and ensure global disease protection.

Social and behavioral science plays a crucial role in helping the CDC carry out its mission. Scientists from fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods.

These scientists play a key role in the CDC's surveillance and monitoring efforts, which collect and analyze data to better target public health prevention efforts. For example, the Behavioral Risk Factor Surveillance System, which collects data about Americans' health-related risk behaviors and events, chronic health conditions, and use of preventive services, is used to establish and track State and local health objectives, plan health programs, implement disease prevention and health promotion activities, and monitor trends.

Another vital contribution of the social and behavioral sciences to CDC activities is in identifying and understanding health disparities. Although the overall health of Americans has improved over the last decades, differences in health based on race, ethnicity, gender, income, geographical location, education level, disability status, and sexual orientation persist. Rigorous, cross-disciplinary efforts are needed to develop effective interventions to reduce these entrenched disparities and inequities.

The social and behavioral sciences play an important role in the evaluation of CDC programs. When programs conduct strong, practical evaluations on a routine basis, the findings are better positioned to inform their management and improve program effectiveness.

COSSA requests $172 million—$160 million in budget authority and $12 million from the Prevention and Public Health Fund—for the National Center for Health Statistics (NCHS), the Nation's principal health statistics agency. NCHS collects data on chronic disease prevalence, healthcare disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance, to name a few. It provides critical data on all aspects of our healthcare system through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and the National Vital Statistics System (NVSS) are used by agencies across the Federal Government, State and local governments, public health officials, Federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists.

The requested increase for NCHS' budget authority would be used to continue expansion of the electronic death registration system (EDRS) to facilitate monitoring of data on deaths of public health importance, including prescription drug overdose

deaths. The additional funding from the Prevention and Public Health Fund would enable NCHS to continue with planned expansion to NHIS questions and sample size and to the sample size of the National Ambulatory Medical Care Survey. Without this appropriation, these expansions will be discontinued.

*Agency for Healthcare Research and Quality ($375 million), U.S. Department of Health and Human Services*

COSSA urges the Subcommittee to appropriate $375 million for the Agency for Healthcare Research and Quality (AHRQ). AHRQ funds the science that tells us how we can make healthcare safer, higher quality, more accessible, equitable, and affordable. It is the only Federal agency whose sole purpose is to produce the evidence to improve America's healthcare system and make sure that knowledge is understood and used by healthcare providers, patients, hospitals, and public and private payers.

The research AHRQ supports is based on the understanding that developing new treatments is only part of the battle; we need to know how to get those treatments to the people who need them, efficiently and effectively. AHRQ findings arm healthcare providers with the knowledge they need to provide the best care for their patients. The science it supports can help us improve the safety of all healthcare settings and provide better care more efficiently through improved access to healthcare services and better understanding of the cost and quality of care.

The important health services research AHRQ supports includes:

—Research on preventing healthcare-associated infections (HAIs): AHRQ's evidence-based protocol for reducing HAIs, the Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP), saved more than 1,500 lives and nearly $200 million in healthcare costs—just in its first 18 months. Since its implementation in 2003, it has been expanded to hospitals in all 50 States, the District of Columbia, and Puerto Rico.

—Learning how to improve care for patients suffering from multiple chronic conditions: An estimated 66 percent of the Nation's healthcare costs go to treating people with more than one chronic condition, a number which will only grow as the population ages. AHRQ funds the Multiple Chronic Conditions Research Network, which aims to conduct the foundational research that will tell us how to best meet the needs of this population.

—The National Quality Measurement Clearinghouse: A repository of detailed information on measures that are proven to be associated with better or worse care, giving physicians and other healthcare providers, health plans, delivery systems, and others easy access to evidence-based information to inform their healthcare decisions.

—The congressionally-mandated National Healthcare Quality Report and National Healthcare Disparities Report: The only comprehensive sources of information on healthcare quality and healthcare disparities among racial and ethnic minorities, women, children, and low-income populations.

—The Medical Expenditure Panel Survey (MEPS): The Nation's only national source of comprehensive annual data on the how Americans use and pay for medical care. MEPS collects data on the specific health services that Americans use, how frequently they use them, the cost of these services, and how they are paid for, as well as data on the cost, scope, and breadth of health insurance held by and available to U.S. workers. This data provides vital information on the impact of healthcare on the U.S. economy.

COSSA urges the Subcommittee to ensure robust support for AHRQ's critical health services research.

*Institute of Education Sciences ($703.6 million), U.S. Department of Education*

The Institute of Education Sciences is the research arm of the Department of Education. COSSA recommends a funding level of $703.6 million for IES, which would restore the cuts it has faced since 2009. As this Committee knows, IES supports research and produces statistics and data to improve our understanding of education at many levels—early childhood, elementary and secondary education, and higher education. Research examining special education, rural education, teacher effectiveness, education technology, student achievement, reading and math interventions, and many other areas is also supported by IES. There is an increasing call for using evidence-based practices in education. Adequate funding for IES would support studies that not only increase knowledge of the factors that influence teaching and learning, but also apply those findings to improve educational outcomes. The COSSA-recommended funding level will allow IES to build upon existing findings and to conduct much-needed new research.

Thank you for the opportunity to present this testimony on behalf of the social and behavioral science research community. Please do not hesitate to contact me should you require additional information.

[This statement was submitted by Angela L. Sharpe, MG, Deputy Director, Consortium of Social Science Associations.]

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PREPARED STATEMENT OF ELIZABETH CONTINO

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

PREPARED STATEMENT OF KATHRYN COOK

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF THE CORPORATION FOR SUPPORTIVE HOUSING

The Corporation for Supportive Housing (CSH) is a nonpartisan, nonprofit organization helping communities develop supportive housing (SH) and reorient systems to improve resource allocation to create and sustain evidence-based solutions. We have offices in 12 States (California, Arizona, Texas, Illinois, Indiana, Ohio, Minnesota, Michigan, New York, Georgia, and Connecticut) and the District of Columbia and have a presence in several others. Supportive housing is affordable housing

combined with stabilizing services to help families and individuals address their disabling conditions while living in safe apartments. CSH has helped communities create and develop supportive housing for populations with substance use addiction, mental health illness, chronic diseases, involvement with child welfare, exiting the criminal justice system and homeless young adults.

Supportive housing providers receive a portion of the funds necessary to build or secure affordable housing from the Department of Housing and Urban Development (HUD) or State housing resources. There is also a need for the Department of Health and Human Services (HHS) to ensure that resources are available for services such as case management, landlord negotiation, connection to health services, counseling and medication management. Providers often use a combination of State, local, foundation and privately raised funds to pay for the vital social services chronically homeless populations may need to stay housed. Increasingly, organizations are able to access Medicaid to provide services when the service is part of the benefit package for a household and the provider is licensed to bill Medicaid. In order to build the housing units needed to end homelessness, serve those leaving institutional care, help families with children stay together and afford homeless transition age youth, the Department of Health and Human Services must increase its investment in services that are paired with housing programs. To this end, CSH recommends the following:

—Allocate $100 million for services for people experiencing homelessness within the Programs of Regional and National Significance (PRNS) accounts of both SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

—Increase funding for the Projects for Assistance in Transition from Homelessness (PATH) program to $75 million, the fully authorized level.

—Increase funding for the Runaway and Homeless Youth Act Programs to $165 million, its authorized funding level.

—Provide $1.5 billion in the discretionary Community Health Center program and $3.6 billion in Affordable Care Act mandatory funding, both are located within the Health Resource Services Administration. This would result in $447.3 million for the Health Care for the Homeless program.

—Provide $80 million for the Social Innovation Fund (SIF) program in the Corporation for National and Community Service.

*Background*

While HUD has made significant housing investments, there is a need for HHS to increase its role in providing services resources for organizations to create supportive housing. A supportive housing residents live with serious mental illness, substance use disorders or chronic health conditions and to retain housing must have access services that require HHS resources.

We know supportive housing works. Over 80 percent of residents remain housed after the first year. In addition, work CSH has done targeting frequent users of health, jails or prisons illustrates the cost effectiveness of supportive housing. In California, we implemented the Frequent Users of Health Services Initiative (FUHSI). Through this study, we found that by placing clients into supportive housing we reduced their emergency room costs by 59 percent, reduced their inpatient days by an average of 62 percent and reduced average inpatient charges by 69 percent.

Our project targeting frequent users of jails and prisons has shown similar results. In New York, CSH's Frequent Users of Services Enhancement (FUSE) Initiative was a joint project between the New York City Departments of Corrections and Homeless Services with assistance from the Department of Health and Mental Hygiene and the New York City Housing Authority. By assisting ex-offenders and providing supportive housing to those who need it, NYC was able to help clients reduce jail stays by 33 percent and reduce mental health stays by 18 percent. For the 86 people served, the FUSE initiative was able to offset over $3,500 in either jail or mental health costs per client.

In addition, there are several other subpopulations experiencing either homelessness or housing instability that would benefit from increased social services oriented funding. On a small scale, SAMHSA programs have targeted youth, veterans and families to ensure that all people who could benefit from mental health and substance use treatment can receive specialized support. However, without increased funding, communities will not be able to fully implement the supportive housing model for the hundreds of thousands of people who can benefit from it.

*SAMHSA Support Services for Supportive Housing Projects*

CSH recommends allocating $100 million for services in permanent supportive housing within SAMHSA's Center for Mental Health Services and Center for Substance Abuse Treatment.

Years of reliable data and research demonstrate that the most successful intervention to solve chronic homelessness is linking housing to appropriate support services. Current SAMHSA investments in homeless programs are highly effective and cost-efficient. However, funding for SAMHSA homeless programs has remained flat for the past 3 years, often making it difficult for communities to increase the number of homeless households they are serving with the service dollars. As communities are investing additional housing resources into serving high-need homeless populations, Congress should increase funding for services to help those populations address their long-term health related issues.

*Projects for Assistance in Transition from Homelessness (PATH)*

CSH recommends that Congress increase PATH funding to $75 million and adjust the funding formula to increase allocations for small States and territories.

PATH provides outreach to eligible consumers and ensures that those consumers are connected with mainstream services, such as Supplemental Security Income (SSI), Medicaid, and welfare programs.

PATH supported programs served over 181,537 people through outreach in fiscal year 2013. Of those for whom a diagnosis was reported, approximately 66 percent were receiving community mental health services and 56 percent had co-occurring substance use disorders.

One issue that needs consideration, under the PATH formula grant, approximately 30 States share in the program's annual appropriations increases. The remaining States and territories receive the minimum grant of $300,000 for States and $50,000 for territories. These amounts have not been raised since the program was authorized in 1991. To account for inflation, the minimum allocation should be raised to $600,000 for States and $100,000 for territories. Amending the minimum allocation requires a legislative change. If the authorizing committees do not address this issue, we hope that appropriators will explore ways to make the change through appropriations bill language.

*Community Health Centers and Health Care for the Homeless (HCH) Programs*

CSH recommends $1.5 billion in the discretionary Community Health Center program and $3.6 billion in Affordable Care Act mandatory funding for community health centers. This would result in $447.3 million for the Health Care for the Homeless program.

Persons living on the street suffer from health problems resulting from or exacerbated by being homeless, such as hypothermia, frostbite, and heatstroke. In addition, they often have infections of the respiratory and gastrointestinal systems, tuberculosis, vascular diseases such as leg ulcers, and hypertension.[1] Healthcare for the homeless programs are vital to prevent these conditions from becoming fatal. Congress allocates 8.7 percent of the Consolidated Health Centers account for HCH projects.

*Runaway and Homeless Youth Program*

CSH recommends $165 million for the Runaway and Homeless Youth (RHYA) Act Programs. RHYA programs are dedicated to reaching homeless youth. RHYA funding goes towards outreach to youth living on the street, emergency shelters and transitional housing programs. CSH recommends including a Pay for Success Initiative in the RHYA account to test models that serve high-need youth, such as those with disabling conditions or those who have had multiple placements in out-of-home care. A Pay for Success Model could braid funding from RHYA, HUD and Title IV–E to fund supportive services for this target population.

On any given night, approximately 46,000 youth are homeless. Homeless youth leave their current homes for many reasons, including physical abuse, sexual abuse, extreme poverty or other trauma. Unfortunately, less than 5,000 youth are able to access stable housing resources each year. RHYA is the only dedicated resource that is made available to serve this population. Increasing funding for the three core programs is critical to reduce the number of youth living on the streets. Further, a Pay

[1] Harris, Shirley N, Carol T. Mowbray and Andrea Solarz. Physical Health, Mental Health and Substance Abuse Problems of Shelter Users. Health and Social Work, Vol. 19, 1994.

for Success program that targets youth with higher needs will allow providers to blend different models to achieve positive outcomes for youth.

*Child Abuse and Prevention Treatment Act (CAPTA)*

CSH recommends funding the Administration request for CAPTA but include an additional $20 million funding for services for families or eligible youth receiving Family Unification vouchers. The Administration requested $20 million for Family Unification vouchers that assist families involved with child welfare or youth exiting foster care.

The Child Abuse and Prevention Treatment grants are dedicated to the prevention, assessment, identification and treatment of child abuse and neglect. Currently, ACF is using discretionary grants to fund the Partnerships to Demonstrate the Effectiveness of Supportive Housing for Families with Child Welfare Involvement that connects housing and services to create a program that focuses on both family preservation and reunification, reduce out-of-home care and ultimately end cycles of involvement with child welfare. Through this demonstration, services and case management have played a critical role in family stability and reducing time in out of home care for children of homeless families. CSH recommends an additional $20 million in CAPTA discretionary grants to allow ACF to attach services and case management to Family Unification vouchers that serve families involved with child welfare or youth exiting foster care.

*Social Innovation Fund, CNCS*

CSH recommends providing $80 million for the Social Innovation Fund (SIF) at CNCS and 20 percent of the funding be set aside for Pay for Success Initiatives.

CSH is actively involved with Social Innovation Fund projects and Pay for Success projects that are geared towards reducing healthcare costs for homeless populations that are high utilizers of emergency healthcare systems. Through the Social Innovation Fund initiative, CSH is working with four organizations to implement an integrated supportive housing model that incorporates care management to help households address behavioral and physical health conditions while reducing costs. In addition, CSH recently received a Pay for Success grant to help strengthen the supportive housing creation pipeline, using the Pay for Success grant, nonprofit community-based providers will create evidence based programs that are aimed at helping low-income families overcome challenges and improve economic opportunities and healthy outcomes.

*Conclusion*

As communities implement plans to end homelessness, work to move people out of institutional care and seek to end the cycle of over using public systems, they are struggling to find funding for the services that vulnerable populations need to maintain housing. The Federal investments in mental health services, substance abuse treatment, primary care, youth housing, and case management discussed above will help communities create stable housing programs and change social systems which will prevent and end homelessness for millions of Americans.

[This statement was submitted by Deborah DeSantis, President/CEO, Corporation for Supportive Housing.]

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## PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. CSWE is a nonprofit national association representing more than 2,500 individual members and more than 700 master's and baccalaureate programs of professional social work education. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce to meet the healthcare needs of the Nation through professional education, training, and financial support programs for social workers at the Department of Health and Human Services (HHS) and the Department of Education (ED). CSWE requests:

| Agency | Account | Program | Funding requested |
|---|---|---|---|
| HHS | HRSA | Title VII and Title VIII Health Professions Programs | $524 million |
| HHS | HRSA | Title VII Mental and Behavioral Health Education and Training Program | $10 million |

| Agency | Account | Program | Funding requested |
|---|---|---|---|
| HHS | SAMHSA-HRSA | SAMHSA-HRSA Behavioral Health Workforce Education and Training Grant Program | $56 million |
| HHS | SAMHSA | Minority Fellowship Program | $10.7 million, including at least $5.4 million for MFP core activities |
| ED | N/A | Pell Grant | $5,915 for the maximum Pell Grant |
| ED | N/A | GAANN | $31 million |
| ED | N/A | Loan Repayment Programs | Support without a cap on repayment |
| HHS | NIH | Overall Funding For National Institutes of Health | $32 billion |

Recruitment and retention in social work continues to be a serious challenge that threatens the workforce's ability to meet societal needs. The U.S. Bureau of Labor Statistics estimates that employment for social workers is expected to grow faster than the average for all occupations through 2022.[1] While CSWE understands the difficult funding decisions facing Congress, it is my hope that the Committee will prioritize funding for health professions training in fiscal year 2016 to help ensure that the Nation continues to foster a sustainable, skilled, and culturally competent workforce that will be able to keep up with the increasing demand for social work services and meet the unique healthcare needs of diverse communities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide $524 million in fiscal year 2016 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), which is equal to the fiscal year 2012 enacted level. HRSA's Title VII and Title VIII health professions programs represent Federal programs designed to train healthcare providers in an interdisciplinary way to meet the healthcare needs of all Americans, including the underserved and those with special needs, and expand minority representation in the healthcare workforce. The Title VII and Title VIII programs, for which social workers and social work students are eligible, provide loans, loan guarantees, and scholarships to students, as well as grants to institutions of higher education and non-profit organizations to help build and maintain a robust healthcare workforce.

In the 2010 reauthorization of the Title VII and Title VIII programs, a new Title VII program was authorized in the Patient Protection and Affordable Care Act (Public Law 111–148), which recognized the severe shortages of mental and behavioral health providers within the healthcare workforce. The Mental and Behavioral Health Education and Training (MBHET) Grants Program provides grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment, as well as professional education and training. The program received first-time funding of $10 million in the final fiscal year 2012 appropriations bill. "In Academic Year 2013–2014, the Mental and Behavioral Health Education and Training (MBHET) grants supported more than 190 graduate-level students participating in either a social work practicum or a pre-degree internship in clinical psychology."[2]

Also, CSWE supports the creation of the Clinical Training in Interprofessional Practice Program, funded in the President's fiscal year 2016 Budget Request, as long as it would include social workers. This program would promote the training of interprofessional teams that can provide high quality care for patients and communities. In these teams, CSWE encourages the explicit inclusion of social workers.

[1] U.S. Bureau of Labor Statistics. 2012. Occupational Outlook Handbook: Social Workers, http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm. Retrieved March 21, 2014.

[2] Department of Health and Human Services fiscal year 2016, Health Resources and Services Administration, Justification of Estimates for Appropriations Committees, http://www.hrsa.gov/about/budget/budgetjustification2016.pdf, Retrieved March 3, 2015, Pg 152.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION/HEALTH RESOURCES AND SERVICES ADMINISTRATION

BEHAVIORAL HEALTH WORKFORCE EDUCATION AND TRAINING PROGRAM

The Behavioral Health Workforce Education and Training (BHWET) Program, a partnership between HRSA and the Substance Abuse and Mental Health Services Administration (SAMHSA), has provided critical support to increase the number of behavioral health professionals. This program builds on HRSA's mental and behavioral health training efforts by providing important grant funding for mental health and substance abuse workforce serving children, adolescents, and transitional-age youth at risk for developing, or who have developed, a recognized behavioral health disorder.[3] This program is significant to CSWE and social work. In 2015, for the first year of this program, social work programs were awarded about $19,087,780 and we estimate about 4,196 students will be served through this program. This makes important progress in meeting the workforce needs for mental and behavioral health providers.

The President's fiscal year 2016 budget request would continue to support the SAMHSA/HRSA program by providing $56 million. This funding is an increase of $21 million above the fiscal year 2015 enacted level and would expand behavioral health workforce activities and award additional grants. CSWE urges the Committee to support $56 million for the SAMHSA-HRSA BHWET Grant Program.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate the highest level possible for the Minority Fellowship Program (MFP) in fiscal year 2016. The goal of the SAMHSA Minority Fellowship Program (MFP) is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance use fields.[4] CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. Other grantees include national organizations representing nursing, psychology, psychiatry, marriage and family therapy, and professional counselors. SAMHSA makes grants to these six organizations, who in turn recruit minority doctoral students into the program from the six distinct professions. CSWE administers the funds to qualified doctoral students and helps facilitate mentoring and networking throughout the duration of the fellowship as well as facilitates an alumni group to help continue to engage former fellows long after their formal fellowship has ended.

In addition, CSWE also administers funds for the Minority Fellowship Program-Youth (MYP–Y). The purpose of the program is to reduce health disparities and improve behavioral healthcare outcomes for racially and ethnically diverse populations by increasing the number of culturally competent master's-level behavioral health professionals serving children, adolescents, and populations in transition to adulthood (aged 16—25).

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program continues to struggle to keep up with the demands facing these health professions. Severe shortages of mental health professionals often arise in underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than within Tribal communities, where mental illness and substance use go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Also, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.[5] The President's fiscal year 2016 budget request includes $10.7 million to support six MFPs, two MFP–Y, two MFP–AC grants, and three technical assistance and evaluation support contracts. CSWE urges the Committee to support this request, includ-

[3] Http://www.integration.samhsa.gov/integrated-care-models/safety__net__providers.

[4] According to SAMHSA, minorities make up over one-fourth of the population, but less than 20 percent of behavioral health providers come from ethnic minority communities. Retrieved from SAMHSA Minority Fellowship Program, http://www.samhsa.gov/minorityfellowship/.

[5] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2001). Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General. Retrieved from http://www.surgeongeneral.gov/library/mentalhealth/cre/sma-01-3613.pdf.

ing at least $5.4 million for MFP core activities. The same as the fiscal year 2015 enacted level.

DEPARTMENT OF EDUCATION: STUDENT AID PROGRAMS

CSWE supports full funding to keep the maximum Pell Grant at $5,915 in fiscal year 2016. While Congress is understandably focused on identifying a solution that will place the Pell Grant program on solid ground with regard to its fiscal future, we urge you to remember that these grants help to ensure that all students, regardless of their economic situations, can achieve higher education. Moreover, as described above with regard to the SAMHSA Minority Fellowship Program, one goal of social work education is recruiting students from diverse backgrounds (which includes racial, economic, religious, and other forms of diversity) with the hope that they will return to serve diverse communities once they have completed their education. In many cases, this includes encouraging social workers to return to their own communities and apply the skills they have acquired through their social work education to individuals, groups, or families in need. Without support such as Pell Grants, many low-income individuals would not be able to access higher education, and in turn, would not acquire the skills needed to best serve in the communities that would most benefit from their service.

The Graduate Assistance in Areas of National Need (GAANN) program provides graduate traineeships in critical fields of study. Currently, social work is not defined as an area of national need for this program; however it was recognized by Congress as an area of national need in the Higher Education Opportunity Act of 2008. We encourage ED to recognize the importance of including social work in the GAANN program in future years. Inclusion of social work would help to significantly enhance graduate education in social work, which is critically needed in the country's efforts to foster a sustainable health professions workforce. CSWE urges the Subcommittee to provide the fiscal year 2012 pre-sequester funding level of $31 million for the GAANN Program and include social work as an area of national need.

CSWE supports efforts at ED to help students with high debt loads serve in low paying positions. The Income-Based Repayment (IBR) program and the Public Service Loan Forgiveness programs in particular help students graduating from social work programs who wish to serve in high-needs communities, often at a low salary level. CSWE urges the Subcommittee to support loan repayment programs without a cap on repayment support at ED.

NATIONAL INSTITUTES OF HEALTH: SUPPORT FOR RESEARCH

CSWE supports the community's recommendation for at least $32 billion for the National Institutes of Health (NIH) in fiscal year 2016 and advocates for continued investments in biomedical and health-related research that incorporates the social and behavioral science research necessary to better understand, and appropriately address, the needs of high-risk populations including children, racial and ethnic minority populations, and geriatric populations.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

[This statement was submitted by Dr. Darla Spence Coffey, President, Council on Social Work Education.]

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PREPARED STATEMENT OF MARY KAY COWEN

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF PAUL COZIC

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PREPARED STATEMENT OF MARILYNN CREECH

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

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> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Med-

icaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

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PREPARED STATEMENT OF FLOYD B. CRESSEY

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## PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—$32 billion for the National Institutes of Health (NIH). Increase funding for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
—Continued Focus On Digestive Disease Research and Education at NIH, and Support for the Inflammatory Bowel Disease (IBD) Portfolio
—$1,000,000 for the Centers for Disease Control and Prevention's (CDC) IBD Epidemiology Activities.

Chairman Blunt and members of the Subcommittee, thank you for the opportunity to submit testimony on behalf of the Crohn's and Colitis Foundation of America (CCFA). CCFA has remained committed to its mission of finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for over 46 years.

Impacting an estimated 1.4 million Americans, 30 percent of whom are diagnosed in their childhood years, Inflammatory Bowel Diseases (IBD) are chronic disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBD represents a major cause of morbidity from digestive illness and has a devastating impact on both patients and their families.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at $60 billion a year.

### NATIONAL INSTITUTES OF HEALTH

The CCFA would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the CCFA recommends:
—$32 billion for NIH
—$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)

We at the CCFA respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

In the United States today about 1.4 million people suffer from Crohn's disease and ulcerative colitis, collectively known as IBD. These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever.

Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. CCFA would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. CCFA also commends NIDDK for hosting a conference on inflammatory bowel disease in children which could lead to further research in this area. The Committee urges NIDDK to continue efforts to identify the etiology of the disease in order to inform the development of cures for inflammatory bowel disease.

### CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC, in collaboration with a nationwide, geographically diverse network of large managed healthcare delivery systems, has led an epidemiological study of IBD to understand IBD incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, the Crohn's and Colitis Foundation of America, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, the OSCAR investigators have recruited 22 private–practice groups and hospital based physicians in Rhode Island and are that enrolling newly diagnosed patients into the registry. This study found

an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in Inflammatory Bowel Disease Journal, April 2007.

—Over the course of the initial 3–year epidemiologic collaboration, CDC laboratory scientists and epidemiologists worked to improve detection tools and epidemiologic methods to study the role of infections (infectious disease epidemiology) in pediatric IBD, collaborating with extramural researchers who were funded by a National Institutes of Health (NIH) research award.

—Since 2006, CDC epidemiologists have been working in conjunction with the Crohn's and Colitis Foundation of American and a large health maintenance organization to better understand the natural history of IBD and factors that predict the course of disease.

CCFA commends CDC for implementing a robust IBD epidemiology study and communicating study results with the public. CCFA supports the continued exploration of the disease burden of IBD, and communication of these findings to patients and providers in an effort to improve current interventions and inform best public health practices in managing IBD.

CCFA encourages CDC to continue to support a nationwide IBD surveillance and epidemiological program at $1 million in fiscal year 16 to expand current efforts to identify the etiology of the disease and implement preventive measures.

CONCLUSION

The CCFA understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of our patients, we appreciate your consideration of our view. We look forward to working with you and your staff.

[This statement was submitted by Caren Heller, MD, Chief Scientific Officer, National Scientific Advisory Council.]

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PREPARED STATEMENT OF TAMI CUMMINGS

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## PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation (CFF) and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the Senate Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2016. The Foundation requests funding levels of at least $32 billion for the National Institutes of Health (NIH) for the coming year. We encourage special consideration and support for the National Center for Advancing Translational Sciences (NCATS) and programs under its jurisdiction, including the Cures Acceleration Network (CAN) and the Clinical and Translational Science Awards (CTSA) as well as the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung, and Blood Institute (NHLBI), which play a vital role in CF research.

We also recommend that the Committee provide robust resources to the Health Resources and Services Administration (HRSA) under the U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), particularly their work to support nationwide newborn screening programs. Further, we urge the provision of ample funding for the Center for Medicare and Medicaid Innovation (CMMI) under the Centers for Medicare and Medicaid Services (CMS) to allow this agency the resources needed to update and streamline payment systems from the traditional fee for service model.

### LONGSTANDING CUTS TO FUNDING IMPEDE AMERICAN RESEARCH AND THE ECONOMY

The National Institutes of Health is a showcase for American ingenuity. The NIH uses appropriated funds wisely and effectively to promote basic research and encourage collaboration across sectors to develop the building blocks of drug development. Basic research is a vital prerequisite for the discovery of new treatments and cures, and the level to which NIH funding has been diminished is deeply troubling and detrimental to efforts to develop treatments for serious and life threatening diseases.

According to a recent article published in the Journal of the American Medical Association, the NIH budget declined nearly 2 percent per year after the mid 2000's, totaling in a full 13 percent decrease in NIH purchasing power since 2004. This has had devastating and lasting effects on the state of American research labs both at the NIH and in collaborative programs across the country. Success rates for all investigators continue to decline, and new investigators struggle to obtain enough funding to remain in the field.

Cuts to funding at the NIH have been detrimental to those seeking funding for cystic fibrosis research. Large Center Core Grants, awarded by the NIDDK, support

shared resources and facilities for use by multiple investigators and provide much needed funding for clinical and basic cystic fibrosis research centers. As funding dwindles, competition for these grants has greatly increased, and large centers are facing the realities of losing their funding. This is not only detrimental to the individual centers, but also causes immense interruption and uncertainty in CF research overall.

While the funding provided to the NIH has been inadequate to fulfill the urgent need for basic research, work performed at the agency has had large benefits for the U.S. economy, supporting more than 402,000 jobs and $57 billion in economic output in 2012 according to a report by United for Medical Research. Increased investment in this agency can provide even greater economic payoff and support for the scientific progress that makes the United States the worldwide leader in biomedical research.

COLLABORATIVE EFFICIENCY TO PROMOTE COST-EFFICIENT RESEARCH

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and in bringing together various stakeholders in order to streamline the research process.

NIH-funded advances like the mapping of the human genome and the development of high throughput screening were essential to the creation of Kalydeco™, a cystic fibrosis treatment approved in 2012. This breakthrough drug, developed by Vertex Pharmaceuticals with significant support from the CF Foundation, is the first to treat the underlying cause of CF in those with particular genetic mutations that impact about 8 percent of the CF population.

More exciting advancements are in the pipeline, as successful phase 3 clinical trials have been completed on a combination of Kalydeco and a new compound, VX–809. This combination would treat those with the most common CF mutation, comprising about 50 percent of those with CF in the United States. A New Drug Application (NDA) has been submitted to the FDA for this treatment, and a decision is expected by July 6.

Research supported by the NIH takes place at thousands of institutions across the country, and supporting funding for these programs is a vital and efficient way to foster a rich ecosystem of collaborative public and private stakeholders all over the Nation. The CF Foundation works with the NIH to fund and organize a number of initiatives. This collaborative research model allows for an efficient, well-funded research process. For example, the OPTIMIZE study, which is jointly funded by the NIH and the CF Foundation, has brought together hospital systems in nearly 30 States to compare the effectiveness of antibiotics treatments for lung infections in those with cystic fibrosis. The Foundation urges the committee to allow cost-effective and efficient collaboration to expand by providing funding for the NIH to continue growing its efforts.

NIH also jointly funds a research program at the University of Iowa to study the effects of CF in a pig model. The program, funded through research awards from the NHLBI and the CF Foundation, bears great promise to help make significant developments in the search for a cure.

In addition, we urge the Committee to direct support toward the continuation and expansion of research networks, such as NIH's Childhood Liver Disease Research Network (ChiLDReN) consortium at the NIDDK. This successful collaboration helps researchers discover treatments not only for CF liver disease but for other diseases that affect thousands of children each year.

The CF Foundation also urges the Committee to support and facilitate collaborative efforts by the Food and Drug Administration and the National Institutes of Health, such as the Regulatory Science Initiative and initiatives that allow for the placement of employees who will be employed part-time at FDA and part-time at the National Institutes of Health (NIH). Collaboration between the NIH and FDA has the potential to help move innovative new drugs more quickly through the development process and into the hands of patients by leveraging the best ideas and ensuring that the NIH has the resources to support all aspects of the research process, including updated tools and technologies as well as adequate staff support.

THE PRECISION MEDICINE INITIATIVE

There are more than 1900 mutations of the CF gene that can impact those with CF, and with the advent of precision medicine, therapies like Kalydeco are being customized to treat a patient's specific genetic makeup. We urge the Committee to support the President's full funding request of $215 million for the Precision Medi-

cine Initiative to spearhead the research and development of therapies that treat the underlying genetic cause of different diseases.

This promising new frontier will likely necessitate changes in the structure of research being performed at the NIH. It is yet unclear if the Precision Medicine Initiative will ultimately extend to all institutes housed by the agency or if it will be a supplemental focus of several select research groups. The Foundation urges the NIH to adopt precision medicine as a focus in a wide array of applicable areas, but the undertaking of such a broad and powerful initiative is concerning given the current state of funding levels at the NIH.

The agency does not have enough support to undertake this vital initiative without drawing much needed resources from other research areas. As such, the Foundation strongly supports robust funding for this agency so that it can have the freedom it needs to promote the development of personalized therapies for serious, life threatening conditions like cystic fibrosis.

PREPARING CMMI FOR A NEW ERA OF MEDICINE

It is additionally important as the Precision Medicine Initiative is developed and the scientific community concentrates efforts on innovative new ways to treat disease, that we also support similar innovation in delivery system reform. To that end, we urge the Committee to provide adequate resources and support the work of the Center for Medicare and Medicaid Innovation (CMMI) and their work to change payment systems to reward greater quality and value of care, rather than the traditional fee for service system.

PRIORITIZING A CENTRALIZED INSTITUTIONAL REVIEW BOARD

Trials evaluating CF therapies are multi-site trials that can be slowed by repetitive review by local institutional review boards (IRBs). We commend the National Institutes of Health (NIH) for publishing and seeking comment on a policy that is intended to produce efficiencies in the clinical trials process while still protecting research participants by centralizing and simplifying the rigorous clinical trial review process.

The CF Foundation sees the NIH as the logical choice to lead the centralization of institutional review boards and requests that the committee take special consideration of the funds needed to implement this valuable initiative. At a time when research resources are restrained, efforts to reduce redundancy and improve efficiency in research are of the utmost importance.

ADVANCING TRANSLATIONAL SCIENCE AT THE NIH

The Foundation requests increased funding for NIH's National Center for Advancing Translational Sciences (NCATS), which catalyzes innovation by improving the diagnostics and therapeutics development process and removing obstacles to translating basic scientific research into treatments to make translational science more efficient, less expensive, and less risky.

The specific programs housed in NCATS are integral to this mission, including the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN), and the Therapeutics for Rare and Neglected Diseases (TRND) program. They are designed to transform the way in which clinical and translational research is conducted and funded. NIH Director Dr. Francis Collins has cited the Cystic Fibrosis Foundation's successful Therapeutics Development Network (TDN) as a model for TRND's innovative therapeutics development model.

CLINICAL TRIAL DATA SHARING

The CF Foundation is enthusiastic about the potential for clinical trials, clinical care, claims, and other healthcare-related data to be utilized to improve drug discovery and development. The Foundation has been a pioneer in the development and utilization of a robust data repository through the CF patient registry, and our Therapeutics Development Network (TDN) has successfully encouraged clinical partners to share data. We ask that Congress support efforts by the NIH to explore strategies and guidelines for clinical trial data sharing. As drug development research advances, data sharing is vital to the acceleration and efficiency of new discovery.

NATIONWIDE NEWBORN SCREENING PROGRAMS

Newborn screening is critically important to the CF community because it allows for the early detection and treatment of disease symptoms as well as early use of

CF corrector therapies, which can significantly reduce cumulative damage caused by the disease.

The Foundation urges the Committee to provide ample funding for HRSA, which evaluates the effectiveness of newborn screening and follow-up programs and provides grants for programs to improve newborn screening programs, educate parents and healthcare providers about newborn screening, and improve follow-up care for infants with a condition detected through newborn screening

We also encourage the Committee to provide adequate funding to the CDC, which is responsible for strengthening and enhancing laboratory quality assurance programs; enabling public health laboratories to develop and refine screening tests; conducting pilot studies; implementing new methods to improve detection of treatable disorders; and enhancing newborn disorder detection through the Innovative Molecular Quality Program.

CONCLUSION

Cystic fibrosis is a rare genetic disease that causes the body to produce thick mucus that clogs the lungs and other bodily systems, resulting in life-threatening infections and other complications. This is a time of great hope and optimism for the cystic fibrosis community and those with other rare diseases as more research is being done to effectively treat these life threatening conditions. Providing at least $32 billion for the National Institutes of Health as well as robust funding for other relevant agencies will not only support and expand the important work already being done in biomedical programs and translational science, but also encourage cost-efficient and effective collaboration of varied experts and stakeholders.

We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

[This statement was submitted by Robert J. Beall, Ph.D., President and CEO, Cystic Fibrosis Foundation.]

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## PREPARED STATEMENT OF ELINOR DEININGER

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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tings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF JUSTIN DERAWAY

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—$32 billion for the National Institutes of Health (NIH) at an Increase of $1 billion over fiscal year 2015. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.

—Continue focus on Digestive Disease Research and Education at NIH, including Inflammatory Bowel Disease (IBD), Hepatitis and other Liver Diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, and Celiac Disease.

—$62.82 million for the Centers for Disease Control and Prevention's (CDC) Division of Viral Hepatitis.

—$50 million for the Center For Disease Control and Prevention's (CDC) Colorectal Cancer Screening and Prevention Program.

Chairman Blunt, Ranking Member Murray, and esteemed members of the Subcommittee, thank you for the opportunity to again submit testimony to the Subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC) is a voluntary health organization comprised of 50 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong Federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at $60 billion a year.

The DDNC would like to thank the Subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends:

—32 billion for the NIH.

—$2.066 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the Subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

### INFLAMMATORY BOWEL DISEASE

In the United States today about 1.4 million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD).

These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD.

The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2016.

VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of State health departments, particularly to enhance resources available to the hepatitis State coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports $62.82 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of $50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

PANCREATIC CANCER

In 2013, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only lout of 4 patients will live 1 year after the cancer is found and only l out of 25 will survive 5 or more years. The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the Subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient

can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

DIGESTIVE DISEASE COMMISSION

In 1976, Congress enacted Public Law 94–562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

The DDNC recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address the numerous digestive disorders that remain in today's diverse population.

CONCLUSION

The DDNC understands the challenging budgetary constraints and times we live in that this Subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

[This statement was submitted by Costas Kefalas, MD, President, Digestive Disease National Coalition.]

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PREPARED STATEMENT OF MARY DIMMOCK

My name is Mary Dimmock and I am submitting this testimony on behalf of my son and the nearly one million people in the United States who suffer from Myalgic Encephalomyelitis, or ME, also called chronic fatigue syndrome (CFS) in the U.S. The Centers for Disease Control (CDC) and the National Institutes of Health (NIH) are the two primary agencies that are tasked with implementing the Federal response to ME.

ME is a devastating, chronic, neuroimmune disease that affects one million Americans as young as five. It strikes without warning and is more debilitating than congestive heart failure, multiple sclerosis, and end-stage renal disease. The most severely ill patients never get out of bed, are unable to feed themselves and cannot tolerate light or sound. Many patients are unable to work and an estimated 250,0000 are bedridden or housebound. The annual economic impact in the U.S. is $18–24 billion. There are no treatments, recovery is rare, and patients may die up to 25 years prematurely from cancer, cardiovascular disease, or suicide.

But what sets this disease apart from other devastating diseases is the response of Health and Human Services for the last 30 years, a response that has been so flawed that it has not only failed to produce a single meaningful outcome but worse, has turned ME into a pariah.

As documented in a recent report by the Institute of Medicine and a separate report by NIH's Office of Disease Prevention, there are no treatments, no diagnostics and little symptomatic relief. Many doctors believe the disease is psychological or question whether it is real. Medical care is nonexistent or inadequate at best and too often abusive and harmful. Disbelief and dismissal is widespread and leaves patients deeply stigmatized and marginalized, sometimes by their own families. As the IOM report states, there has been a "paucity of research funding" and "remarkably little research" into disease etiology, pathophysiology, treatments, diagnostics or natural history. What little research has been done is confounded by conflicting evidence from studies that include "CFS" patients who have non-specific medically unexplained fatigue but not ME. Patients too often commit suicide because of the stigma, the knowledge that no one is doing anything about ME and the lack of hope of ever getting better.

At a recent Senate appropriations hearing, NIH touted the future of precision medicine. But for ME patients, precision medicine is a pipedream because HHS has failed to provide research funding to uncover even the most basic aspects of this disease. What ME patients desperately need is any medicine capable of addressing

their core disease. What ME patients desperately need are doctors who believe they are sick and researchers who study their disease so that patients can have hope in a better future.

Our country has failed ME patients for 30 years, not because ME is an intractable scientific problem but because of misguided HHS policies and actions that include overly broad "CFS" disease definitions, erroneous medical education, an overemphasis on psychological issues, flawed or non-existent research strategies, paltry research funding, NIH institutional barriers that make it difficult to access that funding, a lack of coordination across agencies and HHS's resistance to working in open and honest collaboration with ME patients and disease experts to move this disease forward.

Underscoring all of these issues is the fact that ME has been exiled outside of the NIH institutes, academic centers and medical societies that drive research and delivery of medical care in this country. Not a single NIH institute has been willing to take responsibility for this disease, leaving ME outside of the prioritization processes that decide what diseases get funding. This lack of priority and funding along with the stigma and confusion on the nature of the disease have driven away researchers and likely resulted in the failure of any medical society to take ownership of this disease.

One objective measure of HHS's failure to respond appropriately to ME is NIH's paltry research funding; at $5 million, ME funding ranks at 226 out of 234 diseases funded, below hay fever. Spending on ME is $5 per patient while spending on multiple sclerosis, a disease with similar morbidity and lower prevalence, is $255 per patient, and spending on AIDS is $2,482 per patient, even though AIDS is now a livable disease. Dr. Nancy Klimas, an immunologist who treats both HIV/AIDS patients and ME patients emphasized this point, saying that her HIV/AIDS patients are "hale and hearty" due to decades of research while her ME patients remain "terribly ill and unable to work or participate in the care of their families." What is the political calculus that has consigned ME patients to the medical waste heap?

My son is one of the victims of HHS's failures. Five years ago, he was a recent honors college graduate looking forward to graduate school when he suddenly became ill with ME. Since then, he has been unable to work or go to school, can no longer read or write more than simple paragraphs, cannot tolerate noise, and is largely homebound and often bedbound. Not only are there no treatments but doctors have told him he is just depressed; is on the "wrong life path;" and that he just "wants" to get onto disability, as though that is preferable to the vibrant life he lost. The painful fact is that as things stand today, he will likely spend the rest of his life in terrible debility until he dies prematurely. A promising life crushed by the neglect and disdain of his own government.

For years, ME patients, experts and HHS' own advisory committee (CFS Advisory Committee) has made repeated recommendations for more money, specific types of research, changes to CDC's medical education, an overall strategy, and an appropriate disease definition. Congress has conducted a GAO investigation, has provided guidance through its appropriations process back to at least 1995 and has written letters to HHS with targeted requests. All of these have been largely ignored, with HHS stating that there "remains a lack of definitive evidence regarding the etiology, diagnosis, and treatment" and there are too few interested researchers to warrant more money. This is ironic given that it is HHS that has created this situation and also rings as untrue in the face of the exciting findings from research that is privately funded, largely by wealthy patients. HHS has also said that "the [HHS] agencies have the responsibility for determining funding for all diseases and conditions, unless directed by Congress" but HHS's agency prioritization and budget stewardship processes have utterly failed to provide for ME because it is exiled outside of those processes.

It is scientifically inexcusable and morally wrong that one million terribly disabled Americans have been mistreated and discarded in this way for so many years. This must stop now and for that to happen, Congress must act. Congress must address the government's failure to confront the disease of ME by directing HHS to provide:

—A fair share of funding for biomedical research commensurate with the burden of this disease and aggressively applied to validate existing findings and study the known gaps in etiology, pathophysiology, diagnostics and treatments. Based on the level of funding provided to similarly disabling but lower prevalence diseases, a fair share would be roughly $250 million a year. If the President's budget is passed, a portion of the $1 billion in new funding for NIH should be directed to meet this critical, unmet need. Otherwise, NIH's current prioritization processes must be revised to address the unmet needs of diseases

that fall outside of its institutes. There are no excuses for not providing a fair share of research funding.

—Regional centers of excellence to address the critical need for multi-disciplinary research and the critical gaps in effective, accessible medical care for patients.

—A definitive, time-bound plan to reverse the organizational and institutional barriers resulting from ME being exiled outside of NIH's segmented Institute structure.

—A disease definition such as the Canadian Consensus Criteria for both clinical care and research that accurately describes ME and differentiates it from the overly broad and non-specific "CFS" disease definitions and the "CFS" label.

—A plan to replenish the aging population of researchers and clinicians before it is too late for the next generation to learn from them.

—Disease appropriate clinical guidance and medical education that teaches doctors about the true nature of ME and the best practices to diagnose and treat it.

—A proactive medical education campaign to counter the false beliefs about ME that have been perpetuated for decades.

—A community-driven comprehensive, fully funded, cross-agency strategy, with well defined objectives, timelines and measurable benchmarks and infused with the sense of urgency warranted by the debility of this disease. Such a plan must aggressively foster the academic and drug industry investment that will be required to help these patients.

—A new model for engaging the key stakeholders—the ME patients and disease experts—that is characterized by listening, openness, transparency and collaboration.

I appreciate the Subcommittee's consideration of these requests an am available to answer any questions or provide additional background.

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PREPARED STATEMENT OF DONNA J. DORGAN

Dear Senators: Thank you for the opportunity to address your Committee.

Currently, the Department of Labor does not account for all the money and time spent defending Senior Executive Service managers and senior management officials who engage in discrimination and other inappropriate activities.

The DOL paid out $820,000 to settle the Whitmore whistleblower retaliation case. Whitmore worked for OSHA and OSHA is charged with protecting whistleblowers. The $820,000 does not account for the hundreds of hours spent by Department of Labor and Department of Justice employees trying to justify and defend the Department.

The situation is more egregious in the Employee Benefit Security Administration. For example, the DOL paid out $1.5 million to settle three discrimination lawsuits to former EBSA employees Janet Schmidt, Ekatrina Uzylan and Karin Weng. The DOL and DOJ expended hundreds of hours defending management through a scorched earth policy of litigation. Meanwhile the discriminating officials continued to work for the Department, receive bonuses and promotions. The same officials were involved in all three cases. These are but a few examples.

The problems are not limited to discrimination. For example, one EBSA manager viewed pornography on the government computer. When an employee complained, she was transferred, not the manger. It is analogous to the response of the Catholic Church to priest sex abuse.

Another SES manager, Jonathan Kay, has served on the board of the Working Theater while serving as the Regional Director of the New York Regional Office of EBSA. At the same time, his wife, Patricia Rodenhausen Kay, was the Regional Solicitor of Labor in New York.

Mr. and Mrs. Kay engaged in fundraising activities and made donations to the Working Theater. Neither he nor his wife recused themselves from Department of Labor investigations or cases involving board members, their organizations or donors to the Working Theater. Many of the members were associated with Taft-Hartley benefit plans and labor unions.

Since EEO payments and litigation costs are not allocated to specific agencies, they do not account for these funds; it is buried in the budget.

It is respectfully submitted that the DOL account for the all funds, including hours and time spent by employees, that it expends defending managers who engage in inappropriate activities. Managers who are found to have committed the acts, should be terminated, not promoted.

Respectfully yours,

Donna Dorgan

PREPARED STATEMENT OF MARTHA M. DWYER

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

My brother Thomas Dwyer, who is 58, has resided at Southbury Training School ("STS"), a congregate facility in Southbury, CT, since 1973. He is profoundly what was called "retarded" and is severely autistic and bi-polar and has Parkinsons and PICA. Tommy is receiving excellent care from a trained and experienced staff many members of which have known and cared for him for years. STS is his home and its staff is the part of his family that he sees regularly. In addition, it is on a beautiful campus, has a care unit that minimizes his hospital stays, nurses and doctors who know him on staff, a dental clinic, specialists who visit who are familiar with his conditions and a level of care that cannot be matched in the community.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

Please protect my brother and others like him and include the requested language in your Labor, HHS, and Education and Related Agencies bill.

Thank you for your attention, Martha M. Dwyer

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## PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2016

—Provide $32 billion for the National Institutes of Health (NIH) and proportional increases across its Institutes and Centers
—Continue to support natural history studies on dystonia, like the Dystonia Coalition within the Rare Disease Clinical Research Network (RDCRN) coordinated by the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS)
—Expand dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and other Communication Disorders (NIDCD), the National Eye Institute (NEI), and NCATS

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful for controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

### DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

The DAN urges the Subcommittee to continue its support for natural history studies on dystonia that will advance the pace of clinical and translational research to find better treatments and a cure. In addition, Congress should support NINDS, NCATS, NIDCD, and NEI in conducting and expanding critical research on dystonia.

Currently, dystonia research at NIH is supported by the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the Dystonia Coalition, a partnership between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The Dystonia Coalition has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. Studies like the Coalition remain a priority for the community and Congress should continue to support these initiatives.

The majority of dystonia research at NIH is supported by NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids.

In summary, the DAN recommends the following for fiscal year 2016:

—Provide $32 billion for NIH and a proportional increase for its Institutes and Centers

—Support natural history studies on dystonia like the Dystonia Coalition, part of the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS

—Expand the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and NCATS

THE DYSTONIA ADVOCACY NETWORK

The Dystonia Medical Research Foundation submits these comments on behalf of the Dystonia Advocacy Network (DAN), a collaborative network of five patient organizations: the Benign Essential Blepharospasm Research Foundation, the Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, the National Spasmodic Torticollis Association, and ST/Dystonia, Inc. The DAN advocates for all persons affected by dystonia and supports a legislative agenda that meets the needs of the dystonia community.

DMRF was founded in 1976. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

[This statement was submitted by Janet Hieshetter, Executive Director, Dystonia Medical Research Foundation.]

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PREPARED STATEMENT OF JAYMIE EASTERLING

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF ELDER JUSTICE COALITION

Chairman Blunt, Ranking Member Murray: On behalf of the bipartisan Elder Justice Coalition and its 3,000 members, we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed $25 million funding for the Elder Justice Act.

Our topic has been and must always be a bipartisan issue: preventing elder abuse, neglect and exploitation. We ask this Subcommittee to provide this funding in a bipartisan fashion as part of the solution to the national disgrace of elder abuse.

Elder abuse is a large and growing problem in our society. According to Department of Justice figures, there are more than six million victims of elder abuse per year; roughly one of every ten persons over 60 will end up a victim of elder abuse. However, a New York State study found for every elder abuse case known to agencies, twenty-four were unreported. Victims of elder financial abuse lose an estimated $2.9 billion per year, which can include entire life savings. A new study published by True Link Financial found that the problem of financial exploitation may be as great as $36 billion per year. One-half of those with dementia will fall victim to elder abuse, neglect and/or exploitation. In short, the situation is dire.

The Elder Justice Act, passed in 2010, would address these problems. The Act, if funded, would strengthen the State Long-Term Care Ombudsmen Program. It would provide for the development of forensic centers to study the problem of abuse and how we can better detect abuse and potential abusers. It would also enhance and train long-term care staffing in facilities.

Funding for the Elder Justice Act has not been made in order to fulfill the provisions of the Act. We are very grateful for the first-time funding this Committee made last year for the Act in the amount of $4 million, but the Act needs more of an investment in order to fulfill its potential. This is why we support funding for the Act at the proposed $25 million level.

The funding request includes:

—$15 million for additional demonstration grants to expand participation in the National Adult Maltreatment Reporting System (NAMRS, a national APS data collection system) to up to 15 additional States, bringing approximately 45 percent of the 56 APS jurisdictions online in the second year of implementation. (The fiscal year 2015 funding is being distributed through competitive grants to approximately ten States.)

—$3 million to operate, maintain, and provide technical assistance to the NAMRS system.

—$3.25 million to analyze and evaluate APS services nationwide for effectiveness, evidence-based and best practices, continuing work begun in fiscal year 2015.
—$3 million for research into screening for elder abuse, neglect and exploitation, and foundational research.
—$0.75 million for program implementation and oversight.

Data collection is essential to understanding and preventing elder abuse. Other forms of crime, such as child abuse, have standardized national databases. The National Child Abuse and Neglect Data System (NCANDS) database has been in existence since 1998. This allows States to more easily discover trends and researchers to learn about perpetrators and victims. Further, a lack of data has hurt the elder justice community's efforts to call awareness to the problem of elder abuse and to compete effectively for resources in an era where data often drives dollars. Continuing the work started in fiscal year 2013 with the Prevention and Public Health Fund money which established NAMRS and continued with the $4 million appropriated in fiscal year 2015 is vital for consistency in the field.

The Coalition also supports the evaluation and analysis of APS programs using an evidence-based approach and best practices. To be effective, APS programs must have consistency and high quality nationally. Elder abuse happens in all States and congressional districts, and in some cases, elder abuse happens across county and State lines. Thus, having uniform best practices is key to ensuring that victims receive uniform services.

Research in the elder abuse field, like data collection, is desperately needed. Money has never been specifically appropriated for research; the limited resources the field has go straight into assisting victims. However, victims can be more appropriately—and cost-effectively—assisted if they are identified early via effective screening. A great deal of trauma can be prevented with effective screening. Thus, research into how to screen accurately is exceedingly important.

This increased investment of $25 million would mean that current Federal and State resources could be used more effectively while also responding to elder abuse systematically. For these reasons as well as the potential of lowering rates of future victimization the investment would provide a solid return on investment.

This is an investment because, according to the National Center on Elder Abuse, the direct medical costs associated with elder abuse now exceed $5 billion annually. Since these victims are older adults, Medicare and Medicaid bear the bulk of these costs. Other Federal programs may end up paying for elder abuse victims, including income support programs, because financial abuse victims who were once self-supporting may lose everything in one scam. We can begin to save money for the Federal government if we make this relatively small investment today.

We also support maintaining, if not increasing, the amount of money available for Social Services Block Grant programs, which in addition to providing APS funding, also provides important funding for supportive services available to elder abuse victims. APS is primarily funded through optional State distributions from their Social Services Block Grant allotment; only 37 States provide any additional Federal funding for their Federal APS programs.

Elder abuse victims can be household names like the late Mickey Rooney, Brooke Astor, or Casey Kasem. We offer our testimony for them today but also for those who are not known to the public. The people you have never heard of, the stories that don't even make the local news, are the ones who need a voice that can be heard in this testimony.

Since the Elder Justice Act has many more important provisions that are not funded in this proposal, please view this $25 million as a floor to build on, and not a ceiling. We look forward to working with you to ensure that this elder justice appropriation provides us with the best possible return on investment and outcomes.

Thank you for your past and future support.

[This statement was submitted by Robert Blancato, National Coordinator, Elder Justice Coalition.]

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## PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Mr. Chairman Alexander, Ranking Member Murray, and Members of the Subcommittee: We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 31 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the Subcommittee

begins consideration of funding for programs in fiscal year 2016, the Alliance** urges you to provide adequate funding for programs designed to increase the number of healthcare professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard.

Today's healthcare workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. It is estimated that an additional 3.5 million trained healthcare workers will be needed by 2030 just to maintain the current level of access and quality. Without a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, the Health Resources and Services Administration (HRSA) has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities.

Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately $450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 71 percent increase from today's 41 million older adults. That is why Title VII and Title VIII geriatrics programs and Administration for Community Living (ACL) programs that support family caregivers, and the research efforts of the National Institute on Aging are so critical to ensure that there is a skilled eldercare workforce and knowledgeable, well-supported family caregivers available to meet the complex and unique needs of older adults.

We hope you will support a total of $44.7 million for geriatrics programs in Title VII and Title VIII of the Public Health Service Act, $197.5 million for programs administered by ACL, $1.67 billion to support the research efforts of the NIA, and $6.7 million for additional workforce programs in HRSA. Specifically, we recommend the following levels:

—$44.7 million for Title VII and Title VIII Geriatric Workforce Enhancement Program;
—$197.5 million for Family Caregiver Support Programs; and
—$6.7 million for additional workforce programs from HRSA.

Geriatrics health profession training programs are integral to ensuring that America's healthcare workforce is prepared to care for the Nation's rapidly expanding population of older adults.

In light of current fiscal constraints, EWA specifically requests $44.7 million in funding for the following programs administered through the Health Resources and Services Administration (HRSA) under Title VII and VIII of the Public Health Service Act. In the 2012–2013 Academic Year, these geriatrics and gerontology programs provided training to more than 200,000 individuals.

*Title VII and Title VIII Geriatric Workforce Enhancement Program: Appropriations Request: $44.7 Million*

The Geriatrics Workforce Enhancement program is the only Federal program that increase the number of faculty with geriatrics expertise in a variety of disciplines who provide training in clinical geriatrics, including the training of interdisciplinary teams of health professionals. In December 2014, the Health Resources and Services Administration announced they will combine the Title VIII Comprehensive Geriatric Education Program and the Title VII Geriatric Academic Career Award, Geriatric Education Centers, and Geriatric Training for Physicians, Dentists and Behavioral and Mental Health Providers programs into the Geriatrics Workforce Enhancement Program to provide greater flexibility to grant awardees by allowing applicants to develop programs that are responsive to specific interprofessional geriatrics education and training needs of their communities. In May 2015, HRSA plans to make 40 awards. Our modest funding request increase would allow for 50 awards.

—*Title VII Geriatrics Workforce Enhancement Program*.—This program provides health professions schools and training programs support to provide interprofessional geriatrics education and training responsive to specific needs of their communities. EWA requests $34.4 million.
—*Alzheimer's Disease Prevention, Education, and Outreach Program*.—These funds allow HRSA to expand efforts to provide interprofessional continuing edu-

** The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.
The Eldercare Workforce Alliance is a project of The Advocacy Fund.

cation to healthcare practitioners on Alzheimer's disease and related dementias, utilizing the newly developed Geriatric Workforce Enhancement Programs. EWA requests $5.3 million.

—*Comprehensive Geriatric Education Program*.—This program provides support to train and educate individuals in providing geriatrics care for the elderly. Program goals are accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees in geriatric nursing, long-term care, gero-psychiatric nursing or other nursing areas that specialize in the care of the elderly population. EWA requests $5 million.

*Administration for Community Living Family Caregiver Support: Appropriations Request: $197.5 million*

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

—*Family Caregiver Support Services*.—This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that help family caregivers in caring for their loved ones at home for as long as possible. EWA requests $161 million.

—*Native American Caregiver Support*.—This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services. EWA requests $7 million.

—*Alzheimer's Disease Support Services*.—One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. Funds go towards evidence-based interventions and expand the dementia-capable home and community-based services, enabling older adults to remain in the community for as long as possible. EWA requests $9.5 million.

—*Lifespan Respite Care*.—This program funds grants to improve the quality of and access to respite care for family caregivers of children or adults of any age with special needs. EWA requests $5 million.

—*Family Support Initiative*.—The new initiative will encourage use of community assets and opportunities to help families reduce stress, improve emotional well-being, develop support skills and knowledge, and plan for the future. Special attention will be given to efforts that assist families with balancing workforce participation and caregiving responsibilities, and those facing the dual demands of caring for older parents while raising children and/or supporting a family member with disabilities. EWA requests $15 million.

*National Institute on Aging: Appropriations Request: $1.67 billion*

The National Institute on Aging, one of the 27 Institutes and Centers of the National Institute of Health, leads a broad scientific effort to understand the aging process in order to promote the health and well-being of older adults. Funding will aid in researching training initiatives for the workforce that cares for older adults and research on physician-family communications during end-of-life and critical care.

*Additional Workforce Programs under HRSA: Appropriations Request: $6.7 million*

—*National Health Care Workforce Commission*.—The National Health Care Workforce Commission, established by the ACA, plays a central role in formulating a national strategy for bolstering the healthcare workforce in order to meet the needs of the burgeoning numbers of older Americans. On behalf of the members of the Eldercare Workforce Alliance, thank you for your past support for geriatric workforce programs. EWA requests $3 million.

—*Geriatric Career Incentive Awards Program*.—Congress authorized this program through the ACA. Assuming it is extended, these funds foster greater interest among a variety of health professionals in entering the field of geriatrics, long-term care, and chronic care management. EWA requests $3.3 million.

—*Training Opportunities for Direct Care Workers*.—In the ACA, Congress approved a program administered by HHS that will offer advanced training opportunities for direct care workers. While this vital training program was left out of President Obama's budget, EWA believes Congress must extend and fund it to create new employment opportunities by offering new skills through training. EWA requests $3.4 million.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatrics workforce programs and ask that you join us in supporting the eldercare workforce at this critical time—for all older Americans deserve quality care, now and in the future. Thank you for your consideration.

[This statement was submitted by Nancy Lundebjerg, MPA, and Michéle Saunders, DMD, MS, MPH, Alliance Co-Convener.]

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## PREPARED STATEMENT OF THE EMERGENCY NURSES ASSOCIATION

The Emergency Nurses Association (ENA), with more than 40,000 members worldwide, is the only professional nursing association dedicated to defining the future of emergency nursing and emergency care through advocacy, expertise, innovation, and leadership. Founded in 1970, ENA develops and disseminates education and practice standards and guidelines, and affords consultation to both private and public entities regarding emergency nurses and their practice. ENA has a great interest in the work of the Senate Labor, Health and Human Services, Education Subcommittee and especially its efforts to improve the quality of emergency care for patients in the United States.

For fiscal year 2016, ENA respectfully requests $28 million for Trauma and Emergency Care Programs (HHS; ASPR), $244 million for Nursing Workforce Development programs (HHS; HRSA), $21.116 million for the Emergency Medical Services for Children program (HHS; HRSA), $30.1 million to fund poison control centers (HHS; HRSA), $150 million for the National Institute of Nursing Research (HHS; NIH), and $8.927 million for Rural Health—Access to Emergency Devices (HHS; HRSA).

### TRAUMA AND EMERGENCY CARE PROGRAMS

Trauma is the leading cause of death for persons younger than 44 and the fourth-leading cause of death for all ages. In states with an established trauma system, patients are 20 percent more likely to survive a traumatic injury. Further, victims of traumatic injury treated at a Level I trauma center are 25 percent more likely to survive than those treated at a general hospital.

Our trauma and emergency medical systems are designed to transport seriously injured individuals to trauma centers quickly. However, due to a lack of financial resources, 45 million Americans do not have access to a major trauma center within the "golden hour" following an injury when chances of survival are highest.

Trauma and emergency care programs, which are authorized under the Public Health Service Act, provide much-needed money to the States to develop and enhance of trauma systems. These programs are critical to the efficient delivery of services through trauma centers, as well as to the development of regionalized systems of trauma and emergency care that ensure timely access for injured patients to appropriate facilities. This modest investment can yield substantial returns in terms of cost efficiencies and, most importantly, saved lives.

Therefore, ENA respectfully requests $28 million in fiscal year 2016 for trauma and emergency care programs.

### NURSING WORKFORCE DEVELOPMENT PROGRAMS

The nursing profession faces significant challenges to ensure that there will be an adequate number of qualified nurses to meet the growing healthcare needs of Americans.

A growing elderly population will seek healthcare services in a multitude of settings and the care they depend upon will require a highly educated and skilled nursing workforce. In addition, demand for nurses will grow because of the increased emphasis on preventative care and the growing number of Americans with health insurance. A 2014 projection from the U.S. Bureau of Labor Statistics' 2014 Occupational Outlook Handbook anticipates that the number of practicing RNs will grow 26 percent by 2020 and the employment of Advanced Practice Registered Nurses will grow even more rapidly.

At the same time, the aging of the Baby Boom generation will deplete the nursing ranks as well. During the next 10 to 15 years, approximately one-third of the current nurse workforce will reach retirement age. The retirement of these experienced nurses has the potential to create a serious deficit in the nursing pipeline. At the same time, our colleges cannot keep up with the demand for new nurses. According to a 2013–2014 survey by the American Association of Colleges of Nursing, 78,089 qualified applications were turned away from nursing schools in 2013 alone.

Title VIII Nursing Workforce Development programs address these factors and help support the training of qualified nurses. They not only enhance nursing education at all levels, from entry-level to graduate study, but they also support nursing schools that educate nurses for practice in rural and medically underserved communities. Another important part of Title VIII is the Faculty Loan Program which is critical to alleviating the large shortage in nursing faculty. Overall, more than 65,000 nurses and nursing students were trained and educated last year with the help of Title VIII nursing workforce development programs.

Therefore, ENA respectfully requests $244 million in fiscal year 2016 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act.

EMERGENCY MEDICAL SERVICES FOR CHILDREN

The Emergency Medical Services for Children (EMSC) program is the only Federal program that focuses specifically on improving the pediatric components of the emergency medical services (EMS) system. EMSC aims to ensure state-of-the-art emergency medical care for ill and injured children or adolescents; that pediatric services are well integrated into an EMS system backed by optimal resources; and that the entire spectrum of emergency services is provided to children and adolescents no matter where they live, attend school, or travel.

The Federal investment in the EMSC program produces a wide array of benefits to children's health through EMSC State Partnership Grants, EMSC Targeted Issue Grants, the Pediatric Emergency Care Applied Research Network, and the National EMSC Data Analysis Resource Center.

Therefore, ENA respectfully requests $21.116 million in fiscal year 2016 for the EMSC program.

POISON CONTROL CENTERS

Poisoning is the second most common form of unintentional death in the United States. In 2009, 31,768 deaths nationwide were attributed to unintentional poisoning. Children are especially vulnerable to injury by poisoning and each day 300 children are treated for poisoning in emergency departments across the country and two die.

The Nation's 55 poison control centers handle 3.4 million calls each year, including approximately 680,000 calls from nurses and doctors who rely on poison centers for an immediate assessment and expert advice on poisoning cases.

Not only are America's network of poison centers invaluable for treating victims of poisonings, but the work of the centers also results in substantial savings to our healthcare system. About 90 percent of people who call with poison emergencies are treated at home and do not have to visit an emergency department. In more severe poisoning cases, the expertise provided by poison control centers can decrease the length of hospital stays. It has been estimated that every dollar spent on America's poison control centers saves $13.39 in healthcare costs and lost productivity. The positive impact to the Federal budget is also significant. A 2012 study by the Lewin Group found that poison control centers resulted in $313.5 million in savings to Medicare and $390.2 million in savings to Medicaid.

Therefore, ENA respectfully requests $30.1 million in fiscal year 2016 for poison control centers.

THE NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR's mission is to promote and improve the health of individuals, families, communities, and populations. The Institute supports and conducts clinical and basic research on health and illness to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and improve palliative and end-of-life care.

NINR nurse-scientists examine ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation. Our country must look toward prevention as a way of reducing healthcare expenditures and improving outcomes. The work of NINR is an important part of this effort.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our Nation's nursing schools.

Therefore, ENA respectfully requests $150 million in fiscal year 2016 for the NINR.

RURAL AND COMMUNITY ACCESS TO EMERGENCY DEVICES PROGRAM

Fewer than 10 percent of people who suffer a cardiac arrest outside of a hospital setting survive. According to a 2011 study published in the New England Journal of Medicine, immediate CPR and prompt defibrillation using an automated external defibrillator (AED) can more than double a patient's chance of survival.

The Health Resources and Services Administration (HRSA)'s Rural and Community Access to Emergency Devices Program saves lives of patients with cardiac arrest. Between August 1, 2008, and July 31, 2010, nearly 800 cardiac arrest victims were reportedly saved through this program. Funding for this initiative is used to buy AEDs, locate them in public places where cardiac arrests are more likely to happen, and instruct lay rescuers and first responders in their use. Between March 1, 2010, and Feb. 28, 2011, 3,928 AEDs were placed and 28,776 people were trained in their use.

Therefore, ENA respectfully requests $8.927 million in fiscal year 2016 for the Rural and Community Access to Emergency Devices Program.

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## PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society thanks the Subcommittee for the opportunity to submit the following testimony regarding fiscal year 2016 Federal appropriations for biomedical research.

The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 18,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of basic and clinical scientists who receive Federal support from the NIH to fund endocrine-related research including diabetes, cancer, fertility, aging, obesity and bone disease. The Society's membership also includes clinicians who depend on new scientific advances to better treat and cure their patients' diseases.

*Funding for Endocrine-Related Research: An Investment in the Nation's Health*

Sustained investment by the United States Federal Government in biomedical research has dramatically advanced the health and improved the lives of the American people. The United States' NIH-supported scientists represent the vanguard of researchers making fundamental biological discoveries and developing applied therapies that advance our understanding of, and ability to treat human disease. Their research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries.

Endocrinologists are a vital component of our Nation's biomedical research enterprise and integral to the healthcare infrastructure in the United States. Endocrine researchers study how hormones contribute to the overall function of the body, and how the glands and organs of the endocrine system work together to keep us healthy.[1] Consequently, endocrinologists have a unique approach and understanding of how the various systems of the human body communicate and interact to create a comprehensive picture of health. The areas governed by the endocrine system are broad and essential to overall well-being; endocrine functions include reproduction, the body's response to stress and injury, sexual development, energy balance and metabolism, bone and muscle strength, and others. Endocrinologists study glands such as the adrenal glands, pancreas, thyroid, and specific glands of the brain including the hypothalamus. Endocrinologists also study interrelated systems, for example how the skin, liver, and kidneys work together to produce and metabolize Vitamin D.

Endocrinologists study and treat some of the most complex disease areas, such as diabetes, obesity, bone disease, thyroid disorders, and reproductive health. Many of these conditions represent growing areas of disease burden for the United States population. NIH-funded endocrine scientists continue to make remarkable contributions in areas of critical national interest, for example:

—Endocrine scientists found a direct correlation between low vitamin D levels and impaired glucose metabolism. This study helps clarify the connection between vitamin D, obesity, and diabetes and suggests that outdoor activity may also affect the risk of developing diabetes.[2]

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[1] Http://www.hormone.org/hormones-and-health/the-endocrine-system Accessed March 19, 2015.

[2] Clemente-Postigo et al., "Serum 25-Hydroxyvitamin D and Adipose Tissue Vitamin D Receptor Gene Expression: Relationship With Obesity and Type 2 Diabetes." J Clin Endocrinol Metab. 2015 Feb 23. Electronic publication ahead of print.

—Endocrine scientists discovered how the microbes living in our intestines change as people develop diabetes. This finding suggests that one's gut bacteria can help predict the risk of developing diabetes and can inform healthy eating habits.[3]

—Endocrine scientists study of obesity helped develop prevention and treatments resulting in a 43 percent decrease in the obesity rate for children age 2 to 5 years.[4, 5]

*The Future of Endocrine Research*

We are rapidly entering a new era of precision medicine. Insights into genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. Translating these new discoveries and technologies into personalized patient care offers the possibility of more effective treatments, less toxicity, increased disease prevention, improved quality of life, and lower healthcare costs. Several endocrine-specific conditions are on the cusp of a breakthrough in diagnostic testing. The ability to test for specific genetic mutations that cause the syndrome of resistance to thyroid hormone can dramatically alter potential treatment options. Additionally, rare adrenal tumors called pheochromocytomas and paragangliomas are notoriously challenging to diagnose. Genetic tests can reduce delays in diagnosis, help determine whether a tumor is likely to be malignant, and provide doctors with critical data to help monitor family members who might also carry a problematic mutation.[6] More NIH-funded basic and clinical research to help us understand how genetics can predispose us to, or protect us from disease is critical to develop and refine genetic testing strategies so that they are more reliable and more widely available.

*Sequestration Threatens Scientific Momentum*

The Endocrine Society is particularly concerned about the impact of cuts on biomedical research supported by the NIH. At a time when we should be investing more in research to save more lives, research funding is in serious jeopardy. Since 2004, the number of NIH research grants to scientists in the United States has been declining. Consequently, the likelihood of a scientist with a highly-regarded grant application successfully being awarded a new research grant has dropped from 31.5 percent in 2000 to 18.1 percent in 2014.[7] This means that experienced scientists are increasingly spending time writing grant applications instead of applying their expertise to productive research. Additionally, younger scientists struggle to find jobs that make use of the unique skills developed during graduate training.

The lack of sustained government support compounded by austerity measures such as sequestration has created an environment that is leading to a "brain drain" as brilliant scientists pursue other careers or leave the United States to develop impactful research products elsewhere. In 2013, the number of NIH supported scientists declined significantly, with nearly 1,000 NIH scientists dropping out of the workforce.[8] NIH scientists run labs that support high-quality jobs and education while generating breakthrough innovations. In 2011, the NIH directly or indirectly supported over 432,000 jobs across the country.[9] For example, as a result of sequestration, Missouri and Washington lost an estimated $24 million and $46 million respectively in fiscal year 2012.[10]

We may never be able to quantify the opportunities we have missed to improve the health and economic status of the United States due to persistent underinvestment in research. We do know however, that when "laboratories lose financing; they

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[3] Https://www.endocrine.org/news-room/current-press-releases/gut-microbial-mix-relates-to-stages-of-blood-sugar-control Accessed March 19, 2015.

[4] Casagrande et al., "The Prevalence of Meeting A1C, Blood Pressure, and LDL Goals Among People With Diabetes, 1988–2010." Diabetes Care, Aug 36;8 (2013) 2271–9.

[5] Sabrina Tavernise, "Obesity Rate for Young Children Plummets 43 percent in a Decade." The New York Times. Feb 25, 2014.

[6] Eric Seaborg, "Family History." Endocrine News, Feb. 2015. 15–17.

[7] Http://report.nih.gov/success_rates/Success_ByIC.cfm Accessed March 19, 2015.

[8] Jeremy Berg "The impact of the sequester: 1,000 fewer funded investigators." ASBMB Today. March (2014). https://www.asbmb.org/asbmbtoday/201403/PresidentsMessage/Accessed March 20, 2014.

[9] Everett Ehrlich "Engine Stalled: Sequestration's Impact on NIH and the Biomedical Research Enterprise." United for Medical Research. (2012).

[10] "NIH Sequestration Factsheet." http://www.faseb.org/portals/2/PDFs/opa/Sequestration%20factsheet.pdf Federation of American Societies for Experimental Biology. Accessed March 19, 2015.

lose people, ideas, innovations and patient treatments.[11] " Based on the personal stories of researchers who have been forced to curtail research programs, we know that research programs to understand how genetics can influence heart disease, develop therapeutic treatments for Parkinson's disease, and evaluate the effect of metal contaminants on reproductive health, among many others, are delayed or terminated.[12]

*Fiscal year 2016 NIH Funding Request*

The Endocrine Society recommends that the Subcommittee provide at least $32 billion in funding for NIH in the fiscal year 2016 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation.

It is critical that we continue to invest in biomedical research to improve the Nation's future financial situation. Rising healthcare costs threaten to consume an increasing percentage of the United States' GDP and also the individual budgets of workers and businesses.[13] The cost of diabetes, in particular, represents a staggering $245 billion in 2012 alone.[14]

Federal investment in the NIH and in programs such as the National Diabetes Prevention Program (NDPP) provides opportunities for substantial returns to the Nation. The NDPP is based on the NIH-funded Diabetes Prevention Program clinical research study which found that even modest weight loss (5–10 percent) could prevent or delay the onset of type 2 diabetes by 58 percent. As a result of these findings, the Centers for Disease Control and Prevention (CDC) implemented the NDPP, which has now been expanded to over 794 sites in 39 States; it has been estimated that the program could save the country as much as $191 billion if fully implemented. Moreover, 75 percent of these savings would benefit Federal healthcare programs that provide services for seniors and the poor—individuals who share a disproportionate risk of being diagnosed with diabetes.

We live during an age of tremendous scientific opportunity that can only be realized through Federal funding of biomedical research. Researchers are just beginning to harness the power of big data to solve complicated problems. Innovative new experiments and clinical research hold promise to solve some of the United States' greatest medical challenges and discover new ways to improve our quality of life. Government support is critical to these opportunities, and we encourage the Appropriations Committee to actively support promising and innovative research. We fully understand that the Appropriations Committee faces challenging decisions in fiscal year 2016, however we assert that additional cuts to the NIH and other non-defense discretionary programs is not the way to solve the budgetary issues facing the United States.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the Federal Government. Flat funding in recent years, combined with the impact of sequestration, threaten the Nation's scientific enterprise and make adequate fiscal year 2016 appropriations for the NIH increasingly important. The Society strongly supports increased Federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status as the preeminent research engine. The Endocrine Society therefore asks that the NIH receive at least $32 billion in fiscal year 2016.

[This statement was submitted by Lisa Fish, MD, President, The Endocrine Society.]

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## PREPARED STATEMENT OF THE ENTOMOLOGICAL SOCIETY OF AMERICA

The Entomological Society of America (ESA) respectfully submits this statement for the official record in support of funding for insect-borne disease research at the U.S. Department of Health and Human Services (HHS). ESA requests a robust fis-

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[11] Teresa K. Woodruff "Budget Woes and Research." The New York Times. September 10, 2013.

[12] Sequester Profiles: How Vast Budget Cuts to NIH are Plaguing U.S. Research Labs. United for Medical Research. http://www.unitedformedicalresearch.com/advocacy__reports/sequestration-profiles/Accessed March 20, 2014.

[13] Dan Mangan "Job health insurance costs rising faster than wages." CNBC. 9 Dec. 2014. http://www.cnbc.com/id/102249938#. Accessed March 19, 2015.

[14] Http://www.diabetes.org/advocacy/news-events/cost-of-diabetes.html Accessed March 19, 2015.

cal year 2016 appropriation for the National Institutes of Health (NIH), including the President's proposed increase in funding for insect-borne disease research at the National Institute of Allergy and Infectious Diseases (NIAID). The Society also supports the President's increased investment in the core infectious diseases budget and the global health budget within the Centers for Disease Control and Prevention (CDC) in order to fund scientific activities related to vector-borne diseases.

Advances in the biological sciences, including the field of entomology, help to address some of our most pressing societal needs related to environmental and human health. Certain species of insects carry, spread, and transmit an array of infectious diseases that threaten populations across the globe, including those in the United States as well as U.S. military personnel undertaking missions abroad. Insect-borne diseases can present an especially challenging health problem; few vaccines have been developed against them, and insects are often difficult to control and can develop resistance to insecticides. The risk of emerging infectious diseases grows as global travel becomes easier and environmental factors continue to change. For example, West Nile virus, which is transmitted by mosquitoes and was not present in the U.S. before 1999, infected 5,674 Americans in 2012.[1] Entomological research to understand the biological relationship between insect vectors and the infectious diseases they carry—such as dengue, malaria, West Nile virus, and Lyme disease—can significantly contribute to our ability to monitor and predict outbreaks, prevent disease spread and transmission, and more reliably diagnose and treat infection. Given the important role that insect vectors play in impacting human health, ESA urges the subcommittee to support vector-borne disease research programs that incorporate the entomological sciences as part of a comprehensive approach to addressing infectious diseases.

NIH, the Nation's premier medical research agency, advances human health by funding research on basic human biology and disease and the development of prevention and treatment strategies. More than 80 percent of NIH funding is competitively awarded to scientists at approximately 2,500 universities, medical schools, and other research institutions across the Nation. As one of NIH's 27 institutes and centers, NIAID conducts and supports fundamental and applied research related to the understanding, prevention, and treatment of infectious, immunologic, and allergic diseases. One example of NIAID-funded research on infectious diseases is a study examining the mechanism by which certain species of mosquitoes known to transmit dengue and malaria are attracted to humans. The scientists discovered that specific types of nerve cells in the insects act as sensitive detectors of human odors. With this knowledge, the researchers were able to identify safe and natural chemical compounds with the potential to neutralize or overwhelm the specific insect nerve cells, a discovery that could have implications for the control of mosquitoes and their associated diseases.[2] In another recent study supported by NIAID, researchers determined that live, disease-free ticks can be used as a safe tool for testing for the presence of Lyme disease bacteria in patients who have completed antibiotic therapy.[3] Lastly, the President's fiscal year 2016 budget request also spotlights advancements made in chikungunya research. Specifically, research supported by NIAID developed "a genetically engineered, live-attenuated chikungunya vaccine that protected non-human primates with a single dose and may also interrupt viral transmission in mosquitoes."[4] To ensure funding for future groundbreaking projects like these, ESA supports increased funding for NIAID and encourages the committee to support insect-borne disease research at NIH. In particular, ESA supports the President's requested increase of $94.508 million above the fiscal year 2015 enacted level for Biodefense and Emerging Infectious Diseases.

CDC, serving as the Nation's health protection agency, conducts science and provides health information to prevent and respond to infectious diseases and other global health threats, whether naturally arising or related to bioterrorism. Within the core infectious diseases budget of CDC, the Division of Vector-Borne Diseases (DVBD) seeks to protect our Nation from the threat of viruses and bacteria transmitted primarily by mosquitoes, ticks, and fleas. DVBD's mission is carried out by a staff of experts in several scientific disciplines, including entomology. For example, among the activities supported by DVBD are the ArboNET surveillance system for

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[1] CDC's Division of Vector-Borne Diseases Factsheet, http://www.cdc.gov/ncezid/dvbd/pdf/dvbd__factsheet.pdf.

[2] Tauxe, GM, et al. Targeting a dual detector of skin and CO2 to modify mosquito host seeking. Cell (2013).

[3] Marques, A, et al. Xenodiagnosis to detect Borrelia burgdorferi infection: A first-in-human. Clinical Infectious Diseases (2014).

[4] NIAID Budget Justification, fiscal year 2016, http://www.niaid.nih.gov/about/Documents/fiscal year 2016CJ.pdf.

mosquito-borne diseases, the TickNET system for tick-borne diseases, and Puerto Rico's new SaludBoricua self-reporting system that was recently expanded to include the public. ArboNET is a nationwide network that monitors West Nile virus and other diseases through activities such as the collection and testing of mosquitoes, and TickNET is a partnership between 16 States to track tick-borne-diseases like Lyme disease and test preventions. The new SaludBoricua system will help to monitor vector-borne diseases like dengue, influenza, and chikungunya in Puerto Rico. Furthermore, a component of CDC's global health budget supports activities on parasitic diseases and malaria; this includes the maintenance of a global reference insectary that houses colonies of mosquitoes from around the world to be used by the agency for studies on malaria transmission.

Specifically within the President's CDC Budget Request for fiscal year 2016, there was a proposed increase of $275.562 million for Core Infectious Diseases over the fiscal year 2015 enacted level, which includes the vector-borne diseases program. The CDC fiscal year 2016 budget justification also highlights the chikungunya virus, along with several other vector-borne diseases like dengue, West Nile virus, and Lyme disease, as vector-borne diseases program priorities. Regarding chikungunya, the justification stated, "By December 2014, a million suspect and confirmed cases had been reported from 42 countries throughout the Caribbean and South, Central, and North Americas. In addition, almost 2,000 cases have been reported in Puerto Rico, the U.S. Virgin Islands, and American Samoa. Eleven locally-acquired cases of chikungunya have been detected in Florida and over 2,000 travel-associated cases have been identified from 46 States."[5] ESA is pleased to see that chikungunya and other insect-borne diseases are an upcoming fiscal year 2016 priority for CDC and encourages the inclusion of entomological sciences in future research addressing these diseases. Given the important contributions of CDC, ESA requests that the committee provide the President's requested increased support for CDC programs addressing vector-borne diseases and malaria.

ESA, headquartered in Annapolis, Maryland, is the largest organization in the world serving the professional and scientific needs of entomologists and individuals in related disciplines. Founded in 1889, ESA has nearly 7,000 members affiliated with educational institutions, health agencies, private industry, and government. Members are researchers, teachers, extension service personnel, administrators, marketing representatives, research technicians, consultants, students, pest management professionals, and hobbyists.

Thank you for the opportunity to offer the Entomological Society of America's support for HHS research programs. For more information about the Entomological Society of America, please see http://www.entsoc.org/.

[This statement was submitted by Phil Mulder, Ph.D., President, Entomological Society of America.]

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## Prepared Statement of the Federation of American Societies for Experimental Biology

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a minimum of $32 billion in fiscal year 2016 for the National Institutes of Health (NIH) within the Department of Health and Human Services. We estimate that with a budget of $32 billion (an increase of $1.69 billion), NIH could support 522 new research project grants at current funding levels with commensurate growth for other vital agency programs.

FASEB, a federation of 27 scientific societies, represents more than 120,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. Our mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences.

NIH has produced an outstanding legacy of discoveries that have improved health, saved lives, and generated new knowledge. Many of these advances arose from scientists investigating questions designed to explain fundamental molecular, cellular, and biological mechanisms. Research supported by NIH has also expanded our understanding of the molecular roots of various cancers and led to important insights into how microbial communities affect a range of chronic diseases including obesity and diabetes. In addition, research supported by NIH led to the development of innovative technologies and created entirely new global industries that are a critical component of our Nation's economic growth.

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[5] Center for Disease Control and Prevention Justification of Estimates for Appropriation Committees, fiscal year 2016, http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations__budget__form__pdf/fiscal year 2016__CDC__CJ__FINAL.pdf.

Investment in biomedical research funded by NIH has supported discoveries that lowered death and disability from polio, heart disease, and cancer, prolonging life and reducing suffering. New scientific breakthroughs have given us the opportunity to dramatically accelerate desperately needed progress on therapies for thousands of diseases and conditions. A study published by the National Academy of Sciences found that the key enabling discovery that led to the development of 16 out of 21 drugs with the highest therapeutic impacts was made as a result of federally supported research.

NIH-funded research is continuing to produce the insights that are needed for tomorrow's improvements in health and clinical care. Recent discoveries include:

—Engineering Immune Cells to Improve Cancer Treatment Options: Researchers funded by NIH continue to make progress on immunotherapy which uses the human immune system to fight cancer. Promising results have been reported from several small clinical trials testing adoptive cell transfer (ACT) on patients with acute lymphoblastic leukemia. ACT is a technique that engineers an individual's immune cells to identify and kill tumors. Another form of ACT involves the addition of special receptors, chimeric antigen receptors, to T cells in order to change or improve their specificity.

—Creating Organs on a Chip: A new experimental technology supported through investigator-initiated research uses a series of micro-chambers, fluids, and human cells to simulate a person's internal organs. One example, lung-on-a-chip, mimics the site of oxygen exchange in the lungs, and is being developed to study lung inflammation and infection. Other organs-on-a-chip such as kidney, liver, and heart are also in development. An artery-on-a-chip was created that effectively imitates the molecular and flow conditions of early plaque development in coronary arteries. This chip was used to gauge the disease risk of individuals with high blood lipids and coronary artery plaque, and proved to be an accurate predictor of the extent of disease.

—Developing an Artificial Pancreas: NIH-funded researchers have developed an artificial pancreas that is capable of monitoring blood sugar and delivering appropriate amounts of hormones to control fluctuations in levels. A sensor implanted under an individual's skin measures his or her blood sugar and transmits the information to a smartphone application that determines the amount of insulin necessary. An implantable pump provides the insulin. This device is a critical tool for individuals with type-1 diabetes who must constantly monitor their blood sugar levels to prevent hypoglycemia and other life-threatening complications.

—Editing the Human Genome: A new transformative technology that is revolutionizing biomedical research emerged from investigations of a primitive immune-like system in bacteria. Like humans, bacteria can be infected with harmful viruses. To fight off these infections, bacteria evolved a system in which they incorporate parts of the invading viral deoxyribonucleic acid (DNA) into their own genomes. This DNA serves as both a memory of prior infection (similar to human antibodies) and the basis for directing specific and selective degradation of the viral DNA. NIH-funded investigators reasoned that this system, known as Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR), might be repurposed to edit genes in humans and mammals. CRISPR has already been used to modify genes in bacteria and eliminate Human Immunodeficiency Virus from infected cells in culture. It has also been effective in altering stem cells, which could potentially help treat a wide range of diseases.

—Identifying Compounds That May Lead to Blood Tests for Alzheimer's: As many as five million Americans over age 65 may have Alzheimer's disease today, and that number is projected to triple within the next 35 years. There is no definitive method of diagnosing Alzheimer's in individuals before symptoms appear. Using advanced technologies, a group of NIH-supported researchers analyzed the blood of individuals who had either impaired memory or Alzheimer's to search for biomarkers for early stages of the disease. They found a series of ten compounds in blood that might be able to determine which older adults are at risk for developing cognitive impairment or Alzheimer's. Further evaluation of blood samples from patients produced a preliminary test that was 90 percent accurate in differentiating healthy individuals with no cognitive impairment from those who developed memory problems within 2 or 3 years.

*Stable, Predictable Funding Is Critical to Sustain Discovery*

Stable and predictable increases in Federal funding for research supported by NIH are necessary to take advantage of unprecedented opportunities to improve quality of life, address the rising costs of caring for our aging population, and protect us from new and emerging diseases. As NIH Director Francis S. Collins, MD,

PhD, wrote in a recent viewpoint for the Journal of the American Medical Association, "The 21st century is the century of biology. The nation that invests in biomedical research will reap untold rewards in its economy and the health of its people." [1]

Appropriations for NIH have failed to keep up with inflation since 2003, reducing the agency's capacity to support research by nearly 23 percent. The fact that the NIH budget has not kept pace with rising costs also led to a 34 percent decrease in the number of R01-equivalent awards—the primary mechanism for supporting investigator-initiated research—between 2003 and 2013. In addition, the number of investigators with NIH funding for six consecutive years declined from 10,030 in the fiscal year 2000–2005 period to 9,127 in fiscal year 2008–2013, a reduction of 11 percent.[2]

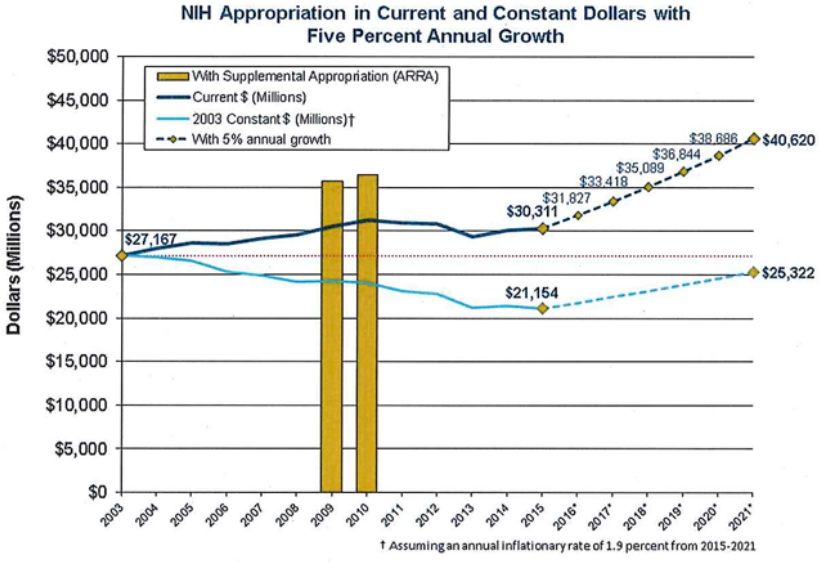
Basic research discoveries and their subsequent translation to clinical applications can take multiple years of collaboration. Budgets that are uncertain and vary in grant support from year to year make such planning difficult. The loss of personnel and scientific expertise may have long-term consequences as highly trained researchers seek employment in other fields.

Congress took an important step in the right direction by providing desperately needed increases for NIH in the fiscal year 2014 and fiscal year 2015 omnibus appropriations bills. However, the additional funding did not restore the lost purchasing power or fully replace money that was cut in 2013 due to sequestration.

To prevent further erosion of the Nation's capacity for biomedical research, and as a first installment of a multi-year program of sustainable increases, FASEB recommends an appropriation of at least $32.0 billion for NIH in fiscal year 2016.

Thank you for the opportunity to offer FASEB's support and funding recommendation for NIH.

[The graphic follows:]

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PREPARED STATEMENT OF PAUL FERRARIO

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serv-

[1] Collins, F. (2015, January 13). Exceptional Opportunities in Medical Science: A View From the National Institutes of Health. Journal of the American Medical Association.

[2] Data Hound (Berg J). Minding the Gap. Data Hound Blog, Sciencetopia. May 15, 2014.

ing people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

*After Deinstitutionalization: Medical Crises at Thirty Days and Dead by 6 Months*

My loved one resides at Sonoma Developmental Center (SDC) in Eldridge, CA. In an act of co-mingling its duties, the state Dept. of Developmental Services sponsored a bill through the "Trailer Bill" mechanism that halted new admissions to California's Developmental Centers and increased the rate of depopulating the Developmental Centers. Recently I was told by a Developmental Center employee that the medically fragile are being removed from SDC. The new law in question provides for follow up at thirty days and at 6 months after deinstitutionalization. The employee reported that the individuals are suffering medically at the thirty day period, often a result of serious medication errors, yet they are prohibited from returning to SDC; and by the six month follow-up many have died.

*Senator Feinstein Tells It Like It Is*

At her weekly Washington D.C constituent breakfast, on June 14, 2001, two parents of individuals residing in California's Developmental Centers spoke up in favor

of maintaining the centers in the face of Assembly bill 896 (Dione Aroner—D—Berkeley) that would close them all and sell off the land.

The Senator voiced her concern and said it reminded her of when Governors Reagan and Jerry Brown were closing state hospitals just as they were beginning to improve.

She added that much of today's homeless population is made up of former state hospital clients.

A member of the audience then spoke up in favor of AB 896, citing the sensational $1.5 Billion consultant's estimate to restructure the remaining Developmental Centers.

The Senator took the microphone and said: "Ma'am I'd like to tell you something." She then proceeded to recount the following:

—While Mayor of S.F. She learned that there were over 700 board and care homes in the city.
—Unannounced, she visited 25 care homes.
—She found many that were unlicensed.
—She believes in "management by walking around" so she looked everywhere, in the refrigerators, in the bathroom, in the bedrooms.
—She found very little food but a lot of drugs in the refrigerators.
—She found terrible staffing problems.

"And I'll spare you the horror stories" she added. The Senator made it loud and clear that aggressive deinstitutionalization is a failure.

Partial List of Investigative Journalism:

—L.A. officials receive video of men sexually assaulting disabled women; (Jan. 6, 2011) www.cnn.com/2011/crime/01/06/california.rape.disabled/index.html?hpt=T2
—Safety Measures Not Required in Thousands of Homes for Elderly, Disabled; June 4, 2013 Investigative Unit NBCBayArea.com; a midnight fire in Nov. 2011 Marina, CA care home killed 5 of the 6 mentally disabled and handicapped adults who lived there.
—California Regional Centers spend without public scrutiny; Sacramento Bee; Nov. 21, 2010; Jack Chang.
—Lawmaker claims quotas for moving disabled exist; State officials who oversee agencies deny charges. Alameda Newspaper Group; By Michele R. Marcucci, Staff writer; Article Last Updated:10/26/2006 05:17:03 AM PDT.
  —The nonprofit agencies charged with overseeing the care of the developmentally disabled have illegal quotas for moving them from the state institutions—homes many have known for decades-into community care, a state legislator has charged.
—San Francisco Chronicle, February, 1997—August, 1998
  —Fifty-six articles were released detailing the abuse, neglect and death that plagued California's system of community-based care for people with mental retardation following the aggressive deinstitutionalization of over 2,000 people. The articles include reference to University peer-reviewed research that finds risk of mortality to be higher in California community-based programs than in the state institutions serving people with mental retardation.
  —The California mortality studies can be accessed on the Internet at http://www.LifeExpectancy.com, link: articles (comparative mortality studies).
  —[Internet Access: http://www.psych-health.com ("developmental disabilities" link, then years 1997 and 1998) or http://www.sfgate.com/chronicle (search link—key words Lempinen and disability).
—Fatal flaws in care net for disabled-SAFETY: Gaps in group-home supervision—and abuse-endanger Californians with developmental disabilities; Orange County Register; August 24, 1997; by Kim Christensen.
—Homes' licenses hard to revoke-SOCIAL ISSUES: Even the most troublesome facilities can be difficult to shut down; Orange County Register; August 25, 1997; by Kim Christensen.
—Putting more care into community care-SOCIAL ISSUES: Programs for the developmentally disabled are fixable experts say; Orange County Register; August 26, 1997; by Kim Christensen.
—Growing Concern; Private Care for the Retarded—A Gamble; Los Angeles Times; Jan. 8, 1989; by John Hurst, Times Staff Writer. First of three articles. Next: Jenny's story.
—Retarded Woman's Story; Move Out of State Home Left Her Gaunt, Incoherent Los Angeles Times; Jan. 9, 1989; by John Hurst, Times Staff Writer. Second of three articles. Next: A group home operator.
—$1.6 Million in Real Estate; Pair Prosper By Providing Homes, Care For Retarded; Los Angeles Times; Jan. 10, 1989; by John Hurst, Times Staff Writer. Last of three articles.

## PREPARED STATEMENT OF SYBIL FINKEN

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

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Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF FOOD & FRIENDS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Food & Friends is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 1million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with

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HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

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Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

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*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Craig Shniderman, Executive Director, Food & Friends.]

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PREPARED STATEMENT OF THE FOOD BANK OF CONTRA COSTA AND SOLANO

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

The Food Bank of Contra Costa and Solano is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide enough food for over 155,000 nutritious meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth

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assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

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Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

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[This statement was submitted by Joël McClurg, CalFresh Outreach Manager, Food Bank of Contra Costa and Solano.]

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Food Outreach, Inc. is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. We have 1,800 HIV/AIDS clients who receive over half a million medically tailored meals annually. Our service area encompasses 189 zip codes in Missouri and Illinois. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

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Thank you.

[This statement was submitted by Greg Lukeman, Executive Director, Food Outreach, Inc.]

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## PREPARED STATEMENT OF SHELLY FORD

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

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Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF JAN FORTNEY

I am a parent of an adult daughter with intellectual and developmental disabilities (I/DD). My daughter receives specialized care and services in an Arkansas ICF/IID. I am writing to urge that the Subcommittee include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision makers" regarding services, supports and policies.

Medicaid law and regulation requires that ICF/IID residents be "Given the choice of either institutional or home and community-based services."

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## Prepared Statement of the Friends of the Health Resources and Services Administration

Friends of HRSA is a non-partisan coalition of 170 national organizations representing millions of public health and healthcare professionals, academicians and consumers invested in HRSA's mission to improve health and achieve health equity. For fiscal year 2016, we recommend restoring HRSA's discretionary budget authority to the fiscal year 2010 level of $7.48 billion. We are concerned that since fiscal year 2010, HRSA's discretionary budget authority has been cut by 18 percent in nominal dollars and 24 percent when adjusted for inflation. Funding for HRSA is too low to address the Nation's current health needs, let alone keep pace with the growing health demands.

Research has shown that access to high-quality primary care improves health and reduces costs. As health coverage increases nationally and we experience a growing, aging and more diverse population, alongside health professionals nearing retirement age, it is ever more critical to make investments that improve access and support a high-performing workforce capable of meeting the changes and expected increases in healthcare demands. Not only are there current and projected shortages in the health professional workforce nationwide, many communities, both urban and rural, experience persistent shortages and lack access to care due to a geographic maldistribution of providers. Restoring funding to HRSA will allow the agency to more effectively fill the preventive and primary care gaps for people living outside of the medical and economic mainstream where the need has been demonstrated and is reflected by suboptimal health outcomes.

HRSA operates programs in every State and U.S. territory and is a national leader in improving the health of Americans by supporting a workforce of sufficient size and skill, and providing high-quality health services. HRSA programs work synergistically and in coordination with each other to maximize resources and leverage efficiencies. For example, Area Health Education Centers, a health professions training program, was originally authorized at the same time as the National Health Service Corps to create a complete mechanism to provide primary care providers for health centers and other direct providers of healthcare services for underserved areas and populations. AHECs serve as an integral part of the mechanism that recruits providers into primary healthcareers, diversifies the workforce and develops a passion for service to the underserved in these future providers.

In addition to internal coordination, HRSA is also working to increase coordination across the Federal Government to enhance the collective impact of improved health outcomes. Through maternal and child health programs, HRSA has contributed to the decrease in infant mortality rate, a widely used indicator of the Nation's health. HRSA programs have helped reduce AIDS-related deaths through providing drug treatment regimens for people living with HIV and have the potential to prevent the spread of HIV by 96 percent by ensuring that people living with HIV have access to regular care and adhere to their antiretroviral medications. The Title X Family Planning Program, the only Federal grant program dedicated to providing people with comprehensive family planning and related preventive health services,

has greatly contributed to decreasing unintended pregnancy—helping to prevent an estimated 870,000 unintended pregnancies in 2013.

Now is the time to make a strong investment in a robust workforce and to improve access to care to continue achieving the health improvements HRSA has made and to pave the way for new achievements. The Nation only stands to benefit from a healthier population which can translate into a stronger and better functioning Nation, a thriving and productive workforce, and reduced healthcare costs. Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs including:

—Health workforce programs support the education, training, scholarship and loan repayment of primary care physicians, nurses, oral health professionals, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the Nation's changing demographics. For example, HRSA provides interdisciplinary education and training to health professionals to improve care for special populations such as older adults.

—Primary care programs support more than 9,000 health center sites in every State and territory, improving access to preventive and primary care for more than 21 million patients in geographically isolated and economically distressed communities. For nearly 50 years health centers have provided quality services. Health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services—often delivering the range of services in one location. Close to half of all health centers serve rural populations. In addition, health centers target populations with special needs, including agricultural workers, homeless individuals and families and those living in public housing. As health insurance expands, health centers and other programs administered by HRSA will continue to play a critical role in the healthcare system serving as vital source of care for newly insured patients, and remaining an important source of care for those who cannot gain access to coverage.

—Maternal and child health programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality healthcare for 42 million women and children. MCH programs help assure that nearly all babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that a community-based system of family centered services is available for coordinated long-term follow up for babies with a positive screen and for all children with special healthcare needs such as children with autism and other developmental disabilities.

—HIV/AIDS programs provide the largest source of Federal discretionary funding assistance to States and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for about half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.

—Family planning Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for over 4.5 million women, men and adolescents. Healthcare services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. Title X service sites provide the only continuing source of healthcare and education for four out of ten women, and six out of ten women consider it their main source of care.

—Rural health programs improve access to care for the nearly 50 million people living in rural areas that experience a persistent shortage of healthcare services. The Office of Rural Health Policy serves as the Nation's primary voice for programs and research on rural health issues. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program and other programs are designed to support community-based disease prevention and health promotion projects,

help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas. In addition to improving the health of rural residents, a recent analysis completed in 2013 showed that for every dollar HRSA invested, about $1.63 in additional revenue was generated in the community—the cumulative impact added up to $19.4 million in new local economic activity over a 3-year project period of an original investment of $11.9 million.

—Special programs include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Special programs also include the Poison Control Program, the Nation's primary defense against injury and death from poisoning for over 50 years. For every dollar spent on the poison center system, $13.39 is saved in medical costs and lost productivity, totaling more than $1.8 billion every year in savings.

Strong and sustained investments in public health and prevention programs are essential to meeting the health challenges facing our Nation. Unfortunately, the current austerity measures in place pose a threat to the agency's ability to adequately and effectively respond to the evolving healthcare needs of patients and families, and as a result may compromise public health and lead to increased costs to our healthcare system. We urge you to consider HRSA's central role in strengthening the Nation's health and advise you to adopt our fiscal year 2016 request of $7.48 billion for HRSA's discretionary budget authority. Thank you for the opportunity to submit our recommendation to the subcommittee.

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PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Chairman Blunt, Ranking Member Murray, and members of the Committee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), www.friendsofnia.org, a coalition of more than 50 academic, patient-centered and non-profit organizations that supports the research and training missions of the National Institute on Aging (NIA) by promoting and advocating for the NIA and its initiatives as public policies in health and research take shape. We appreciate the opportunity to provide testimony in support of the NIA and to comment on the need for sustained, long-term growth in aging research funding. Considering the resources the Federal Government spends on the healthcare costs associated with age-related diseases, we feel it makes sound economic sense to increase Federal resources for aging research. Specifically, given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends an additional $500 million in the fiscal year 2016 National Institutes of Health (NIH) budget to support biomedical, behavioral, and social sciences aging research efforts at the NIH. We believe that this funding is the minimum essential to sustain research needed to make progress in attacking the chronic diseases that are driving significant increases in our national healthcare costs. In addition, to ensure that overall NIH research progress continues, the Coalition endorses the Ad Hoc Group for Medical Research in supporting at least $32 billion for NIH in fiscal year 2016.

NIA's mission is urgent. The number of Americans aged 65 and older is growing at an unprecedented rate. By 2030, there will be 72 million Americans in this age group; more than double the number from 2000. The number of "oldest old"—people age 85 or older—is expected to more than triple between 2010 and 2050. Age is a primary risk factor for many disabling diseases and conditions—most notably, Alzheimer's disease (AD). The NIA is the primary Federal agency responsible for AD research and receives nearly 70 percent of the NIH Alzheimer's disease research funding. We know that as many as 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.2 million by 2050. NIA's comprehensive AD research program spans the spectrum of discovery, from basic neuroscience through translational research and clinical application. The National Alzheimer's Plan, 2012 and 2015 Research Summits, and allocation of additional funds from the NIH Director in 2012 and 2013 have accelerated momentum in this field. In 2016, several exciting trials incorporating biomarkers of disease will be active). NIA will also continue to support treatment trials to slow the disease or alleviate its symptoms, such as the recent study in which NIA-supported researchers found that the anti-depressant citalopram may be a safer and more effective treatment for disruptive agitation in AD than the treatments currently in use.

Efforts in AD research have been bolstered by the advent of new technologies to generate and analyze enormous data sets. These new technologies have been particularly effective in identifying risk and protective genes for AD. Researchers can now access the first batch of genome sequence data from the Alzheimer's Disease Sequencing Project (ADSP), a collaboration between the NIA and the National Human Genome Research Institute to facilitate identification of risk and protective genes. NIH recently awarded grants to eight academic medical centers around the Nation for using innovative new technologies and computational methods to analyze the genome sequencing data generated during the ADSP's first phase. The investigators will use ADSP data to identify rare genetic variants that protect against or contribute to Alzheimer's; explore differences in data from different racial/ethnic groups; and examine how brain images and other biomarkers are associated with genome sequences.

Because aging is the single biggest risk factor for the development of many chronic diseases, a better understanding of the basic biology of aging may open up new avenues for prevention and cures. The establishment of the trans-NIH GeroScience Interest Group (GSIG) to facilitate discovery on the common risks and mechanisms behind age-related diseases and conditions has invigorated the field of basic geroscience, as have groundbreaking recent findings such as the discovery that the protein GDF–11 can reverse aging-related cardiac hypertrophy (a dangerous thickening of the heart muscle) in mice—the first time a circulating factor has been shown to reverse age-related damage in a mammal. Recommendations from the 2013 GSIG Summit entitled "Advances in Geroscience: Impact on Healthspan and Chronic Disease" continue to energize researchers in this field.

NIA maintains an ongoing commitment to supporting basic behavioral and social research in aging. The NIA-supported Health and Retirement Study remains the world's premier multidisciplinary source of data on the health and well-being of older Americans, linking objective and subjective measures of health with information about retirement, economic status, family structure, personality, as well as health behaviors and service utilization. Funds from ARRA facilitated expansion of the study, including genotyping DNA samples from participants. In fiscal year 2016, research will be ongoing to take advantage of the newly available genetic data to advance understanding of how genetic, behavioral, and psychosocial factors affect health and well-being. NIA remains an active participant in the trans-NIH Science of Behavior Change initiative and the Basic Behavioral and Social Science Opportunity Network. NIA has also established an initiative to elucidate why the United States lags behind most other industrialized countries in health at older ages and longevity.

The Institute continues to place a strong emphasis on translating scientific discovery into health. For example, researchers with the Lifestyle Interventions and Independence for Elders study found that a carefully structured, moderate physical activity program can reduce the risk of losing the ability to walk without assistance, perhaps the single most important factor in whether vulnerable older people can maintain their independence. This is the first specific intervention proven in a randomized trial to prevent mobility disability. Other NIA-supported investigators have recently proposed the first diagnostic criteria for age-related sarcopenia, a loss of muscle mass that is often associated with weakness and is a frequent contributor to frailty in older age. NIA is also partnering with the Patient-Centered Outcomes Research Institute on a major intervention study to prevent injurious falls, a key cause of disability in older people.

NIA also supports several innovative programs dedicated to training the next generation of aging researchers. The Advancing Diversity in Aging Research through Undergraduate Education Program, which supports creative and innovative undergraduate-level research education programs to diversify the workforce in aging; the Grants for Early Medical/Surgical Specialists Transition to Aging Research program to encourage specialists to consider geriatrics research careers; a new initiative combining medical school with a Ph.D. in behavioral or social science; and the Paul Beeson Career Development Awards in Aging Research for outstanding clinician-scientists, all exemplify NIA's commitment to excellence and diversity in aging research.

Unfortunately, NIA's current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. While the current dollars appropriated to NIA seem to have risen significantly since fiscal year 2003, when adjusted for inflation, they have decreased more than 20 percent in the last 10 years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward supporting the work of the NIA-compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and

Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases. With an infusion of much needed support in fiscal year 2016, NIA can achieve greater parity with its NIH counterparts and expand promising, recent research activities, such as:

—Implement new prevention and treatment clinical trials, research training initiatives, care interventions, and genetic research studies developed to meet the goals of the National Plan to Address Alzheimer's disease;
—bolster trans-NIH initiatives developed by the NIH GeroScience Interest Group to understand basic cellular and molecular underpinnings of aging as a principal risk factor for chronic disease and to explore common mechanisms governing relationships between aging and chronic disease;
—understand the impact of economic concerns on older adults by examining work and retirement behavior, health and functional ability, and policies that influence individual well-being; and
—support family caregivers by enhancing physician-family communication during end-of-life and critical care

NIA is poised to accelerate the scientific discoveries that we as a Nation are counting on. With millions of Americans facing the loss of their functional abilities, their independence, and their lives to chronic diseases of aging, there is a pressing need for robust and sustained investment in the work of the NIA. In every community in America, healthcare providers depend upon NIA-funded discoveries to help their patients and caregivers lead healthier and more independent lives. In these same communities, parents are hoping NIA-funded discoveries will ensure that their children have a brighter future, free from the diseases and conditions of aging that plague our Nation today.

We do not yet have the knowledge needed to predict, preempt, and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to prevent, diagnose, and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships among biology, genetics, and behavioral and social factors related to aging. Bold, visionary, and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, and perhaps too late.

We recognize the tremendous fiscal challenges facing our Nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the Nation's aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

[This statement was submitted by Susan Peschin, MHS, Chair, Friends of the National Institute on Aging and President and CEO, Alliance for Aging Research.]

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## PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit testimony to the Subcommittee in support of the National Institute on Drug Abuse (NIDA). The Friends of the National Institute on Drug Abuse is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to preventing and treating substance use disorders as well as understanding their causes through the research agenda of the National Institute on Drug Abuse (NIDA).

Recognizing that so many health research issues are inter-related, we request that the subcommittee provide at least $32 billion for the National Institutes of Health (NIH) and within that amount a proportionate increase for the National Institute on Drug Abuse, in your Fiscal 2016 Labor, Health and Human Services, Education and Related Agencies Appropriations bill. We also respectfully request the inclusion of the following NIDA specific report language.

*Marijuana Research*.—The committee recognizes that many States either have or are considering legalizing or making marijuana available for medical use without appropriate knowledge about its effects on human development, structure and function of their brains. Therefore the committee supports the Adolescent Behavioral Cognitive Development (ABCD) Study being initiated by NIDA and other institutes of NIH. The committee also recognizes that the study will take at least a decade to complete since it will be a comprehensive study of the effects of marijuana and other abused drugs throughout growth from 10 to 20 years of age. Further the committee recognizes the cost of this comprehensive study should not inhibit funding investigator initiated studies and a special appropriation for this study is necessary.

*Opiate Abuse and Addiction*.—The Committee is concerned about the escalating crisis of prescription drug abuse in the U.S. It is now estimated that 120 people die each day in this country from opioid overdose making it one of the highest causes of non-disease related causes of deaths for adolescents and young adults. The June 2011 IOM report on pain indicates that abuse and misuse of prescription opioid drugs resulted in an annual estimated cost to the Nation of $72,500,000,000. Further, the Committee is very concerned with the concomitant rise in heroin abuse, addiction and deaths as the cost of this illegal opioid is less than that for prescription opioids. The Committee urges NIDA to 1) continue funding research on medications to alleviate pain, including the development of pain medications with reduced abuse liability; 2) as appropriate, work with private companies to fund innovative research to enhance the development of such medications; and 3) report on what we know regarding the transition from prescription opiate analgesics to heroin abuse and addiction within affected populations.

*Medications Development*.—The Committee recognizes that new technologies are required for the development of next-generation pharmaceuticals. In the context of NIDA funding, chief among these are NIDA's current approaches to develop viable immunotherapeutic or biologic (e.g., bioengineered enzymes) approaches for treating addiction. The goal of this active area of research is the development of safe and effective vaccines or antibodies that decrease the ability of specific addictive drugs, like nicotine, cocaine, and heroin, or drug combinations to affect the brain. The Committee is excited by this approach—if successful, immunotherapies, alone or in combination with other medications, behavioral treatments, or enzymatic approaches, stand to revolutionize how we treat, and, maybe even someday, prevent addiction. The Committee looks forward to hearing more about work in this area.

*Research to Assist Military Personnel, Veterans, and Their Families*.—The Committee recognizes the significant health challenges, including substance abuse and addiction, faced by military personnel, veterans, and their families. Many of these individuals need help confronting war-related problems including traumatic brain injury, PTSD, depression, anxiety, sleep disturbances, and substance abuse and addiction. The Committee commends NIDA for its successful efforts to coordinate and support research with the Department of Veterans Affairs, Department of Defense, and other NIH Institutes focusing on these populations, and strongly urges NIDA to continue work in this area.

*Raising Awareness and Engaging the Medical Community in Drug Abuse and Addiction Prevention and Treatment.*.—The Committee is pleased with NIDAMed, an initiative designed to reach out to physicians, physicians in training, and other healthcare professionals to increase especially those treating our youth to better recognize the signs that lead to drug abuse and addiction. The Committee urges the Institute to continue its focus on activities to provide physicians and other medical professionals with the tools and skills needed to incorporate drug abuse screening and treatment into their clinical practices.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over $600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease —this new knowledge has helped to correctly emphasize the fact that drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern include the recent increase in lethalities due to heroine, as well as the continued

abuse of prescription opioids and the recent increase in designer drugs availability and their deleterious effects. The need to increase our knowledge about the effects of marijuana is most important now that decisions are being made about its approval for medical use and/or its legalization. We support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2016 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

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## PREPARED STATEMENT OF THE FSH SOCIETY, INC.

Honorable Chairman Blunt and Ranking Member Murray, thank you for the opportunity to submit this testimony. Facioscapulohumeral muscular dystrophy (FSHD), is one of the most common adult muscular dystrophies with a prevalence of 1:8,000.[1] FSHD is a rare disease or an orphan disease (according to U.S. criteria it affects fewer than 200,000 people). For approximately 870,000 men, women, and children worldwide the major consequence of inheriting this genetic form of muscular dystrophy is a lifelong progressive loss of all skeletal muscles. FSHD predominantly initially affects muscles in the face, trunk and upper extremities. FSHD is a crippling and life shortening disease. It can affect multiple generations and entire families.

With FSHD there is a loss of muscle strength that ranges between one and 4 percent a year during a lifetime. In terms of functional impairment, 20 percent of FSHD-affected individuals over age fifty will require the use of a wheelchair. FSHD also has very specific non-muscular manifestations; hearing-loss, respiratory, cardiac (arrhythmias) and vision. 95 percent of individuals with FSHD have the FSHD1 (OMIM: 158900) genetic variation—caused by the contraction of DNA macrosatellite repeat units, termed D4Z4 repeats, on chromosome 4, leading to the release of transcriptional repression of a retrogene (DUX4) believed to be associated with the cause of disease. Of the 5 percent of FSHD individuals remaining, 80 percent of those are the FSHD2 (OMIM: 158901) genetic variation—caused by mutation in the structural maintenance of chromosomes hinge domain 1 (SMCHD1) gene on chromosome 18p that helps to maintain the repressed-State structure of the D4Z4 repeats on the long arm of chromosome 4; which when mutated cause unwanted toxic and inappropriate DUX4 gene/protein expression.

The National Institutes of Health (NIH) is the principal source of funding of research on FSHD currently at the $7 million level. For nearly two decades, this Committee has supported the incremental growth in funding for FSHD research. I am pleased to report that this modest investment has produced remarkable scientific returns.

*Congress has Made a Major Difference*.—I have testified many times before Congress, approximately fifty. When I first testified, we did not know the genetic mechanism of this disease. Now we do. Now we can target it. When I first testified, we assumed that FSHD was a rare. Now we understand it to be the most prevalent forms of muscle disease, based on new ways of evaluating the disease clinically within families. Congress is responsible for this success, through its sustaining support of the NIH and the enactment of the Muscular Dystrophy CARE Act. We are aware that MD Care Act does not set the amount of spending on FSHD or the other dystrophies at the NIH and we recognize that funding levels are determined in the appropriations process and the numbers of grant applications received and funded by the NIH on FSHD. Even though it is a technically separate legislative process, the reauthorization of the MD Care Act does raise the visibility of all the muscular

[1] Deenen JC, et al, Population-based incidence and prevalence of facioscapulohumeral dystrophy. Neurology. 2014 Sep 16;83(12):1056–9. Epub 2014 Aug 13.

dystrophies which can be of help in the appropriations process—and we thank you for your support of the MD Care Act amendments 2014. Given these requisites there are additional efforts and pathways that Congress can request and the NIH can enact to increase the amount of research funding on FSHD in the NIH portfolio that neither increases the NIH budget required nor takes money from another area of research and achieves more efficiency out of a non-growing research budget.

Quantum leaps in our understanding of FSHD.—The past four and a half years have seen remarkable contributions made by a very small but dedicated tribe of researchers funded by NIH and non-profits.

—On August 19, 2010, American and Dutch researchers published a paper which dramatically expanded our understanding of the mechanism of FSHD.[2] A front page story in the New York Times quoted the NIH Director Dr. Francis Collins saying, "If we were thinking of a collection of the genome's greatest hits, this would go on the list."[3] "FSHD patients carry specific single-nucleotide polymorphisms in the chromosomal region distal to the last D4Z4 repeat. This FSHD-predisposing configuration creates a canonical polyadenylation signal for transcripts derived from DUX4, a double homeobox gene of unknown function that straddles the last repeat unit and the adjacent sequence. Transfection studies revealed that DUX4 transcripts are efficiently polyadenylated and are more stable when expressed from permissive chromosomes. These findings suggest that FSHD arises through a toxic gain of function attributable to the stabilized distal DUX4 transcript."[2]

—Two months later, another paper was published that made a second critical advance in determining the cause of FSHD. The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.[4] "The contraction of the D4Z4 repeat in FSHD results in a less efficient suppression of the full-length DUX4 mRNA [DUX4-fl] in skeletal muscle cells. Therefore, FSHD represents the first human disease to be associated with the incomplete developmental silencing of a retrogene array normally expressed early in development."[4]

—On January 17, 2012, an international team of researchers based out of Seattle discovered a stabilized form of a normally suppressed gene called DUX4 affects many different germline genes, retroelements, and immune mediators; all potential targets.[5] "We identify genes associated with germline and early stem cell development as targets of the DUX4 transcription factor, a leading candidate gene for FSHD. The genes regulated by DUX4 are reliably detected in FSHD muscle but not in controls, providing direct support for the model that misexpression of DUX4 is a causal factor for FSHD."[5]

—Six months later, another high profile paper produced by a Senator Paul A. Wellstone Cooperative Research Center of the NIH (mandated by MD CARE Act), used sufficiently "powered" large collections of genetically matched FSHD cell lines generated by the NIH center that are both unique in scope and shared with all researchers worldwide, to improve on the Seattle group's finding by postulating that DUX4-fl expression is necessary but not sufficient by itself for FSHD muscle pathology.[6] "We confirmed that stable DUX4-fl mRNA and protein were expressed in myogenic cells and muscle tissues derived from FSHD affected subjects, including several genetically diagnosed adult FSHD subjects yet to show clinical manifestations of the disease in the assayed muscles. In addition, we report DUX4-fl mRNA and protein expression in muscle biopsies and myogenic cells from genetically unaffected relatives of the FSHD subjects, although at a significantly lower frequency. These results establish that DUX4-fl expression per se is not sufficient for FSHD muscle pathology and indicate

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[2] Lemmers, RJ, et al, A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy Science 24 September 2010: Vol. 329 no. 5999 pp. 1650–1653.

[3] Kolata, G., Reanimated 'Junk' DNA Is Found to Cause Disease. New York Times, Science. Published online: August 19, 2010 http://www.nytimes.com/2010/08/20/science/20gene.html.

[4] Snider, L., Geng, L.N., Lemmers, R.J., Kyba, M., Ware, C.B., Nelson, A.M., Tawil, R., Filippova, G.N., van der Maarel, S.M., Tapscott, S.J., and Miller, D.G. (2010). Facioscapulohumeral dystrophy: incomplete suppression of a retrotransposed gene. PLoS Genet. 6, e1001181.

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that quantitative modifiers of DUX4-fl expression and/or function and family genetic background are determinants of FSHD muscle disease progression."[6]

—On July 13, 2012, a team of researchers from the United States, Netherlands and France identified mutations in a gene causing 80 percent of another form of FSHD called FSHD1B or FSHD2. This paper furthers our understanding of the molecular pathophysiology of FSHD. This work too was supported in part by a program project grant from NIH.[7] "FSHD2 occurs in individuals who inherited both the SMCHD1 mutation and a normal-sized D4Z4 array on a chromosome 4 haplotype permissive for DUX4 expression. Reducing SMCHD1 levels in skeletal muscle results in D4Z4 contraction-independent DUX4 expression. Our study identifies SMCHD1 as an epigenetic modifier of the D4Z4 metastable epiallele and as a causal genetic determinant of FSHD2 and possibly other human diseases subject to epigenetic regulation."[7]

—On September 25, 2014, researchers from United States, France, Spain, Netherlands and United Kingdom narrow the focus mechanistically opening the possibility of all types of FSHD having an epigenetic basis.[8] "In FSHD1, for individuals with D4Z4 repeat arrays of 1–6 units, the clinical severity mainly depends on the size of the D4Z4 repeat. However, in individuals with arrays of 7–10 units, the clinical severity also depends on other factors that regulate D4Z4 methylation because affected individuals, but not non-penetrant mutation carriers, have a greater reduction of D4Z4 CpG methylation than can be expected based on the size of the pathogenic D4Z4 repeat array. In FSHD2, this epigenetic susceptibility depends on the nature of the SMCHD1 mutation in combination with D4Z4 repeat array size with dominant negative mutations being more deleterious than haploinsufficiency mutations. Our study thus identifies an epigenetic basis for the striking variability in onset and disease progression that is considered a clinical hallmark of FSHD."[8]

—On March 29, 2015, different researchers involved with the NIH Senator Paul A. Wellstone Cooperative Research Center using its large collection of different FSHD patient samples and different techniques arrive at the same answer that there is an underlying principle of epigenetics defining asymptomatic or non-manifesting and playing a role in disease severity.[9] "The epigenetic status of the distal 4qA D4Z4 repeat correlates with FSHD disease; FSHD-affected subjects have hypomethylation, healthy unaffected subjects have hypermethylation, and non-manifesting subjects have characteristically intermediate methylation. Thus, analysis of DNA methylation at the distal D4Z4 repeat could be used as a diagnostic indicator of developing clinical FSHD. In addition, the stability of epigenetic repression upstream of DUX4 expression is a key regulator of disease and a viable therapeutic target."[9]

Many of these researchers have started their efforts in FSHD with seed funding from the FSH Society and have received continued support from the FSH Society, the NIH, and the Muscular Dystrophy Association and other partners. In simpler terms, the above research shows that our own genes within us are being inappropriately expressed in tissue at a time and place where they do not normally reside or function by a confluence of events in a variety of ways giving rise to the decay and destruction of skeletal muscle; and we begin to focus on the very narrow stretch of DNA down to the nucleotide level in an area adjacent to the toxic gene inappropriately turned on so-named DUX4-fl. You might think of it as the opposite of cancer rather than runaway genes causing unbridled cell division; runaway genes are causing unbridled cell death. What is fascinating is, though one has all the requisites to have FSHD (e.g. the presence of a chromosome 4qA containing a DUX4 polyadenylation signal; and either a truncation of D4Z4; or a SMCHD1 mutation with D4Z4 repeat array with array sizes at the lower end of the normal repeat size spectrum) there are modifiers that allow a person to have a severe course of disease whilst other genetically tested positive relatives are spared of disease symptoms e.g. methylation. We can see clearly now that the stability of epigenetic repression by the region just upstream of DUX4 gene on the very last distal D4Z4 repeat, regardless of which route DUX-fl was stabilized and presented FSHD1, FSHD2, FSHD3, etc., is a key regulator that can be modified perhaps via its methylation level/status.

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[7] Lemmers, RJ, et al, Digenic inheritance of an SMCHD1 mutation and an FSHD-permissive D4Z4 allele causes facioscapulohumeral muscular dystrophy type 2. Nat Genet. 2012 Dec;44(12):1370–4. Epub 2012 Nov 11.

[8] Lemmers RJ, et al. Inter-individual differences in CpG methylation at D4Z4 correlate with clinical variability in FSHD1 and FSHD2. Hum Mol Genet. 2015 Feb 1;24(3):659–69. doi: 10.1093/hmg/ddu486. Epub 2014 Sep 25.

[9] Jones, TI, et al. Individual epigenetic status of the pathogenic D4Z4 macrosatellite correlates with disease in facioscapulohumeral muscular dystrophy. Clinical Epigenetics 2015, 72–6, 29 March 2015.

We can see clearly that FSHD2 modifies FSHD1 in individuals who carry both mutations presenting even more severe disease. Even more remarkably, we know of and we have compounds and techniques to modify and target modifiers and expression of DUX-fl, and still the FSHD research and clinical enterprise is starved for Federal funding from NIH! In 2014, the FSH Society funded projects to silence the DUX4 gene using leading-edge genome-editing technologies (CRSPR/Cas9, TALEN), helped support efforts in development efforts and models to test anti-sense oligonucleotide (ASO) and morpholino and we aided the development of animal models and a novel method that we believe will revolutionize FSHD diagnostics. We are thrilled that our grantees and colleagues have data that proves that DUX4-fl and cascading events can be turned off.

*We Must Keep Moving Forward*.—In October the FSH Society held its annual FSHD International Research Consortium meeting in San Diego, California. The meeting was funded in part by the NIH NICHD University of Massachusetts Medical School Wellstone center for FSHD. Nearly 80 researchers from around the world gathered to present latest data and discuss research strategies. There was considerable progress achieved when comparing to the 2013 agenda. The discussion agenda focused on being prepared for intervention development and clinical readiness. To keep the discussion focused, we followed the path: Genetics > Mechanisms and targets > Models > Patients. For each area, an expert moderator was nominated. The priorities stated for 2015, at the October 18, 2014, FSH Society FSHD IRC meetings can be found at: http://www.fshsociety.org/international-research-consortium/.

Additionally, on March 17th, 2015, the FSH Society presented to the Federal advisory committee mandated by the MD CARE Act called the Muscular Dystrophy Coordinating Committee (MDCC) its concern about the small number of NIH grants and that much greater funding is required to address the most pressing challenges for FSHD research, including research on the following topics:

—Mechanisms of DUX4 toxicity
—More molecular, imaging and functional markers of disease progression
—Modifiers of disease: genetic, chemical, and lifestyle
—Preclinical models validated to represent aspects of FSHD pathophysiology
—Better animal models based on low expression of DUX4 as seen in patients
—Mechanisms of pathology in patients' muscles
—Normal functions of DUX4 in tissues other than muscle
—Methods of administering anti-DUX4 agents to muscle
—Muscle regeneration capacity in FSHD muscles
—Large animal models (monkey, marmoset)
—Biomarkers that can indicate impact of therapeutic agents.

We need to be prepared for this new era in the science of FSHD. Many leading experts are now turning to work on FSHD because it represents the potential for great discoveries, insights into stem cells, transcriptional processes, new ways of thinking about disease of epigenetic etiology, and for treating diseases with epigenetic origin.

*NIH Funding for Muscular Dystrophy*.—Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since Congress passed the MD CARE Act in 2001, research funding at NIH for muscular dystrophy has increased 4-fold (from $21 million). While FSHD research funding has increased 14-fold (from $0.5M) during this period, the level of funding is still anemic and, for FSHD, has been astonishingly flat for the past 7 years.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY FUNDING

| | Fiscal Year | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015e | 2016e |
| All MD ($ millions) ..... | 38.7 | 39.5 | 39.9 | 47.2 | 56 | 83 | 86 | 75 | 75 | 76 | 78 | 79 | 81 |
| FSHD ($ millions) ..... | 2.2 | 2.0 | 1.7 | 3 | 3 | 5 | 6 | 6 | 5 | 5 | 7 | 7 | 7 |
| FSHD ( percent total MD) | 6 | 5 | 4 | 5 | 5 | 6 | 7 | 8 | 7 | 7 | 9 | 9 | 9 |

Sources: NIH/OD Budget Office & NIH OCPL & NIH RePORT RCDC (e = estimate)

Despite the great success of the past four and a half years in the science of FSHD brought about by Congress we are concerned that under the current funding environment that new research projects will not be funded or existing programs will not be renewed. We are already seeing this play out with some of the larger program projects in FSHD. We have conveyed to the NIH leadership at the Office of the Di-

rector, NIAMS, NINDS, NICHD, NHLBI and the Executive Secretary of the MDCC our grave concern that FSHD research is way too under-represented in the NIH portfolio and needs a proactive effort on the part of NIH. At the March 17, 2015, MDCC meeting we re-iterated to Alan E. Guttmacher, MD., Director, NICHD and Chair of the MDCC and all MDCC members that we are fully supportive of his efforts and the Action Plan for Muscular Dystrophy; while at the same time we requested that NIH redress the imbalance of funding in the muscular dystrophy portfolio by fostering opportunities for multidisciplinary research on FSHD commensurate with its prevalence and disease burden. The future action plan and NIH activity should address this issue head-on. We are stunned if not baffled that while on one hand, 5 years ago, NIH Director Dr. Francis Collins said "If we were thinking of a collection of the genome's greatest hits, this [FSHD] would go on the list"3 that—on the other hand, the National Human Genome Research Institute (NHGRI) has only one R01 on FSHD!

In the last year alone, incredible opportunities for public, private and non-profit entities engaged in FSHD research and clinical research have emerged. Oddly these discoveries clearly belonging to the leading edge of human genetics and our understanding the epigenome and treating epigenetic diseases are sitting idle at NIH. NIH needs to see through the thick fog of flat funding and austerity and maximize research funding by capitalizing on the low hanging fruit that FSHD presents as a gateway to treating human epigenetic disease. There are 26 active projects NIH-wide as of March 12, 2015, according to the NIH Research Portfolio Online Reporting Tools (RePORT) http://report.nih.gov within these 26 are: one F32 training grant, 6 R21, 12 R01, 1 P01, 2 U01, and 2 U54. NHGRI has only one R01. NHLBI has none. NICHD has no R21, no R01. In last 25 years, NIH has funded 76 grants in FSHD including only three training grants, 18 R21, and 25 R01. Remarkably, no grants ever on FSHD from key institutes studying heart, lung, blood, hearing, and vision.

While all muscular dystrophy research funding at NIH increased from $39.9 million in 2006 to $81 million; FSHD increased from $1.7 million to $7 million. The economy of scale is so vastly different in particular for FSHD, being equally devastating and burdensome as the disease receiving the most funding in this category called muscular dystrophy, and though it functions in the exact same U.S. Federal research infrastructure. We request for fiscal year 2016, a tripling of the NIH FSHD research portfolio to $21 million or a level of approximately 25 percent of the total estimated muscular dystrophy funding at NIH. This will allow an expansion of basic research awards, expansion of post-doctoral and clinical training fellowships, dedicated centers to design and conduct clinical trials on FSHD and more U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers.

We are aware of the great pressures on the Federal budget, but NIH can easily help increase its portfolio on FSHD given the breakneck speed of discovery in FSHD. These are easy ways for NIH to convey to researchers that it has a revised plan and an interest in funding research in FSHD. There are no quotas on peer-reviewed research above pay line at the NIH, and NIH can help by issuing written announcements that efforts invested in writing FSHD grant applications will be met with interest. This is the time to fully and expeditiously exploit the advances in the best scientific opportunities for which the American taxpayer has paid. Thank you for this opportunity to testify before your committee.

[This statement was submitted by Daniel Paul Perez, President & CEO, FSH Society, Inc.]

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## PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Blunt, Ranking Member Murray, and members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2016 appropriations funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of 25 nonprofit organizations working together to promote policies that advance research and development (R&D) of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, and other tools—to combat global health diseases. The GHTC's members strongly believe that to meet the global health needs of tomorrow, it is critical to invest in research today so that the most effective health solutions are available when we need them. This need has never been more evident than now, as the world is facing a persistent Ebola outbreak, and many other health areas are seeing resurgences of disease. My testimony

reflects the needs expressed by our member organizations, which work with a wide variety of partners to develop new and more effective lifesaving technologies, for the world's most pressing health issues. We strongly urge the Committee to continue its established support for global health R&D by (1) sustaining and supporting U.S. investment in global health research and product development and fully funding the NIH at a level of at least $32 billion, and providing robust funding for the CDC, with $469 million for the CDC Center for Global Health, and $669 million for the CDC Center for Emerging Zoonotic and Infectious Diseases (NCEZID); (2) requiring leaders at the NIH, CDC, the Food and Drug Administration (FDA), and the Secretariat of the U.S. Department of Health and Human Services (HHS) to join leaders of other U.S. agencies to develop a cross-U.S. Government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined; and (3) ensuring that contributions from the National Center for Advancing Translational Science (NCATS) are included in the joint CDC, FDA, and NIH global health strategy describing coordination and prioritization of global health research activities within the three agencies.

*Critical Need For New Global Health Tools*

Our Nation's investments have made historic strides in promoting better health around the world: nearly ten million people living with HIV/AIDS now have access to lifesaving medicines; new, cost-effective tools help us diagnose diseases quicker and more efficiently than ever before; and innovative new vaccines are making significant dents in childhood mortality. While we must increase access to these and other proven, existing health tools to tackle global health problems, it is just as critical that we continue to invest in developing the next generation of tools to stamp out disease and address current and emerging threats. For instance, newer, more robust, and easier to use antiretroviral drugs—particularly for infants and young children—are needed to treat and prevent HIV, and even an AIDS vaccine that is 50 percent effective has the potential to prevent one million HIV infections every year. Drug-resistant tuberculosis (TB) is on the rise globally, including in the United States, however the only vaccine on the market is insufficient at 90 years old, offers little protection when given to adolescents and adults, and most therapies available today are more than 50 years old, extremely toxic, and too expensive. New tools are also urgently needed to address fatal neglected tropical diseases such as sleeping sickness, for which diagnostic tools are inadequate and the few drugs available are toxic or difficult to use. There are many very promising technology candidates in the R&D pipeline to address these and other health issues; however, these tools will never be available if R&D is not supported and sustained.

*Research and U.S. Global Health Efforts*

The United States is at the forefront of innovation in global health technologies. The U.S. Government is involved in 200 of the 365 global health products currently in the pipeline, with the NIH and CDC involved in much of this research.

NIH

The NIH has helped make the United States a leader in research globally. Dr. Francis Collins, director of the NIH, has named global health as one of the agency's five top priorities, and recent NIH global health research activities have led to the development of new tools to combat neglected diseases, including vaccines for dengue fever and trachoma, new drugs to treat malaria and TB, and multiple projects to develop diagnostics, vaccines and treatments for Ebola, including the development of ZMapp and the development and testing of Ebola vaccine candidates. While we are pleased with recent increases to the NIH budget, spending growth still lags behind the expenses necessary for biomedical research which include maintaining and equipping laboratories. Dr. Collins recently noted that the Bureau of Economic Analysis has calculated that because of rising costs of biomedical research expenses, the NIH has had a 23 percent drop in purchasing power since 2003. As the world's largest supporter of global health R&D, maintaining steady support for the NIH is critical in working to ensure that new global health tools are available to address current and future health challenges.

Under the purview of the NIH, NCATS was established to accelerate new treatments and cures for diseases. NCATS has the potential to play a much needed role in global health research, and in the past has contributed to the development of early stage compounds to treat diseases including Chagas disease, schistosomiasis, giardia and HIV. Currently, through the Center's Therapeutics for Rare and Neglected Diseases (TRND) program, NCATS is working on treatments for some infectious diseases including malaria and Lassa fever. NCATS contributions towards accelerating translational research for global health is critical, and improving coordination and prioritization throughout HHS should improve efficiencies, leverage lim-

ited resources, and ensure critical gaps are realized and filled. Additionally, we remain concerned about the legislative mandate currently limiting NCATS in their clinical trial work. NCATS is the only NIH center to be limited by a legislative mandate in its clinical trial work. There is no risk of NCATS duplicating the global health activities of private industry as this sector does not typically target neglected diseases due to small commercial markets. We hope you will consider removing this statutory barrier. We must not lose traction on the investments made in global health at NIH.

*CDC*

The CDC also makes significant contributions to global health research. The CDC's ability to respond to disease outbreaks, such as the 2014 Ebola Virus Disease outbreak in West Africa, is essential to protecting citizens both at home and abroad. The work of its scientists has led to major advancements against devastating diseases, including the eradication of smallpox and early identification of the disease that became known as AIDS.

Within the CDC, the efforts of the Center for Global Health and NCEZID are critical to protecting lives and must be continued. Ongoing investments in the development of new vaccines, drugs, microbicides and other tools have the potential to greatly accelerate efforts to combat HIV/AIDS, TB, malaria, diarrheal disease, pneumonia, and other less well known diseases such as leishmaniasis, dengue fever, schistosomiasis, hookworm, sleeping sickness, and Chagas disease. This request also takes into account the increase necessary for the CDC's role in the National Strategy for Combating Antibiotic Resistant Bacteria, which could have tremendous lifesaving potential in fighting infectious diseases like drug-resistant tuberculosis, as well as increases for the CDC's Global Health Security Agenda, which will prioritize global capacity building for responding to future outbreaks and global health risks.

*Leveraging the Private Sector for Innovation*

The NIH, CDC, and other U.S. agencies involved in global health R&D regularly collaborate with the private sector in developing, manufacturing, and introducing important technologies such as those described above through public-private partnerships, including product development partnerships. These partnerships leverage public-sector expertise in developing new tools, partnering with academia, large pharmaceutical companies, the biotechnology industry, and governments in developing countries to drive greater development of products for neglected diseases in which private industries have not historically invested. This unique model has generated dozens of new global health products and has enormous potential for continued success if robustly supported. NIH Director Dr. Francis Collins has stated that such partnerships are key to the development of therapies and health tools based on NIH-funded research.

*Innovation as a Smart Economic Choice*

Global health R&D brings lifesaving tools to those who need them most. However, the benefits these efforts bring are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a $100 billion enterprise in the United States. Sixty-four cents out of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. In a time of global financial uncertainty, it is important that the United States support industries, such as global health R&D, which build the economy at home and abroad.

An investment made today can help save significant money in the future. The meningitis A vaccine, MenAfriVac, is projected to save nearly $570 million in healthcare costs over the next decade. In addition, new therapies to treat drug-resistant TB have the potential to reduce the price of TB treatment by 90 percent and cut health system costs significantly. The United States has made smart investments in research in the past that have resulted in lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must now build on those investments to turn those discoveries into new vaccines, drugs, tests, and other tools.

*Recommendations*

In this time of fiscal constraint, support for global health research that improves the lives of people around the world—while at the same time creating jobs and spurring economic growth at home—should unquestionably be among the Nation's highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following:

—Sustain and support U.S. investments in global health research and product development and fully fund the NIH at a level of at least $32 billion, and provide robust funding for the CDC, with $469 million for the CDC Center for Global Health and $669 million for the NCEZID.
—Require leaders at the NIH, CDC, the FDA, and the Office of Global Affairs to collaborate with the U.S. Agency for International Development, the State Department, the Department of Defense, and Office of the U.S. Global AIDS Coordinator to develop a cross-U.S. Government global health R&D strategy to ensure that U.S. investments in global health research are efficient, coordinated, and streamlined.
—Ensure that contributions from NCATS are included in the joint CDC, FDA, and NIH global health strategy describing coordination and prioritization of global health research activities within the three agencies and remove the current statutory and legislative barriers limiting NCATS' clinical trial mandate.

On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

[This statement was submitted by Erin Will Morton, Coalition Director, Global Health Technologies Coalition.]

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PREPARED STATEMENT OF GOD'S LOVE WE DELIVER

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

God's Love We Deliver is the leader of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 1.3 million medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
—More ER visits[4] & increased morbidity and mortality[5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

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Continued

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Karen Pearl, President & CEO, God's Love We Deliver.]

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## PREPARED STATEMENT OF DOUG GRACEY

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, in-

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seling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

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cluding AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

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The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF MR./MRS. ROBERT AND EVELYN GREENE

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

To Committee Members: Our daughter, 53 years of age, has been "institutionalized" (on the campus of a large congregate facility caring for the developmentally disabled) for 50 years. She is profoundly disabled and receives excellent loving care. She needs to be tended to 24/7. We know from past experience that many in her condition do not survive the transfer to community homes and certainly do not receive the same level of care. For too many it means a very uncomfortable death. We plead with you to act according to the Olmstead Decision.

Thank you for listening to the very concerned and loving parents.

Robert and Evelyn Greene

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## PREPARED STATEMENT OF THE GUILLAIN-BARRÉ SYNDROME AND CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY FOUNDATION INTERNATIONAL

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), variants and related conditions as you work to craft the fiscal year 16 L-HHS Appropriations Bill.

### ABOUT GBS, CIDP, VARIANTS AND RELATED CONDITIONS

*Guillain-Barré Syndrome*

GBS is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord. It's also known as Acute Inflammatory Demyelinating Polyneuropathy and Landry's Ascending Paralysis.

The cause of GBS is unknown. We do know that about 50 percent of cases occur shortly after a microbial infection (viral or bacterial), some as simple and common as the flu or food poisoning. Some theories suggest an autoimmune trigger, in which the patient's defense system of antibodies and white blood cells are called into ac-

tion against the body, damaging myelin (nerve covering or insulation), leading to numbness and weakness.

GBS in its early stages is unpredictable, so except in very mild cases, most newly diagnosed patients are hospitalized. Usually, a new case of GBS is admitted to ICU (Intensive Care) to monitor breathing and other body functions until the disease is stabilized. Plasma exchange (a blood "cleansing" procedure) and high dose intravenous immune globulins are often helpful to shorten the course of GBS. The acute phase of GBS typically varies in length from a few days to months, with over 90 percent of patients moving into the rehabilitative phase within four weeks. Patient care involves the coordinated efforts of a team such as a neurologist, physiatrist (rehabilitation physician), internist, family physician, physical therapist, occupational therapist, social worker, nurse, and psychologist or psychiatrist. Some patients require speech therapy if speech muscles have been affected.

Recovery may occur over 6 months to 2 years or longer. A particularly frustrating consequence of GBS is long-term recurrences of fatigue and/or exhaustion as well as abnormal sensations including pain and muscle aches. These can be aggravated by 'normal' activity and can be alleviated by pacing activity and rest.

*Chronic Inflammatory Demyelinating Polyneuropathy*

CIDP is a rare disorder of the peripheral nerves characterized by gradually increasing weakness of the legs and, to a lesser extent, the arms.

It is the gradual onset as well as the chronic nature of CIDP that differentiates it from GBS. Fortunately, CIDP is even rarer than GBS. The incidence of new cases is estimated to be between 1.5 and 3.6 in a million people (compare to GBS: 1–2 in 100,000).

Like GBS, CIDP is caused by damage to the covering of the nerves, called myelin. It can start at any age and in both genders. Weakness occurs over two or more months. Unlike GBS, CIDP is not self-limiting (with an end to the acute phase). Left untreated, 30 percent of CIDP patients will progress to wheelchair dependence. Early recognition and treatment can avoid a significant amount of disability.

Post-treatment life depends on whether the disease was caught early enough to benefit from treatment options. Patients respond in various ways. The gradual onset of CIDP can delay diagnosis by several months or even years, resulting in significant nerve damage that may take several courses of treatment before benefits are seen. The chronic nature of CIDP differentiates long-term care from GBS patients. Adjustments inside the home may need to be made to facilitate a return to normal life.

ABOUT THE FOUNDATION

The Foundation's vision is that every person afflicted with GBS, CIDP, or variants has convenient access to early and accurate diagnosis, appropriate and affordable treatments, and dependable support services.

The Foundation's mission is to improve the quality of life for individuals and families across America affected by GBS, CIDP, and their variants by:

—Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.

—Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.

—Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

JIM'S STORY

I had GBS in 1973. This is important because the subject matter, IVIG treatments, were not available in 1973 and I believe that because it was not available, my experience with GBS was many times worse than it needed to be. I was totally paralyzed and only my head was able to move side to side. When the disease hit me, I was a college student in St. John's University in NYC in my fourth year and a newlywed of 3 months and I was also working thirty hours a week as a night manager in a busy Tire and Auto repair business. My wife and I were just beginning our lives together when GBS struck us down like a lightning bolt. My wife was also working full time and now the care of her totally paralyzed husband was in the hands of a 19 year woman who was asked to do things and make decisions that no 19 year old women should have to make. I never finished college due to the amount of medical bills the accumulated and this affected my working life for decades. Keeping in mind the year, 1973, ICU care was very different then it is now.

She was only allowed to visit me in the ICU for five minutes every hour. The rest of the time, she spent in a tiny waiting room with other ICU patient's families. She was at the hospital before work, at lunchtime and in the evening totaling about forty minutes a day. Imagine the stress on this young lady. I spent five weeks in the ICU, totally paralyzed with a tracheotomy and with no movement and no ability to communicate in anyway at all. Any need that I had had to be guessed by the four person nursing staff who also had a dozen other very ill patients who were in the open room that held all of these patients. Nights were a nightmare. They were long mostly because I was not sleeping well, day or night. Minutes seemed like hours, and hours seemed like weeks. I was aware all of the time and it was like I was in a glass shell, unable to get out. The hospital staff tried, but no one could understand what it was like to be in that bed. One memorable evening, the tube that was connected to the MA–1 ventilator popped out of my neck and I was not getting any oxygen. Nobody saw that the bellows of the ventilator had dropped down. Someone had to see the situation or I was in big trouble. I had passed out from lack of air. Someone finally saw that it was not breathing for me. The "crash cart" finally got to me and I began to get some air. People started yelling "why didn't the alarm sound" There was an alarm that sounds if the machine failed for any reason. Two D cells powered the alarm and they were dead. Two D cells almost did me in.

I firmly believe that if IVIG was available for me in 1973, I would have never been so paralyzed and in need of a ventilator. My life was in the hands of a hospital staff and machinery and humans who make mistakes. Time and time again, IVIG has arrested the progress of GBS patients and prevented a patient from needing a vent and putting their life in danger. GBS in and of itself generally does not cause a patient to die, it is poor care or a late diagnosis or preexisting conditions. IVIG is a lifesaver and huge factor in reducing the level of paralysis and the amount of time that a patient is in hospital and rehab. I wish that IVIG was available when I had GBS. Its availability would have a huge difference in my case.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into GBS, CIDP, and related disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

—The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) less than in fiscal year 2003.

—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CIDP is a progressive condition with serious health impacts. Patients can end up almost completely paralyzed and on a ventilator. The key to limiting serious health impacts is an early and accurate diagnosis. The time it takes for a CIDP patient to begin therapy is linked to the length of therapy and the seriousness of the health impacts. An early diagnosis can mean the difference between a 3 month or 18 month hospital stay, or no hospitalization at all. For the Federal healthcare system,

there is an economic incentive to ensure early and accurate diagnosis as longer hospitalizations equate to higher costs.

CDC and NCCDPHP have resources that could be brought to bear to improve public awareness and recognition of CIDP and related conditions. In order to initiate new, potentially cost-saving programs, CDC requires meaningful funding increases to support crucial activities.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest research portfolio focused on GBS, CIDP, variants and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. In fact, NINDS, NIAID, and the Office of Rare Diseases Research (ORDR) housed within NCATS have expressed interest in hosting a State-of-the-Science Conference on autoimmune peripheral neuropathies. This conference would allow intramural and extramural researchers to develop a roadmap that would lead research into these conditions into the next decade. While such a conference would not require additional appropriations, the Foundation urges you to provide NIH with meaningful funding increases to facilitate growth in the GBS, CIDP, and related conditions research portfolio.

Thank you for your time and your consideration of the community's requests.

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PREPARED STATEMENT OF DAVID HART

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DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

I act as co-conservator for my 52 year old autistic sister who was recently evicted from her home of over 40 years, Lanterman Developmental Center in California, upon its recent closure.

The general community is simply not equipped or prepared to provide humane treatment for the profoundly developmentally disabled. She has lost services, a sense of community and independence as a result of her displacement. We have recently been refused funding to support her adequately in her new home and are forced to represent her in court at great personal expense. Our Nation is failing our developmentally disabled. One Size Does Not Fit All!

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request.

I support VOR's testimony.

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PREPARED STATEMENT OF THE HARM REDUCTION COALITION

On behalf of the Harm Reduction Coalition, we thank you for the opportunity to submit testimony on fiscal year 2016 Appropriations priorities for the Department of Health and Human Services. The Appropriations process provides a critical opportunity to review the Nation's strategies and commitments to addressing the Nation's public health challenges. One of our greatest challenges is the current opioid crisis, claiming a growing number of lives through drug overdose along with health consequences ranging from addiction to hepatitis C to neonatal abstinence syndrome. Harm Reduction Coalition believes that many of these consequences are preventable or treatable through targeted investments in sound, evidence-based interventions. Therefore, we support HHS Secretary Burwell's Opioid Initiative, which calls for $99 million in additional funds to increase efforts on opioid prescribing, naloxone access, and medication-assisted treatment. Harm Reduction Coalition firmly believes in a comprehensive approach to the opioid crisis that strengthens all three of the Secretary's priority areas in tandem. We specifically ask for the Subcommittee's consideration and support of three key public health strategies: (1) Preventing overdose deaths through expanded access to naloxone; (2) Strengthening prevention of hepatitis C; and (3) removing the Federal funding ban on syringe exchange.

*(1)—Preventing Overdose Deaths Through Expanded Access to Naloxone*

Opioid overdose fatality is a leading cause of accidental death in the United States and has been declared an epidemic by the Centers for Disease Control and Prevention (CDC). According to CDC data, overdose deaths involving opioids—prescription painkillers or heroin—claimed more than 24,000 lives in 2013. Overdose prevention education and training programs that distribute the FDA-approved, opioid rescue medication naloxone have been proven to lower incidence of overdose as well as significantly reduce mortality. When administered in a timely fashion, naloxone can reverse an opioid overdose; however, tragically it is not yet neither utilized broadly nor widely available in many parts of the country. If naloxone was more accessible and overdose education and awareness efforts were expanded, countless lives could be saved.

Harm Reduction Coalition commends Congress for including, in the final fiscal year 2015 Labor-Health and Human Services-Education (LHHS) Appropriations measure, funding and language that help advance overdose prevention efforts, particularly those that focus on overdose education and naloxone distribution. Specifically, for the first time, Congress importantly recognized the need to provide Federal funding to the Office of Rural Health within the Health Resources and Services Administration (HRSA) to support the purchase of "emergency devices used to rapidly reverse the effects of opioid overdoses, as well as training licensed healthcare professionals and emergency responders on their use."[i]

In response to the opioid overdose epidemic, numerous communities and States have taken action to make naloxone available within their jurisdictions but resources to support overdose education and naloxone distribution are still scarce. Moreover, many efforts are focused solely on traditional first responders while non-healthcare professionals are more likely to be the first on the scene of an overdose. As such, Harm Reduction Coalition urges Federal policymakers to support and expand initiatives to prevent and reduce opioid overdose fatalities, particularly those with a focus on family members and other laypersons likely to encounter someone who has overdosed.

The fiscal year 2016 HHS Budget Request includes a range of proposals to address the opioid epidemic under the auspices of the Secretary's Opioid Initiative, totaling over $99 million in new funding requested. Harm Reduction Coalition supports this request and encourages Congress to invest additional resources in tackling the multiple dimensions of the opioid epidemic. At a minimum, Harm Reduction Coalition asks that Congress support the SAMHSA request for $12 million in fiscal year 2016 for Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths.

Specifically, Harm Reduction Coalition calls upon Congress and the Administration to build upon the progress being made at the community and State levels and the initial investment made in the final fiscal year 2015 funding measure, by:

—Providing $12 million to SAMHSA to provide grants to States to support community-based opioid overdose fatality prevention efforts and purchase of naloxone, with a focus on those initiatives that provide overdose recognition and intervention training and education alongside access to rescue medications to family members and other laypersons, and facilitate linkage to treatment and recovery services.

*(2)— Strengthening Prevention of Hepatitis C*

According to CDC, new hepatitis C infections increased by 75 percent between 2010 and 2012. This increase is largely attributable to the increase in injection of prescription opioids and heroin. At least 30 States have reported substantial increases in new hepatitis C infections. The typical profile of a person newly infected with hepatitis C is a young person in their 20s living in a rural or suburban area. Considering the significant costs of hepatitis C treatment, there is a compelling financial case to increase investments in prevent in order to avert both liver disease and mortality as well as substantial economic burdens of medical and treatment costs.

In their fiscal year 2016 Budget Justification, CDC requests an addition $31 million to the Division of Viral Hepatitis to expand testing and linkage to care, strengthen health department capacity, reduce perinatal hepatitis B transmission, and prevent new hepatitis C infections. Harm Reduction Coalition supports the requested increase, and asks that at a minimum CDC should receive an additional $8 million for hepatitis C prevention to halt the burgeoning hepatitis C epidemic associated with prescription opioid and heroin use.

—Providing $8 million to CDC's Division of Viral Hepatitis for the prevention of new hepatitis C infections through grants to State and local health departments and community-based organizations to strengthen hepatitis C prevention efforts among people who inject drugs, with priority to high-burden jurisdictions and organizations with demonstrated experience and expertise in engaging this population.

*(3)—Removing the Federal Funding Ban on Syringe Exchange*

The Federal funding ban on syringe exchange, maintained through LHHS Appropriations language, hampers the ability of States and communities to deploy all available and appropriate tools for early intervention in local opioid epidemics and prevent HIV and hepatitis C outbreaks. Those States on the frontlines of the opioid epidemic must have the flexibility to direct their Federal funds to effective and evidence-based programs capable of reaching people who inject drugs and linking them to healthcare, treatment and recovery services. Syringe exchange programs accomplish these goals without increasing nor encouraging drug use.

—Remove the ban on use of Federal funds for syringe exchange programs

We thank you for your consideration of these requests. For further information on any of these areas, please contact Harm Reduction Coalition's Policy Director, Daniel Raymond.

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## PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record recommending $524 million in fiscal year 2016 for the health professions education and training programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA).

HPNEC is an alliance of national organizations dedicated to ensuring the healthcare workforce is trained to meet the needs of the country's growing, aging, and diverse population. Titles VII and VIII are the only federally-funded programs that seek to improve the supply, distribution, and diversity of the health professions workforce, with a focus on primary care and interdisciplinary training. By providing

educational and training opportunities to aspiring and practicing health professionals, the programs also play a critical role in helping the workforce adapt to meet the Nation's changing healthcare needs.

Titles VII and VIII are structured to allow grantees to test educational innovations, respond to changing delivery systems and models of care, and address timely topics in their communities. By assessing the needs of the communities they serve, Titles VII and VIII are well positioned to fill gaps in the workforce and increase access to care for all populations. Further, the programs emphasize interprofessional education and training, bringing together knowledge and skills across disciplines to provide effective, efficient and coordinated care.

While HPNEC recognizes the Subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting healthcare workforce development should remain a high priority. The Nation faces a shortage of health professionals, which will be exacerbated by increasing demand for healthcare services. Failure to fully fund the Title VII and Title VIII programs would jeopardize activities to fill these vacancies and to prepare the next generation of health professionals.

The Title VII and Title VIII programs can be considered in seven general categories:

—The Primary Care Medicine and Oral Health Training programs support education and training of primary care professionals to improve access and quality of healthcare in underserved areas. According to HRSA, approximately 20 percent of Americans live in rural or urban areas designated as health professional shortage areas (HPSA). The primary care medical and oral health training grants are also used to develop curricula and test training methods to transform healthcare practice and delivery, including innovations in the primary care team's management of chronic disease, patient-centered models of care, and transitioning across healthcare settings. The General Pediatrics, General Internal Medicine, and Family Medicine programs provide critical funding for primary care physician training in community-based settings and support a range of initiatives, including medical student and residency training, faculty development, and the development of academic administrative units. The Rural Physician Training Grants focus on increasing the number of medical school graduates practicing in rural communities. The primary care cluster also provides grants for Physician Assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. The General Dentistry, Pediatric Dentistry, Dental Public Health, and Dental Hygiene programs provide grants to dental schools, dental hygiene schools, and hospitals to create or expand primary care dental training.

—Because much of the Nation's healthcare is delivered in remote areas, the Interdisciplinary, Community-Based Linkages cluster supports community-based training of health professionals. These programs are designed to encourage health professionals to return to such settings after completing their training and to encourage collaboration between two or more disciplines. The Clinical Training in Interprofessional Practice program supports interdisciplinary training opportunities that prepare providers to deliver coordinated, efficient, and high-quality care. The Area Health Education Centers (AHECs) offer clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs improve health by leading the Nation in the recruitment, training, and retention of a diverse health workforce for underserved communities. By leveraging State and local matching funds to form networks of health-related institutions, AHECs also provide education services to students, faculty, and practitioners. The Geriatric Health Professions programs, including the Geriatric Academic Career Award program and Geriatric Education Centers, are all designed to bolster the number and quality of healthcare providers caring for the rapidly growing number of older adults and to expand geriatrics training to all healthcare professionals. For example, the programs provide interprofessional education and training on Alzheimer's disease and related dementias. The Graduate Psychology Education (GPE) program is the Nation's only Federal program dedicated solely to the education and training of doctoral-level psychologists. GPE supports the interprofessional training of doctoral-level psychology students in providing supervised mental and behavioral health services to underserved populations (i.e. older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families) in rural and urban communities. The Mental and Behavioral Health Education and Training Grant Program supports the training of psychologists, social workers, and child and adolescent professionals. These programs together

work to close the gap in access to quality mental and behavioral healthcare services by increasing the number of qualified mental health clinicians.

—The Minority and Disadvantaged Health Professionals Training cluster helps improve healthcare access in underserved areas and the representation of minority and disadvantaged individuals in the health professions. Diversifying the healthcare workforce is a central focus of the programs, making them a key player in mitigating racial, ethnic, and socio-economic health disparities. Further, the programs emphasize cultural competency for all health professionals, an important role as the Nation's population is growing and becoming increasingly diverse. Minority Centers of Excellence support increased research on minority health, establish educational pipelines, and provide clinical experiences in community-based health facilities. The Health Careers Opportunity Program helps to improve the development of a competitive applicant pool through partnerships with local educational and community organizations and extends the healthcareers pipeline to the K–12 level. The Faculty Loan Repayment and Faculty Fellowship programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students supports students from disadvantaged backgrounds who are eligible and enrolled as full-time health professions students.

—The Health Professions Workforce Information and Analysis program provides grants to institutions to collect and analyze data to advise future decisionmaking on the health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed valuable, policy-relevant studies on the distribution and training of health professionals. The National Center for Workforce Analysis performs research and analysis on health workforce issues, including supply and demand, to help inform both public and private decisionmaking.

—The Public Health Workforce Development programs help increase the number of individuals trained in public health, identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. Preventive Medicine Residencies, which do not receive funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. This cluster also includes a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The Pediatric Subspecialty Loan Repayment Program offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for service in underserved areas.

—The Nursing Workforce Development programs under Title VIII provide support for nurses and nursing students across the entire education spectrum improve the access to, and quality of, healthcare in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2006 and 2013 alone, supported over 520,000 nurses and nursing students as well as numerous academic nursing institutions and healthcare facilities. At the same time, the need for high-quality nursing services is expected to grow, particularly in rural and underserved areas. The Advanced Nursing Education program awards grants to train a variety of nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, certified registered nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Nursing Workforce Diversity grants help to recruit and retain students from minority and disadvantaged backgrounds to the nursing profession through scholarships, stipends, and other retention activities. Graduate nursing students are provided reimbursement for tuition and program costs through the Advanced Education Nursing Traineeships and Nurse Anesthetist Traineeships. The Nurse Education, Practice, Quality, and Retention program helps schools of nursing, academic health centers, nurse-managed health centers, State and local governments, and other healthcare facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The Loan Repayment and Scholarship Program repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds in exchange for 2 years of practice in a designated critical shortage facility. The Comprehensive Geriatric Education grants support the education of registered

nurses and nursing professionals who will provide direct care to older Americans, develop and disseminate geriatric curricula, train faculty members, and provide continuing education. The Nurse Faculty Loan program supports graduate students pursing the opportunity to become nursing faculty members through loan repayment in exchange for service as nursing faculty.

—The loan programs under Student Financial Assistance support financially disadvantaged health professions students. The NURSE Corps supports undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans for financially needy health professions students based on institutional determination. These programs are funded out of each institution's revolving fund and do not receive Federal appropriations. The Loans for Disadvantaged Students program provides grants to institutions to make loans to disadvantaged students.

Title VII and Title VIII programs guide individuals to high-demand health professions jobs, helping individuals reach their goals and communities fill their health needs. Further, numerous studies demonstrate that the Title VII and Title VIII programs graduate more minority and disadvantaged students and prepare providers that are more likely to serve in Community Health Centers (CHC) and the National Health Service Corps (NHSC).

The multi-year nature of health professions education and training, coupled with provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand the budget limitations facing the Subcommittee, we respectfully urge support for $524 million for the Title VII and VIII programs. We look forward to working with the Subcommittee to prioritize the health professions programs in fiscal year 2016 and into the future.

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PREPARED STATEMENT OF THE HEARTLAND HEALTH OUTREACH, INC.

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Heartland Health Outreach, Inc. is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, metropolitan Chicago, our organization provides nutritious food for more than 420,000 million meals annually through distribution at grocery centers, home delivered food boxes and home delivered meals. In all cases, participants choose the food or meals they want, and dietitians tailor the menus to address each participant's health issues and dietary requirements. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe and chronic illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth

assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
—More ER visits[4] & increased morbidity and mortality[5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, U.S.A. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[8] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learn-

each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Deborah Hinde, Chief Development Officer, Heartland Health Outreach, Inc.]

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ing, Philadelphia, PA, U.S.A. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

PREPARED STATEMENT OF THE HEPATITIS APPROPRIATIONS PARTNERSHIP

The Hepatitis Appropriations Partnership (HAP) is a national coalition based in Washington, DC. The coalition includes community-based organizations, public health and provider associations, national hepatitis and HIV organizations, and diagnostic, pharmaceutical and biotechnology companies. HAP works with policy makers and public health officials to increase Federal support for hepatitis prevention, testing, education, research and treatment. On behalf of HAP, we urge your support for increased funding for Federal hepatitis programs in the fiscal year 2016 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for hepatitis programs in fiscal year 2016:

| Agency | Program | HAP Funding request |
|---|---|---|
| Centers for Disease Control and Prevention | Division of Viral Hepatitis | $62.8 million |

The Centers for Disease Control and Prevention (CDC) has estimated that up to 5.3 million people are living with chronic hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as many as 75 percent are not aware of their infection. However, these figures are based on National Health and Nutrition Examination Survey (NHANES) data, which does not include homeless and unstably housed individuals, those living in nursing homes, the incarcerated, the military, or many immigrant and migrant populations—populations disproportionately affected by viral hepatitis. Without a confirmed diagnosis and linkage to and retention in care, 15–40 percent of those living with viral hepatitis will eventually develop liver cirrhosis and/or liver cancer. In 2012 alone, 40,599 cases of HBV and 145,762 cases of HCV were reported to the CDC. Unfortunately, due to the lack of an adequate surveillance system, these estimates are likely only the tip of the iceberg. Without the necessary access to care and/or treatment, viral hepatitis can lead to chronic liver disease, cirrhosis, liver cancer and liver failure and complications from these chronic infections claim between 15,000 and 50,000 lives annually. Analyses of viral hepatitis-related morbidity and mortality have found that the mortality rate attributed to viral hepatitis has increased over the last several years.

Viral hepatitis disproportionately impacts several communities, particularly people who inject drugs (PWID), men who have sex with men (MSM), persons living with HIV, Native Americans, African Americans, Asian Americans, Latinos and residents of rural and remote areas with limited access to medical treatment and culturally and linguistically-appropriate services. "Baby Boomers," persons born between 1945 and 1965, have the greatest risk for HCV-related morbidity and mortality—1 in 33 people born in this time period are hepatitis C positive. Both CDC and the United States Preventive Services Task Force (USPSTF) have released HBV and HCV screening guidelines recommending that providers offer a one-time HCV screening to anyone in this birth cohort, and that anyone at high-risk for HBV and HCV should be screened. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined, representing 75 percent of new HCV cases. In fact, 35 States reported increases in persons newly infected with HCV from 2010 to 2012.

Even with these challenges, the availability of effective new curative treatments for HCV, and an effective vaccine and treatments to control HBV, brings the elimination of HCV and HBV in the United States within our reach, setting the stage for an enormous new public health victory. The elimination of HCV and HBV in the United States is possible—but not without increased investments in comprehensive, national viral hepatitis prevention, screening, linkage to care, education and surveillance programs.

CDC DIVISION OF VIRAL HEPATITIS

HAP encourages funding of $62.8 million for the CDC Division of Viral Hepatitis (DVH) to more effectively combat the epidemics. In fiscal year 2012, Congress demonstrated a commitment to increasing the Federal response to the viral hepatitis epidemics with the creation of the first-ever viral hepatitis screening initiative through the Prevention and Public Health Fund (PPHF). This brought the total funding at DVH to $29.7 million. The viral hepatitis community is appreciative that Congress recognized the importance of the identification and linkage to care of people living with viral hepatitis who are unaware of their status. While past funding increases have been helpful, these have only been small steps toward building a

more comprehensive response to viral hepatitis. The CDC's 2010 professional judgment (PJ) budget recommended $90.8 million each year from fiscal year 2011-fiscal year 2013, $170.3 million annually from fiscal year 2014-fiscal year 2017, and $306.3 million annually from fiscal year 2018-fiscal year 2020 for DVH to comprehensively address the hepatitis B and hepatitis C epidemics. HAP's requested increase of $31.5 million, to $62.8 million, is in line with the needs determined by that PJ and with the goals of the Action Plan for the Prevention, Care, & Treatment of Viral Hepatitis (Viral Hepatitis Action Plan). HAP recommends that these funds be used on the following priority areas, allocated in proportion to HBV and HCV burden, using available epidemiological data.

SCREENING AND LINKAGE TO CARE

At present, only 25–35 percent of people living with chronic viral hepatitis are aware of their infection. The Viral Hepatitis Action Plan established a goal of increasing the proportion of persons who are aware of their hepatitis infection to 66 percent for both HBV and HCV. In addition to identifying youth who are living with hepatitis C who are unaware of their status, DVH must also increase the percentage of Baby Boomers who are aware of their HCV status, and foreign-born and 2nd generation immigrants from Asian or African countries that have HBV infection rates of 10 percent or higher. This is why full implementation of the CDC and USPSTF recommendations for HBV and HCV testing and linkage to care by State Medicaid programs, Medicare, and private health systems and providers are so necessary. Of course, these systems do not capture all of the populations at risk. Although health departments receive no categorical funding for testing, they were able to leverage other resources to test over 125,000 people in 2013. This leveraged funding is not consistent from year to year, nor is it enough to reach those populations at highest risk for hepatitis. In the absence of a Federal commitment to a nationwide awareness, testing and linkage to care initiative, we remain concerned about the ability of the Federal Government to meet the goals of the Viral Hepatitis Action Plan.

SURVEILLANCE

As testing and linkage to care activities increase and improve, strengthening local and State capacity to execute viral hepatitis monitoring and surveillance activities takes on an even greater importance. The CDC currently funds only 5 State health departments and 2 local health departments to conduct minimal surveillance in their jurisdictions. CDC also provides funds to State and local health departments, the cornerstone implementers of national public health policies, to coordinate prevention efforts via the Viral Hepatitis Prevention Coordinator Program (VHPC). The VHPC program is the only national program dedicated to the prevention and control of the viral hepatitis epidemics. This program provides funding to support a coordinator position in each jurisdiction, but provides no money for the provision of public health services, such as surveillance, public education and access to prevention services like testing and hepatitis A and B vaccinations, which must be cobbled together from other sources year-to-year. With increased investments in nationally coordinated surveillance activities, key stakeholders (States, health departments, policy makers, and providers) would be equipped with information that is critical to understanding the burden and impact of the hepatitis epidemics, identify and avert outbreaks, and that will allow for improved targeting of resources to the most impacted communities.

ADDRESSING THE EMERGING HEPATITIS C EPIDEMIC AMONG YOUNG PERSONS AT RISK

HCV prevalence among PWIDs is as high as 70 percent, and between 20–30 percent of uninfected people who inject drugs acquire HCV each year. In recent years, State health departments have reported an alarming increase in new HCV cases among people under the age of 30 in many States, including but not limited to: Alabama, Colorado, Connecticut, Georgia, Indiana, Kentucky, Maine, Maryland, Massachusetts, Montana, New Mexico, North Carolina, Oregon, Tennessee, Washington and West Virginia. Unlike historical trends of HCV infections (i.e., concentration in larger, urban city centers), new HCV infections are increasingly found in suburban and rural settings, especially in Appalachia. This trend is largely due to the prescription opiate epidemic and the transition many young people have made from using opiate pills to injecting heroin. This increase makes the need to enhance and expand these prevention efforts all the more urgent and underscores the need to prioritize immediate support in the field, strengthening health department and community responses that target youth and young adults, specifically persons who inject drugs, persons under 30 years old, and persons living in rural areas.

ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION OF HEPATITIS B

Although we have made great strides in reducing the burden of HBV among newborns and young people, due in part to the success of the Perinatal Hepatitis B Coordinator program at CDC's National Center for Immunization and Respiratory Diseases (NCIRD), between 800 to 1,000 perinatal HBV transmissions occur each year. Further, one of the greatest remaining challenges for hepatitis A and B prevention is the vaccination of high-risk adults. Additional funding at NCIRD for an Adult HBV Vaccination Initiative is necessary to prevent the transmission of HBV, and especially perinatal HBV. High-risk adults account for more than 75 percent of all new cases of HBV infection each year and annually result in an estimated $658 million in medical costs and lost wages, despite the fact that HBV is preventable.

As you contemplate the fiscal year 2016 Labor, Health and Human Services, Education and Related Agencies appropriations bill, we ask that you consider these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the viral hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's fight against these epidemics.

[This statement was submitted by Mariah Johnson, Coordinator, Hepatitis Appropriations Partnership.]

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PREPARED STATEMENT OF JOY HIGGINS

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

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AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

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Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

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## PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other healthcare professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS in the U.S. and globally, lead HIV prevention programs and conduct research that has led to the development of effective HIV prevention and treatment options. As you work on the fiscal year 2016 appropriations process, we urge you to invest in the medical research supported by the National Institutes of Health (NIH) and sustain robust funding for the Ryan White Program at the Health Resources and Services and Administration (HRSA) as well as the Centers for Disease Control and Prevention's (CDC) HIV and STD prevention programs.

Early access to effective HIV treatment helps patients with HIV live healthy and productive lives and is cost effective.[1] Treatment not only saves the lives of individuals with HIV but directly benefits public health by reducing HIV transmission risk to near zero.[2] However, despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious epidemic in the United States with a record 1.1 million people living with HIV and an estimated 50,000 new infections occurring annually. In our country, HIV infection disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving healthcare and treatment. The rate of new HIV infection in African Americans is 8 times that of whites based on population size.[3] Globally there are more than 35.3 million people living with HIV, the great majority of them in Sub-Saharan Africa. We are beginning to see improvements thanks in large part to U.S. investments in programs like PEPFAR, and the CDC Global AIDS Program is a critical partner in country level efforts to achieve epidemic control. We call for a funding level of at least $132 million to sustain CDC this vital lifesaving role.

The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to mount an effective response to the domestic HIV epidemic and meet the need in communities across the country.

*NIH—Office of AIDS Research (OAR).*—HIVMA strongly supports an fiscal year 2016 funding level of at least $32 billion for the NIH, including at least $3.2 billion for the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of men, women and children in the U.S. and in the developing world. Years of flat funding for biomedical research has eroded our capacity to sustain our Nation's historic worldwide leadership in HIV/AIDS research and innovation, and is discouraging cultivation of the next generation of scientists.

Our past investment in comprehensive HIV/AIDS research paid off enormously in dramatic gains that resulted in reductions in mortality from AIDS of nearly 80 per-

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[1] Kitahata, Gange, Abraham, et al. Effect of early versus deferred antiretroviral therapy for HIV on survival. New Engl J Med 2009;360:1815–26.

[2] Cohen, Myron S., et al. Prevention of HIV–1 Infection with Early Antiretroviral Therapy. 2011 New England Journal of Medicine 493–505: V365, no 6, http://www.nejm.org/doi/full/10.1056/NEJMoa11052.

[3] CDC Fact Sheet, February, 2014, accessed online at: http://www.cdc.gov/hiv/risk/racialethnic/aa/facts/index.html.

cent in the U.S. and in other countries where treatment is available. This research also helped reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available.

Strong, sustained NIH funding is a critical national priority that will foster better health, economic revitalization and game-changing new discoveries that hold promise for an HIV vaccine and ultimately a cure. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. Congress should ensure our Nation does not delay vital HIV/AIDS research progress.

*HRSA—HIV/AIDS Bureau (HAB).*—It is critical to maintain level funding for the Ryan White Program, which annually serves more than half a million individuals living with HIV. The Ryan White Program provides expert, comprehensive HIV care and treatment that helps most patients achieve viral suppression, allowing them to live for close to a normal lifespan and reducing their infectiousness to others to almost zero. Estimated authorization levels for the program in fiscal year 2016 would call for an increase of at least $136 million to the Ryan White program. For Ryan White Part C program, that supports HIV medical clinics, HIVMA requests $225.1 million, or a $24 million increase. These additional funds would help to support the ever increasing need for these lifesaving services. Part C HIV medical clinics currently struggle to meet the demand of increasing patient caseloads. The expert, comprehensive HIV care model or "medical home" that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. Patients with HIV who receive Ryan White services are more likely to be prescribed HIV treatment and to be virally suppressed.[4] We also know that the annual healthcare costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.[5]

Additionally, while HIVMA welcomes the proposed increase for Part C programs in the President's fiscal year 2016 budget, we do not support the proposal to consolidate Ryan White Part D funding into Part C. Ryan White Part C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women, including pregnant women, HIV-exposed infants, and young people in care. The programs provide services tailored to women and young people and in some communities, Part D-funded programs are the main providers of HIV care and treatment.

While the Affordable Care Act (ACA) provides important new healthcare coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. High cost sharing, benefit gaps and limited state uptake of the Medicaid expansion, especially in the South, necessitate an essential and ongoing role for the Ryan White Program to avoid life-threatening and costly disruptions in care.

*CDC—National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP).*—HIVMA strongly supports the much needed increase of $44 million proposed in the President's fiscal year 2016 budget for the CDC's NCHHSTP, especially the proposed $31.5 million for viral hepatitis, as well as increases of $6.3 million for HIV prevention and surveillance, and $6.3 million for the Division of Adolescent School Health (DASH). We are also especially concerned about flat funding of CDC's global HIV programs, and request an increase of at least $3.3 million to that line item for a total of $132 million, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.

*Policy Riders—Remove the Harmful Ban on Federal Funding for Syringe Exchange Programs.*—HIVMA strongly urges the Committee to lift the ban on Federal funding for syringe exchange programs (SEPs). HIVMA is committed to evidence-based public health interventions that both increase access to healthcare and decrease transmission of HIV, viral hepatitis, and other blood-borne pathogens. Injection drug use is a major route of transmission for these infectious agents. Because transmission occurs through the sharing or re-use of infected paraphernalia, access to uninfected injection equipment is a key part of infection prevention programs—and is especially critical at this time, given the recent resurgence of injection drug

[4] Bradley, H., et al. Ryan White HIV/AIDS Program Assistance and HIV Treatment Outcomes in the United States. CROI 2015. Abstract: 1064. Accessed online at: http://www.croiconference.org/sessions/ryan-white-hivaids-program-assistance-and-hiv-treatment-outcomes-united-states.

[5] Based on data from Gilman BH, Green, JC. Understanding the variation in costs among HIV primary care providers. AIDS Care.2008:20;1050—6.

use in many parts of the Nation. The current HIV outbreak in Indiana, which is related to injection drug use, underscores the salience of this issue.

SEPs also help improve individual and community public health by engaging individuals in medical care. SEPs are associated with decreases in HIV and viral hepatitis incidence, and provide an important point of healthcare access, including initiation of HIV and viral hepatitis education, counseling and testing, and entry into substance use treatment. SEPs also benefit community safety by reducing the number of improperly disposed syringes as well as reducing needle stick injuries to law enforcement officers and other first responders.

CONCLUSION

We are at serious risk of losing ground against the HIV pandemic if we fail to prioritize public health and research programs. HIV remains the leading infectious killer worldwide, and we must fully leverage and invest in HIV prevention, care and treatment and research to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe.

[This statement was submitted by Dr. Adaora Adimora, MD, MPH, FIDSA, HIV Medicine Association.]

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PREPARED STATEMENT OF ELAINE HOPKINS

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Med-

icaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

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PREPARED STATEMENT OF REVEREND NANCY S. HULL

Let me preface my stance on this issue by making you aware that I work in the field of intellectual/developmental disabilities and as President/CEO of a church related agency that has a ministry to over 100 clients/residents and their families. We believe in choice, and offer both a community home option and an intermediate care facility (ICF) option to families. The families we serve whose children or family member resides in the ICF have made a conscious choice that this is the setting that best serves their family member's needs. I cannot understand why no one is listening to them. Recently we presented to the Ohio House of Representatives petitions signed by 18,500 persons who are urging you to stop the Disability Rights of Ohio group, the Department of Justice, and others who are misusing government dollars by attempting to make decisions for families which are the right of the family member or individual served.

I would invite any of you to come to Flat Rock Care Center in Seneca County, Ohio to see a model of facility where individuals served live in houses of 6 persons, all of which are individual units with living rooms, dining rooms, activity rooms, kitchens, and bedrooms that have individual space designed for two persons but giving each privacy. Each bedroom has a handicapped bathroom attached. Our gym area and campus are used by community children and adults on a weekly basis. This facility is not isolating, it is integrating.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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## PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

On behalf of the Infectious Diseases Society of America (IDSA), thank you for the opportunity to provide testimony in support of the U.S. Department of Health and Human Services (HHS) agencies and programs that contribute to the prevention, detection and treatment of infectious diseases (ID). IDSA represents more than 10,000 ID physicians and scientists devoted to patient care, prevention, public health, education, and research. IDSA recommends increased fiscal year 2016 Federal investments in public health and biomedical research to save lives, contain healthcare costs, and promote economic growth. More specifically, IDSA encourages the Subcommittee to provide a program level of $7.8 billion for the Centers for Disease Control and Prevention (CDC) as well as at least $32 billion for the National Institutes of Health (NIH).

IDSA is particularly supportive of initiatives contained in the President's Budget Request (PBR) for fiscal year 2016 to address the growing public health crisis of antibiotic resistance. These proposals enable implementation of the recently released National Action Plan for Combating Antibiotic-Resistant Bacteria (CARB). The Action Plan reflects recommendations put forward by the President's Council of Advisors on Science and Technology (PCAST) in their September 2014 Report to the President on Combating Antibiotic Resistance. In particular, IDSA urges the Subcommittee to fund the proposed CDC Antibiotic Resistance Solutions Initiative. We ask that the final fiscal year 2016 Labor-HHS-Education appropriations bill also support the role of the National Institutes of Health (NIH) and the Biomedical Advanced Research and Development Authority (BARDA) in stimulating research and development (R&D) for rapid ID diagnostics and antibiotics.

### CENTERS FOR DISEASE CONTROL AND PREVENTION

The recent outbreak of Ebola virus disease (EVD) in West Africa and subsequent cases in the United States demonstrates that infectious diseases respect no national borders and that the CDC must be appropriately funded to maintain readiness ahead of new crises. IDSA members are partnering with the CDC and other Federal agencies to respond to the EVD crisis. We ask that the Subcommittee support collaborations between government, industry, academia and other non-governmental organizations to address the full range of infectious diseases confronting the public. Our country requires on a fully engaged and stably supported CDC to address public health needs such as slowing the rise of antibiotic resistance, increasing immunization rates and stopping the spread of HIV.

Conservative estimates indicate that more than two million Americans suffer from antibiotic-resistant infections each year and that approximately 23,000 will die. Additionally, there were half a million Clostridium difficile (C. difficile) infections in the United States in 2011, and 29,000 died within 30 days of the initial diagnosis. C. difficile is a unique bacterial infection that, although not significantly resistant

to the drugs used to treat it, is directly related to antibiotic use and resistance. Carbapenem-resistant Enterobacteriaceae (CRE) has been labeled a "nightmare bacteria." Nearly half of individuals who develop a bloodstream infection from CRE will die. Each year, antibiotic resistance results in an additional 8 million hospital days and costs in excess of $20 billion to the U.S. healthcare system. The actual human and financial costs are likely far higher, as our surveillance and data collection capabilities cannot yet capture the full disease burden. The death and financial tolls rise with each day that we fail to act.

PCAST and the CDC have recommended actions in four core areas to address the problem, including prevention, tracking, antibiotic stewardship, and development of new antibiotics and rapid ID diagnostics. The CDC has proposed fiscal year 2016 activities in each of these areas for which new funding is needed.

*National Center for Emerging and Zoonotic Infectious Diseases (NCEZID)*

The NCEZID leads CDC efforts to address antibiotic resistance. As such, we ask that it be provided at least the $699 million requested by the Administration, including at least $264 million for the Antibiotic Resistance Solutions Initiative. This initiative would build prevention programs in all 50 States and 10 large cities, utilizing evidence-based approaches to stop the spread of drug-resistant bacteria and preserve the effectiveness of existing antibiotics. The initiative also supports a new network of regional labs to improve tracking of and response to outbreaks of serious and potentially deadly bacteria. The CDC projects that over 5 years, the initiative will lead to a 60 percent decline in health-care associated CRE, 50 percent reduction in C. difficile, 50 percent decline in bloodstream methicillin-resistant Staphylococcus aureus (MRSA), 35 percent decline in health-care associated multidrug-resistant Pseudomonas spp., and 25 percent reduction in multidrug-resistant Salmonella infections, more than covering the costs of investing in these programs now.

IDSA also supports the proposed $14 million increase for the National Healthcare Safety Network (NHSN) to expand the number of participating healthcare facilities to 17,000 and increase the number of sites reporting antibiotic use and antibiotic resistance data. Information provided via NHSN is critical for evaluating the success of interventions designed to reduce inappropriate antibiotic use and limit the development of resistance and is therefore an integral component to broader efforts to address resistance.

IDSA thanks Congress for funding the Advanced Molecular Detection (AMD) initiative in fiscal year 2015 and recommends that at least $30 million be allocated for it in fiscal year 2016. AMD strengthens CDC's molecular sequencing tools and bioinformatics capacity to more rapidly and accurately detect infectious diseases and resistance. During the most recent Ebola virus disease outbreak, AMD methods were utilized to determine whether the virus was changing as it spread through different populations, which facilitated appropriate responses.

*Global Health*

IDSA supports CDC efforts to expand the Global Health Security Agenda, which would strengthen the capacity of nations to prevent, detect and slow the spread of infectious diseases across borders, simultaneously reducing threats to the United States. We ask that you provide the initiative with at least the funding requested in the fiscal year 2016 PBR.

IDSA also encourages the Subcommittee to increase research, monitoring, and evaluation efforts for malaria and neglected tropical diseases. Chikungunya, as well as Chagas disease and dengue fever have been reported in the United States. At least 40 percent of the world's population is at risk of serious illness and death from mosquito-borne viral diseases.

*National Center for Immunization and Respiratory Diseases*

Immunizations are among the most cost-effective clinical preventative services. However, according to the CDC February 2015 Morbidity and Mortality Weekly Report, national adult immunization rates remain low for most routinely recommended vaccines. Each year in the United States, tens of thousands of adults die from illnesses that are preventable through vaccination. Additionally, vaccine-preventable diseases and related complications result in billions of dollars annually in direct and indirect healthcare costs. During the last year, measles outbreaks and a sub-optimal influenza vaccine have reminded us of the importance of immunizations to public health.

IDSA opposes the $50 million reduction to the CDC Immunization Grant Program (Section 317) contained in the PBR. Although the Affordable Care Act requires insurers to cover immunizations, this alone will not guarantee access or utilization. Section 317 funds are critical to help providers obtain and store vaccines; establish and maintain vaccine registries; as well as to educate providers and the public about

vaccine recommendations, effectiveness and safety; and promote universal vaccination of healthcare workers.

IDSA recommends that the Subcommittee provide at least the $188 million proposed in the PBR for CDC efforts to control influenza. CDC plays a critical role in seasonal and pandemic influenza preparedness and response, including conducting surveillance activities that inform response efforts and providing public communications regarding influenza prevention and treatment. Insufficient funding for these efforts could lead to increased incidence and severity of influenza, as well as increased hospitalization costs and mortality rates. Sustained support for these efforts is more cost-effective than periodic emergency supplemental funding.

NATIONAL INSTITUTES OF HEALTH

*National Institute of Allergy and Infectious Diseases (NIAID)*

Within NIH, we believe that the National Institute of Allergy and Infectious Diseases should be funded at least at $4.62 billion as requested by the Administration in the fiscal year 2016 PBR. Decreases in the purchasing power of NIAID have limited investment in new research and provided a disincentive for the pursuit of ID research careers so critical to the discovery of new vaccines, antimicrobials, diagnostics, and prevention strategies.

The NIAID is central to pursuits of new rapid ID diagnostics and antibiotics. A recent IDSA report, Better Tests, Better Care: The Promise of Next Generation Diagnostics explains that advances in biomedical research over the last few decades create the potential for increasingly simple, fast and reliable diagnostic tests for infectious diseases. By allowing physicians to quickly distinguish between bacterial and viral infections, better diagnostics can lead to faster and more appropriate treatments for patients, help preserve the utility of our existing drugs, and aid in identifying individuals to participate in clinical trials. Last year, NIAID stated its intention to place special emphasis on rapid diagnostics. Several initiatives have been announced, such as funding for diagnostics to quickly detect bacteria responsible for drug-resistant infections acquired in hospital settings and tests to identify reservoirs of latent HIV infection.

While increased funding is urgently needed, IDSA also recommends that the Subcommittee promote necessary and appropriate collaboration between academic researchers who receive NIH funding and industry by urging HHS to clarify its conflict of interest (COI) rules. Diagnostic test developers often require expert input or independent validation of a potential test during development from individuals at academic institutions. Institutional COI policies are often much more strict than the HHS COI regulatory framework, which was intended to provide guidance to institutions on how to manage COI. These COI policies vary widely between institutions and are sometimes misinterpreted. This results in an unnecessary stifling of needed collaboration between academic researchers and industry when appropriate, which in turn forces developers to forgo expert input or use laboratories lacking the expertise for independent validation.

The NIAID supports the Antibacterial Resistance Leadership Group (ARLG), led by researchers at Duke University and the University of California San Francisco. With sufficient funding, the research network/infrastructure will continue studies to address antibiotic resistance. Severe economic disincentives continue to cause private companies to leave the antibiotics market, making federally funded research in this area more critical than ever.

The ARLG has supported early clinical research on diagnostics that rapidly identify resistant bacteria. The research group has created a virtual biorepository, which is a web-based portal that provides researchers with unique access to clinically well-characterized bacteria for the development of diagnostic tests and other research. Diagnostics research is often hampered by lack of clinical samples for testing. IDSA urges the Subcommittee to support NIAID exploration of opportunities to develop virtual biorepositories for viruses, fungi, and other pathogens already collected through its existing funded research.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

*Biomedical Advanced Research and Development Authority (BARDA)*

BARDA is a critical initiator of public-private collaborations for antibiotic, diagnostic and vaccine R&D. PCAST has identified BARDA as best positioned to elicit private investments necessary to address antibiotic resistance. However, the BARDA budget has been flat-funded for several years, with inflation leading to loss of purchasing power. Increased funding would allow BARDA to work with industry as a counter to current market failures. IDSA recommends that the Subcommittee provide at least the $522 million requested for BARDA in the president's budget for

fiscal year 2016. Such funding is necessary to allow BARDA to pursue additional work on antibiotic development while maintaining its strong focus on other medical countermeasures to address biothreats.

Once again, thank you for the opportunity to submit this statement on behalf of the Nation's ID physicians and scientists. We rely on strong Federal partnerships to keep Americans healthy and urge you to support these efforts. Please forward any questions to Jonathan Nurse.

[This statement was submitted by Stephen B. Calderwood, MD, FIDSA, IDSA, President, Infectious Diseases Society of America.]

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## PREPARED STATEMENT OF THE INSTITUTE OF MAKERS OF EXPLOSIVES

### INTEREST OF IME

IME is a nonprofit association founded in 1913 to provide accurate information and comprehensive recommendations concerning the safety and security of commercial explosive materials. Our mission is to promote safety and the protection of employees, users, the public and the environment, and to encourage the adoption of uniform rules and regulations in the manufacture, transportation, storage, handling, use and disposal of explosive materials used in blasting and other essential operations.

IME represents U.S. manufacturers and distributors of commercial explosive materials and oxidizers as well as other companies that provide related services. Millions of metric tons of high explosives, blasting agents, and oxidizers are consumed annually in the U.S. Of this, IME member companies produce over 98 percent of the high explosives and a great majority of the blasting agents and oxidizers. These products are used in every State and are distributed worldwide.

Commercial explosives are pervasively regulated by a myriad of Federal and State agencies. Explosives manufacturing, storage and transportation facilities are subject to OSHA's Explosives and Blasting Agents standard. In addition, all explosives facilities and AN manufacturing facilities comply with the Process Safety Management (PSM) standard.[1] OSHA participates in the Chemical Facility Safety and Security Working Group, or Interagency Working Group ("IWG"), which is engaged in satisfying the requirements of Executive Order ("EO") 13650, Improving Chemical Facility Safety and Security. The IWG's June 6, 2014 status report, Actions to Improve Chemical Facility Safety and Security—A Shared Commitment, includes actions that have the potential to significantly impact the commercial explosives industry.

We offer the following comments on OSHA's request for funds to address chemical facility safety including ammonium nitrate (AN) facilities, and the concurrent need to ensure that the agency's actions complement the regulatory requirements of other Federal agencies while avoiding unnecessary regulation and/or redundancy within and between agency programs.

### BACKGROUND

AN is an indispensable ingredient in blasting agents used in mining, construction, and other industries critical to the U.S. economy. Currently, upwards of 75 percent of the billions of pounds of AN consumed annually is manufactured for the explosives industry. AN-based blasting agents have become the most widely used explosive materials in the world since their introduction in the 1950s. There is no viable alternative.

The "technical" grade of AN used in the explosives industry has the same chemical composition as the "fertilizer" grade of AN used in the agricultural sector, only the density of the prill is different. AN, in either form, is not self-reactive and does not pose a threat of an accidental release of energy or fumes unless subjected to substantial and sustained heat (e.g., fire) or shock from high explosives.

### OSHA'S PSM BUDGET REQUEST

OSHA is requesting $23,306,000 to fund Safety and Health Standards activity.[2] This includes an increase in funding to support EO 13650. In connection with that effort, OSHA states that it will use the appropriation to modernize PSM as well as other standards impacting the commercial explosives industry (e.g., ammonium ni-

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[1] AN manufacturing facilities are covered by PSM because they use anhydrous ammonia in the manufacturing process.

[2] fiscal year 2016 OSHA Congressional Budget Justification, p. 24.

trate storage updates and clarifications in the Explosives and Blasting Agents standard), and to develop several related guidance documents in consultation with other Federal agencies.[3] In pursuing the requirements of the EO, OSHA, in December 2013, published a Request for Information (RFI) on PSM. Among other things, OSHA inquired whether AN should be included on an expanded list of substances covered by PSM. We do not believe that any resources appropriated to support OSHA's programs should be used to fund an expansion of the PSM program to include AN. Rather, should OSHA choose to address AN safety, its resources should be allocated to the enhancement of existing OSHA regulations governing this material.

Since 1971, the storage and handling of AN has been regulated under OSHA rules that specifically address the properties of this material. These rules at 29 CFR 1910.109(i) are part of the Explosives and Blasting Agents standard and are based on NFPA safety codes.[4] There is no known accidental detonation of AN where a facility has been compliant with this OSHA standard.[5] In fact, the safe management of AN is not complicated and is easily achieved by following very basic, well-understood safety practices. When handled in accordance with these simple tenets, AN is a stable, relatively inert material; it is not the type of highly hazardous chemical that Congress intended to cover under the PSM program. While efforts to include AN under PSM are not necessary or appropriate, we do support the appropriation of sufficient funds to allow OSHA to update 29 CFR 1910.109(i) to comport with the most recent edition of NFPA's code addressing AN and with modern industry best practices and standards.

In support of this recommendation, we urge the Subcommittee to include the following language submitted by Senator John Barrasso in the Subcommittee's fiscal year 2016 appropriations bill:

(X) None of the funds made available by this Act may be used imposed new regulations on the storage of solid ammonium nitrate unless those funds are used to update section 1910.109(i), title 29, Code of Federal Regulations, to be consistent with the safety standards for the storage of solid ammonium nitrate issued by the National Fire Protection Association in publication NFPA 400 Hazardous Materials Code and such other voluntary standard-setting organization as the Secretary determines appropriate.

We believe that this allocation of available resources will prevent redundant and unnecessary Federal regulation while ensuring the safety of commercial explosives and AN facilities and their host communities.

CONCLUSION

Given the decades-long safety record of OSHA's 1910.109(i) standard on AN, imposing a complex regulatory program like PSM would impose a significant administrative and economic burden on impacted small businesses without any commensurate improvement in safety. While we support the modernization of the 1910.109(i) standard, we believe the inclusion of AN in the PSM standard would amount to over-regulation, would prove exceedingly costly, and would do nothing to enhance the safety of workers or the public. Any funding provided to OSHA should include a prohibition on the expansion of PSM to include AN.

[This statement was submitted by Cynthia Hilton, Executive Vice President, Institute of Makers of Explosives.]

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## PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

—$32 billion for the National Institutes of Health (NIH) at an increase of $1 billion over fiscal year 2012. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.

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[3] Id.

[4] NFPA 400, Hazardous Materials Code. The 2016 edition of the code is scheduled for publication in December 2015.

[5] In addition, AN is subject to various ATF, EPA, DHS, and DOT safety and security regulations.

—Continue focus on Digestive Disease Research and Education at NIH, including), Irritable Bowel Syndrome (IBS), Fecal Incontinence Gastroesophageal Reflux Disease (GERD) Gastroparesis, and Cyclic Vomiting Syndrome (CVS).

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Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal and motility disorders (FGIMD) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by FGMIDs, and providing education and support for patients, healthcare providers, and the public. IFFGD also works to advance critical research on FGIMDs in order to develop better treatment options and to eventually find cures. IFFGD has worked closely with the National Institutes of Health (NIH) on many priorities, and I served on the National Commission on Digestive Diseases (NCDD), which released a long-range plan in 2009, entitled Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases.

The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for FGIMDs are close to my heart. My own experiences of suffering from FGIMDs motivated me to establish IFFGD, and I was shocked to discover that despite the high prevalence of FGIMDs among all demographic groups, such a lack of research existed. This translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among the medical community and the public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery. Most FGIMDs have no cure and limited treatment options, so patients face a lifetime of chronic disease management. The costs associated with these diseases range from $25–$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

### IRRITABLE BOWEL SYNDROME (IBS)

IBS affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. It is a chronic disease that causes abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a "functional disorder," IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests. Without a diagnostic test, IBS often goes undiagnosed or misdiagnosed for years. Even after IBS is identified, treatment options are limited and vary from patient to patient. Due to persistent pain and bowel unpredictability, individuals may distance themselves from social events and work. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Many people also dismiss their symptoms or attempt to self-medicate with over-the-counter medications. Outreach to physicians and the general public remain critical to overcome these barriers to treatment and assist patients.

### FECAL INCONTINENCE

At least 12 million Americans suffer from fecal incontinence. Incontinence crosses all age groups, but is more common among women and the elderly of both sexes. Often it is associated with neurological diseases, cancer treatments, spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, and uterine cancer. Causes of fecal incontinence include: damage to the anal sphincter muscles, damage to the nerves of the anal sphincter muscles or the rectum, loss of storage capacity in the rectum, diarrhea, or pelvic floor dysfunction. People may feel ashamed or humiliated, and most attempt to hide the problem for as long as possible. Some don't want to leave the house in fear they might have an accident in public; they withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly is the primary reason for nursing home admissions, an already significant social and economic burden in our aging population. In 2002, IFFGD sponsored a consensus conference entitled, Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities. IFFGD also collaborated with NIH on the NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults in 2007.

NIDDK recently launched a Bowel Control Awareness Campaign (BCAC) that provides resources for healthcare providers, information about clinical trials, and advice for individuals suffering from bowel control issues. The BCAC is an important step in reaching out to patients, and we encourage continued support for this cam-

paign. Further research on fecal incontinence is critical to improve patient quality of life and implement the research goals of the NCDD.

GASTROESOPHAGEAL REFLUX DISEASE (GERD)

GERD is a common disorder which results from the back-flow of stomach contents into the esophagus. GERD is often accompanied by chronic heartburn and acid regurgitation, but sometimes the presence of GERD is only revealed when dangerous complications become evident. There are treatment options available, but they are not always effective and may lead to serious side effects. Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year and even more premature infants. GER results from immature upper gastrointestinal motor development. Up to 8 percent of children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction and may require long-term treatment.

GASTROPARESIS

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting, or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, and is present in 30 percent to 50 percent of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications. In many patients the cause cannot be found and the disorder is termed idiopathic gastroparesis.

CYCLIC VOMITING SYNDROME (CVS)

CVS is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea and vomiting, accompanied by abdominal pain, prostration, and lethargy, last hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in many age groups, including adults. CVS patients often go for years without correct diagnosis. CVS leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Research is needed to help identify at-risk individuals and develop more effective treatment strategies.

SUPPORT FOR CRITICAL RESEARCH

IFFGD urges Congress to fund the NIH at level of $32 billion for fiscal year 2016. Strengthening and preserving our Nation's biomedical research enterprise fosters economic growth and supports innovations that enhance the health and well-being of the Nation. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to strengthen the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) with a level of funding at $2.066 billion for fiscal year 2016. Such support would expedite the implementation of recommendations from the NCDD. It is also vital for NIDDK to work with the National Institute of Child Health and Human Development (NICHD) to expand its research on the impact FGIMDs have on pediatric populations. Following years of near level-funding, research has been negatively impacted across all NIH Institutes and Centers. Without additional funding, medical researchers run the risk of losing promising research opportunities that could benefit patients.

We applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposement hold the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2016.

Thank you for the opportunity to present these views on behalf of the FGIMD community.

[This statement was submitted by Tegan Gaetano, Program Specialist, International Foundation for Functional Gastrointestinal Disorders.]

PREPARED STATEMENT OF THE INTERSTATE MINING COMPACT COMMISSION

We are writing in support of the fiscal year 2016 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the Subcommittee to support a full appropriation for State assistance grants for safety and health training of our Nation's miners pursuant to section 503(a) of the Mine Safety and Health Act of 1977. MSHA's budget request for State assistance grants is $8,441,000. While the proposed amount goes a long way in helping the States provide important safety training and is appreciated by the States, it is approximately the same amount that has been appropriated for State assistance grants by Congress over the past several fiscal years and, as such, does not fully consider inflationary and programmatic increases being experienced by the States. We urge the subcommittee to restore funding to the statutorily authorized level of $10 million for State assistance grants so that States are able to meet the training needs of miners and to fully and effectively carry out State responsibilities under section 503(a) of the Act. We believe the States can justify the need for funding at the statutorily authorized level.

The Interstate Mining Compact Commission is a multi-State governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 26 member States. The States are represented by their Governors who serve as Commissioners.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted State assistance grants as meaning "training grants" only, Section 503 was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mining Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for "Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation's coal mines." (H. Conf. Report 91–761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to $10 million. The training of miners was only one part of the obligation envisioned in Congress.

With respect to the training component of our mine safety programs, IMCC's member States are concerned that without full, stable funding of the State Grants Program, the federally required training for miners employed throughout the U.S. will suffer. States are struggling to maintain efficient and effective miner training and certification programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation has been further complicated by new statutory, regulatory and policy requirements that have grown out of the various reports and recommendations attending the Upper Big Branch investigation. We greatly appreciate Congress' recognition of this fact and this Subcommittee's strong support for State assistance grants, especially over the past few years when the Administration sought to eliminate or substantially reduce those moneys.

Our experience over the past 35 years has demonstrated that the States are often in the best position to design and offer mine safety and health training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. MSHA estimates in its budget justification document for Educational Policy and Development (EPD) that the States will train approximately 180,000 miners in fiscal year 2016. The most recent accounting of the number of miners trained by a sampling of the States based on fiscal year 2014 reporting for coal and metal/nonmetal is as follows:

—Kentucky: Trained or tested over 17,758.
—Alaska: 1,119 miners trained.
—New Mexico: 1,942 miners trained.
—Illinois: 13,227 miners and contractors trained (including Aggregate Part 46, Coal Mine Accident Prevention, certification and EMT training).
—Indiana: 3,247 miners and contractors trained.
—Oklahoma: 4,180 miners trained.
—Pennsylvania: 6,535 miners trained.
—Ohio: 7,000 miners trained.
—Colorado: 4,731 miners trained.
—Arkansas: 2,573 miners and contractors trained.
—Nevada: 2,329 miners trained.
—North Carolina: 8,515 miners trained.
—Maryland: 452 miners trained (fiscal year 2013).

—Arizona: 2,612 miners trained.
—Virginia: 4,940 miners trained and 2,422 certifications issued.
—Mississippi: 175 miners and contractors trained.

Note that the numbers of miners trained has decreased over the past few years due to the reductions and/or delays in State grant funding. This continues to be a serious challenge for State training programs in fiscal year 2015 with States still awaiting the allocation of grant awards as of March 20, 2015—six months into the fiscal year. Given MSHA's reluctance to date to utilize interim grant allocations during the fiscal year (as other Federal agencies do), these delays in authorizing grant allocations are unduly disrupting the States' ability to run effective training programs that rely on certain, consistent and timely funding. Another complicating factor is MSHA's intention to utilize a new formula for distributing grant moneys among the States based on production and employment figures over a 5 year period of time. While we have yet to see the details of this new approach, the States are concerned about its appropriateness, fairness and overall effectiveness in meeting the respective needs of the States, to say nothing of the certainty and reliability of grant amounts into the future.

As you consider our request to increase MSHA's budget for State training grants, please keep in mind that the States play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) and the Spanish-speaking community in meeting their required training needs.

We also want to bring another matter to your attention because of the implications it may have for mine safety and health programs, as well as related programs under the Surface Mining Control and Reclamation Act of 1977 (SMCRA). Recently, MSHA attempted to assert jurisdiction over an abandoned mine land (AML) project site being reclaimed by the Commonwealth of Pennsylvania as part of its approved AML program under Title IV of SMCRA. Because the project involves the incidental extraction of coal that will be removed from the site and sold (with the proceeds being reinvested in the project), MSHA believes this triggers its jurisdiction under the Mine Act. The project is being undertaken pursuant to a duly promulgated rule by the Office of Surface Mining (OSM) under SMCRA authorizing these types of "AML enhancement projects". Since these types of projects began in 1999, MSHA has seldom, if ever, exercised jurisdiction over them.

In an attempt to seek resolution regarding the appropriateness of MSHA jurisdiction over this class of AML projects, the States, through IMCC, met recently with both MSHA and OSM officials to discuss the matter. We learned during the meeting that MSHA is not only seeking to exercise jurisdiction over AML enhancement projects, but over any and all AML projects that involve "reclamation", arguing that courts have held that "reclamation" of extraction sites is covered under the Mine Act Section 3(h) definition of "mine" because it restores lands, etc. whose condition is caused by ("resulting from") the work of extraction.

Since the inception of SMCRA in 1977 and the States' implementation of AML programs beginning in 1979, we are unaware of any circumstances where MSHA has asserted jurisdiction over these types of projects involving coal or noncoal reclamation except in those rare circumstances where an AML contractor inadvertently requested an MSHA ID number. Even in those very limited situations, MSHA has seldom pursued inspection and enforcement once it realized an AML project was underway. We are therefore at a loss for MSHA's newfound interest in AML projects, which are already regulated by the States, with Federal oversight by OSM, and which are generally subject to OSHA jurisdiction. While we are still pursuing this matter with MSHA and OSM, the consequences of a decision rendering these sites subject to MSHA jurisdiction could have debilitating consequences for the AML program under SMCRA and significant budgetary implications for MSHA. We therefore urge the Subcommittee to include language in its report on MSHA's budget prohibiting the agency from exercising jurisdiction over AML projects under Title IV of SMCRA.

We appreciate the opportunity to submit our views on the MSHA fiscal year 2016 budget request as part of the overall Department of Labor budget. Please feel free to contact us for additional information or to answer any questions you may have.

[This statement was submitted by Gregory E. Conrad, Executive Director, Interstate Mining Compact Commission.]

## PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION

### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2016

—Provide $1 million for the IC Education and Awareness Program and the IC Epidemiology Study at the Centers for Disease Control and Prevention (CDC)
—Provide $7.8 billion for CDC
—Provide $32 billion for the National Institutes of Heatlh (NIH) and Proportional Increases across all Institutes and Centers
—Support NIH Research on IC, including the Multidisciplinary Approach to the study of Chronic Pelvic Pain (MAPP) research network

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding interstitial cystitis (IC) public awareness and research. ICA was founded in 1984 and is the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments. ICA also works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC is limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

### IC PUBLIC AWARENESS AND EDUCATION THROUGH CDC

ICA recommends a specific appropriation of $1 million in fiscal year 2016 for the CDC IC Program. This will allow CDC to fund the Education and Awareness Program, per ongoing congressional intent, as well as the IC Epidemiology Study.

In December 2014, CDC switched the focus of the IC program from education and awareness to an epidemiology study. The IC community is concerned that eliminating education and awareness activities is detrimental to patients and their families. The CDC IC Education and Awareness Program is the only Federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA urges Congress to provide funding for IC education and awareness in fiscal year 2016.

The IC Education and Awareness program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the Internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public though videos, booklets, publications, presentations, educational kits, Web sites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube,

and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provided patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

IC RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

ICA recommends a funding level of $32 billion for NIH in fiscal year 2016. ICA also recommends continued support for IC research including the MAPP Study administered by NIDDK.

The National Institutes of Health (NIH) maintains a robust research portfolio on IC with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) serving as the primary Institute for IC research. Research currently underway holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes, including epidemiology. The MAPP Study has expanded in its second phase to include cross-cutting researchers and researchers are currently identifying different phenotypes of the disease. Phenotype information will allow physicians to prescribe treatments with more specificity. Research on chronic pain that is significant to the community is also supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Integrative Health (NCCIH). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

Thank you for the opportunity to present the views of the interstitial cystitis community.

[This statement was submitted by Lee Claassen, Executive Director, Interstitial Cystitis Association.]

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## PREPARED STATEMENT OF THE JAMESTOWN S'KLALLAM TRIBE

On behalf of the Jamestown S'Klallam Tribe, I am pleased to submit this written testimony on our funding priorities and requests for the fiscal year 2016 Department of Labor (DOL), Department of Health and Human Services (HHS) and Department of Education (DOE) budgets. Funding for Indian country is appropriated in the non-defense discretionary portion of the Federal budget. We, therefore, renew our request that Congress work together to achieve a balanced approach to the budget deficit that includes raising new revenue sources and that doesn't rely solely on cuts to discretionary spending.

We strongly support the Administration's fiscal year 2016 Budget Proposal as it reflects an improved commitment on behalf of the Federal Government to uphold treaty and trust obligations with an investment in Indian programs. These proposed increases are extremely important to Tribes because we rely on this funding to support our core governmental programs and critical services that promote the safety and well-being of our Tribal citizens and Indian community. We also advocate for the expansion of Self-Governance so that Tribes can continue to have the flexibility to redesign programs and services throughout the Federal Government to better address their community needs.

In addition to the items detailed below, our Tribe would like to reiterate that we are a direct beneficiary of the collective and continuing efforts of the National Congress of American Indians, the National Indian Education Association, the Affiliated Tribes of Northwest Indians, the Northwest Portland Area Indian Health Board, and the Northwest Indian Fisheries Commission.

TRIBAL SPECIFIC BUDGET PRIORITIES

*Department of Labor, Department of Health and Human Services & Department of Education*

—Administration on Aging, Title VI—provide $30 million (HHS)
—Head Start—provide $9.6 billion (HHS)

—Title VII Indian Education—provide $198 million (DOE)
—Employment and Training Administration, Indian and Native American Program (INAP)—provide $65 million (DOL)

NATIONAL BUDGET PRIORITIES

—Exempt Tribes from Sequestration and Rescissions and Restore 2013 Sequestration Cuts

*Department of Health & Human Services*

—Special Diabetes Program for Indians—provide $200 million a year for 5 years
—Full Funding for Streamlined Implementation of the Patient Protection and Affordable Care Act and the Indian Health Care Improvement Act—provide Full Funding
—Restore Funding for Child Welfare Services (Social Security Act Title IV–B, Subpart 1)—provide $280 million
—Substance Abuse and Mental Health Services Administration—American Indian and Alaska Natives Suicide Prevention—restore funding to $2.97 million
—Tribal Prevention Grants Program—provide $45 million over fiscal year 2015 request

*Department of Education*

—Title I, Part A, Local Education Agency Grants provide $25 million
—Impact Aid Title VIII funding provide $2 billion

TRIBAL SPECIFIC BUDGET REQUEST JUSTIFICATION

*Administration on Aging Older Americans Act—Title VI provide $30 million*

The care of elders is a culturally inherent responsibility that provides an important part of maintaining our cultural knowledge and wisdom to strengthen our families and communities. The Administration on Aging Older Americans Act funds a majority of Jamestown's Elder Programs. We use these funds to provide nutrition, health education and to reduce isolation through community and cultural activities which directly impact the health and well-being of our Tribal elders.

*Title VII Indian Education—provide $198 million*

Over 160 American Indians and Alaska Native children have been identified in the Sequim School District. Title VII Indian Education funds allow our staff to provide a culturally sensitive voice to the local school program which has resulted in increased proficiency scores and an increase in the graduation rate of our American Indian and Alaska Native students.

*Employment and Training Administration, Indian and Native American Program (INAP)—$65 million*

The Western Washington Indian Employment and Training Program (WWIETP) consist of a consortium of 25 Western Washington Tribes, including Jamestown. WWIETP is fully funded by the Federal Workforce Investment Act, which was enacted to provide training, education and employment for adults, displaced workers and youth. WWIETP's directive is to provide work experience and education assistance necessary for self-sufficiency exclusively to qualifying American Indians and Alaska Natives. The program allows us the opportunity to serve Tribal Descendants and individuals with other Tribal affiliations residing in our service area.

*Head Start provide $9.6 Billion*

Head start provides early educational services to over 24,000 Native children. Many of Jamestown's children partake in the Head Start program. This program provides Federal dollars to support comprehensive services (education, health and family services) that model traditional Native learning and prepare our Tribal youth for Kindergarten by improving conditions necessary for success in education. Quality early childhood education plays a critical role in the health and educational success of our Native students.

NATIONAL BUDGET REQUESTS

*Exempt Tribes from Sequestration and Further Rescissions and Restore 2013 Sequestration Cuts (BIA and IHS)*

Budgetary reductions undermine Indian Treaty Rights and Federal obligations. The Federal trust obligation must be honored and vital programs and services for Tribes must be sustained despite the budget deficit. Sequestration and rescissions further exacerbates an already precarious budgetary situation undermining the

Tribes abilities to maximize their underfunded operations and provide basic services to our Tribal citizens. We urge Congress to exempt Tribes from any further reductions imposed by the Budget Control Act and to restore funding cuts due to the 2013 sequestration and rescissions.

*Department of Health and Human Services*

*Special Diabetes Program for Indians—$200 million a year for 5 years (Special Appropriations administered by IHS)*

Recently extended until October 1, 2017 at the current rate of $150 million, Special Diabetes Program for Indians (SDPI) has been flat-line since 2004. Continuing support of the SDPI will maintain critical momentum in diabetes research and care to help bring diabetes-related costs under control. The permanency of SDPI would be a great asset to promoting stability for this important health program and for reversing the trend of Type 2 diabetes in Indian Country. In addition it will provide for staff retention, programmatic long-term planning which increases and improves patient care, and more stable outside contracts with vendors and suppliers. American Indian/Alaska Natives (AI/AN) are two to four times as likely to develop diabetes compared to other races. The SDPI program has proven effective in combatting diabetes and enhancing care and education in AI/AN communities. As a result, the program has successfully reduced costly health complications and the incidence of the disease itself.

*Full Funding for the ACA/IHCIA—Full Funding to implement twenty-five unfunded provisions in the IHCIA*

The Indian Health Care Improvement Act (IHCIA) permanently authorizes healthcare to approximately two million American Indians/Alaska Natives served by the Indian Health Service. The law was intended to improve the healthcare conditions in Indian country; however, there are more than twenty-five unfunded provisions in the IHCIA. Implementation of the new authorities and the improvement of the health status of Native health hinges upon the provision of full funding.

*Restore Funding for Child Welfare Services (Social Security Act Title IV-B Subpart 1)—provide—provide $280 million*

Tribal Child Welfare Program Funds are administered at the Tribal community level with a culturally appropriate philosophy that results in better outcomes for American Indian/Alaska Native families. The Child Welfare Services Program allows for flexibility enabling Tribes to provide culturally appropriate services to families along a continuum and is utilized by Tribes to address in-home services, support services for Native children in foster care, case management, training and professional development. Tribes share in the State allocation but the median Tribal grant is a little over $13,000 a year, preventing many Tribes from participating in the program due to the cost of implementation. An increase in program dollars is necessary to ensure that all Tribes are able to address the child welfare needs within their communities.

*Substance Abuse and Mental Health Services Administration—American Indian and Alaska Native Suicide Prevention—restore funding to $2.97 million*

The inability to deal with the root cause of mental health issues has led to an increase in drug and alcohol abuse/misuse among American Indian/Alaska Natives. Alcohol and drug use is at epidemic levels as many individuals use it as a means to self-medicate and the impacts extend beyond the individual to our Tribal families and community. The Substance Abuse and Mental Health Services Administration program provides funding to support technical assistance and training to Tribes on how to leverage existing resources to implement prevention plans to address bullying, violence and suicide in Tribal communities.

*Tribal Prevention Grants Program—provide $45 million over fiscal year 2015 request*

The inaugural funding for the program was in fiscal year 2014 for $5 million which, startling as it may be, was the same level appropriated for fiscal year 2015. Only 20 Tribes received $.02 million annually for 5 years to help them develop the comprehensive plan. We request $45 million over the 2015 enacted amount to expand these activities throughout Tribal communities where behavioral health problems have a powerful negative impact on our citizens and economy.

*Department of Education*

*Title 1, Part A, Local Education Agency Grants—provide $25 million*

Approximately 600,000 American Indian/Alaska Native youth attend the public school system in the United States. Title I of the Elementary and Secondary Edu-

cation Act (ESEA) provides essential financial assistance to schools with high levels of low-income families to ensure that all children meet the required educational standards established by the State. Inflation and sequestration have impacted the ability of States to administer this critical program and a drastic increase in funding is essential.

*Impact Aid Title VIII Funding—provide $2 billion*

Impact Aid provides essential funding to public schools serving American Indian/Alaska Native students. The program provides payments in lieu of taxes to public school districts for loss of property taxes that support their educational programs. In order to ensure that Native students have equal access to quality education, impact aid must be funded.

Thank you on behalf of the Jamestown S'Klallam Tribe. I respectfully request that these recommendations be included in the fiscal year 2016 budget in order to honor the trust responsibility and support Tribal prosperity and well-being.

[This statement was submitted by Honorable W. Ron Allen, Tribal Chairman/CEO, Jamestown S'Klallam Tribe.]

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PREPARED STATEMENT OF COLONEL STANLEY A. JENDRESAK, JR.

I am writing to urge the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse. WHY!—because as morale, responsible citizens, we need to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, into the enforcement of the Americans with Disabilities Act. as well as the need to provide proper settings for care. Several HHS agencies use some of their Federal funding supporting forced deinstitutionalization causing human harm which is cruel and an absurd use of Federal funding.

In particular, AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs. The recently released 300-page policy paper by NCD and related toolkit is another Federal insult to those that cannot speak for themselves. The new narrow Federal definition defined by CMS' for "Home and Community-Based Services" makes me want to vomit.

Over the last 33 years I have had legal guardianship of a brother 7 years younger and have found that often decision makers have no idea of the abilities/challenges that individuals who live in residential settings require. I would like to attempt to put a face to one of these severely challenged individuals who happens to be my brother.

I was able to place a 30-year old brother, Paul, into the Shapiro Developmental Center in August 1985. This placement permitted me to continue to have a Marine Reserve career for the next 16 years. Without this placement, I would have had to retire after 15 years of service. Please note that as a reservist, I worked a total of 11.5 years in uniform over a 31-year period of time that required me to spend periods of service in 21 foreign countries, the last 11 years serving in positions requiring a Top Secret level clearance at the TK level. I also held many other positions that benefited society in my local community only because I had the freedom of time to devote to these causes since my brother did not require my 24-hour supervision. Some of these activities are listed at the end of this document.

The Shapiro Developmental Center has been a blessing in my brother's life and I could easily write a dozen pages describing those positive changes. The purpose of this example, however, is just to highlight a few issues so that people with no personal experience have, can more easily understand the needs of this population. Some individuals could be totally uninformed regarding the services provided by State developmental centers through no fault of their own.

Paul was born normal, crawling at 9 months, walking at 1 year, talking around 18 months, but at 29 months he developed encephalitis, measles, mumps and measles again, all within six weeks which prevented brain growth. Paul has an IQ of 11 and lived with my parents for over 30 years. Parental love kept Paul living at the family residence despite their lack of education and training. My parents had no assistance in "parenting" a child with severe brain damage. They were also petrified of how he would be cared for by an institution.

Fear of the unknown and a lack of social services created an unhealthy, stagnant family environment, which seemed to worsen as Paul grew in age. After my mother's death, my father regretfully admitted that he could no longer care for Paul on his own. I, as Paul's guardian, was fortunate to have my brother admitted to the Shapiro Developmental Center after eleven other State and private facilities rejected his admission.

During the last 2 years living in my parent's residence Paul, at the height of 6'1", grew to a weight of 347 lbs. One might conclude that stress eating was his response to a lack of stimulation and routine; regardless this weight gain was unhealthy and seemed uncontrollable. Additionally, Paul did not seem to have an internal clock and would sleep and wake at all hours of the day and/or night. This would in turn require supervision; since he could not be trusted to leave things or individuals alone. Paul sometimes used the restroom and sometimes did not, requiring major cleanup jobs on a regular basis.

Paul normally was no trouble, but occasionally, without warning, would have a violent tantrum. These outbursts involved physical aggression and property destruction which included a door being torn off the hinges, a chair being used to break a television screen and a kitchen table being put through a window. As Paul grew older, there were less and less visits for Paul outside of the home and fewer visitors came to the house.

Within 7 months of admission to Shapiro, Paul was at his ideal body weight and has been within 5 percent of this ideal for over 29 years. More importantly Shapiro has been an environment in which Paul very rarely has these violent aggressive outbursts but instead has a quality of life whereby each week he spends some of his time meaningfully putting string through beads to make necklaces and bracelets. Paul has supervision that is programmed to be progressive to his optimal potential. I can now take him anywhere without the fear of him hurting himself or someone else. Shapiro has provided him safety, health, opportunity for socialization and growth as a citizen. Shapiro has also provided a sense of hope for my family; knowing that care for Paul is being rendered in a professional and unfailing manner.

Although there are some challenged individuals that can move from specialized care and work settings to smaller, "community-based" settings, Paul cannot. One would not have to be astute, clairvoyant or intuitive to form that judgement. To think otherwise would be ludicrous. This is another reason why, again, I am praying that the language is improved to prohibit the use of HHS funding for forced deinstitutionalization. Paul with an IQ of 11 cannot speak for his needs; he has me to do that for him and other professionals.

While I read about all of the recent unexpected deaths (> 1,000) in community settings, I know that my brother will live out his natural life in a safe, caring, and productive environment. Tragedies are widespread and predictable when fragile citizens are removed from specialized care. In closing, the Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

I have supported the mission and philosophy of nonprofit organizations like the Kankakee Association for Mentally Retarded (KAMR), the Illinois Advocates (ILL–AD) and the Voice of the Retarded (VOR) for decades. These special people have advocated for high quality care and human rights for all people with Intellectual and Developmental Disabilities for over 32 years. In particular, I admire and respect the consistent written testimony of VOR, an organization that quickly exhausts any list of superlatives.

Character is doing the right thing when no one is looking. At this moment there are over 700,000 people looking to see if our elected legislators will stop funding deinstitutionalization and support choice. My prayers are that they do the right thing.

Respectfully Submitted,

Stanley A. Jendresak, Jr.

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## PREPARED STATEMENT OF JOHNSON & JOHNSON

On behalf of Johnson & Johnson's approximately 127,000 global employees, I am pleased to present this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies in support of the National Institutes of Health (NIH) fiscal year 2016 budget. We recommend a fiscal year 2016 NIH budget of at least $32 billion. This level of funding is necessary to ensure the agency's ability to fuel the innovation in medical research that advances healthcare here in the United States and around the world

and to fortify America's position at the forefront of research. The funding request also represents what is needed to remain competitive in addressing the ongoing and emerging health challenges confronting the United States and the world, and to encourage pursuit of the unparalleled scientific opportunities to address these challenges.

As a physician and researcher, I have dedicated much of my life to translating basic scientific research into medical advances. In my current role as head of R&D at Janssen Pharmaceutical Companies and as a board member of Research!America, the Nation's largest not-for-profit public education and advocacy alliance working to make research to improve health a higher national priority, I am acutely aware of the value of our country's investment in basic research. In our country, the majority of basic research into the root causes of disease is publicly funded by the NIH through research grants to more than 2,300 institutions across the U.S. It is this research that leads to drug discovery. It underpins the life sciences economy and enables healthcare companies to transform scientific discoveries of today into the breakthrough healthcare products of tomorrow. Furthermore, the basic research funded by the NIH often enables the business case for the enormous, at-risk investment of money and effort it takes to discover and develop an important new medical treatment.

At Johnson & Johnson, our vision is to impact positively human health through innovation. In 2014, $8.5 billion was invested in research and development across our pharmaceutical, consumer and medical devices companies. As part of our external R&D engine, we help entrepreneurs and scientists realize their dreams of creating healthcare solutions that improve lives. Internally, our team of scientists works tirelessly to accelerate the translation of scientific discoveries into meaningful treatments for patients in need. Much of our work, and that of scientists across the industry, would not be possible without the constant progression of the understanding of underlying disease biology—precisely the type of research funded by the NIH.

The work of the NIH is tied not only to innovation and the vitality of the life sciences, but also to the health of our national economy. The pace of medical research must keep up with the aging of our population. Baby boomers who are now in their 60s and early 70s are likely to spend years or even decades of their lives in declining or poor health. There is an urgent need, both on the individual and socioeconomic level, for strategies to prevent illnesses associated with aging or lifestyle. Diseases such as Alzheimer's, ALS, diabetes and heart disease threaten to overwhelm our healthcare system in just a matter of years with enormous costs of care if we don't find ways to prevent, treat—or even cure—them.

Today, we are at a crossroads in medical research. Computing and other technologies are more powerful than ever before. Investments in biomedical research at the end of the 20th century by the Federal Government, and pharmaceutical, medical device and biotechnology companies, combined with the work of industry and NIH-funded investigators across the country, have produced fundamental scientific advancements, vast new datasets, and increasingly sophisticated areas of scientific research.

There has never been a more critical and promising time to work in medical research. The NIH is working on projects in areas like precision medicine, gene therapy and vaccines to prevent infectious diseases like the flu and HIV, as well as noncommunicable diseases like asthma and Alzheimer's. At Johnson & Johnson, our internal incubator program identifies and nurtures highly innovative ideas arising from our scientific community in areas of potentially disruptive, cutting-edge research, which may lead to novel platforms, products or technologies. These are advancements that the scientific community could only imagine several years ago, yet they are becoming a reality now. Sustainable, robust investment is needed to strengthen this crucial research and to realize its healthcare benefits for improving people's lives and reducing the burden and associated costs of today's major diseases all over the world.

Enormous potential exists, yet, these technologies remain underleveraged. In the U.S., the decrease in financial support for federally-funded medical research organizations including the NIH has persisted for more than a decade. In real terms, NIH has experienced a 23 percent decrease in inflation-adjusted funding since 2003, undermining our ability to respond effectively to disease threats. NIH is losing ground in its ability to collaborate to make societal progress. The scientific advancements over the past two decades that have engendered new ways to address infection, cancer, cardiovascular disease and brain disorders will stall without adequate funding. It is imperative that our government continue to value—and fund —that work, and the innovators who want nothing more than to engage in it.

Johnson & Johnson believes that a commitment to fully funding the NIH represents a commitment to fueling innovation in medical research. It is also a commitment to our parents and children by advancing science to match medical need, to our current and future generations of scientists by stimulating the life sciences economy and to the prosperity of our Nation as a worldwide leader in medical research. Sustained investment in the NIH is critical to medical innovation. We cannot afford to jeopardize innovation. There is simply too much at stake.

[This statement was submitted by William N. Hait, MD, Ph.D., Global Head, Research and Development, Janssen Pharmaceutical Companies of Johnson & Johnson.]

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PREPARED STATEMENT OF CARLENE JONES

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF DOUGLAS M. JONES

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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PREPARED STATEMENT OF THOMAS AND MARGARET KASHATUS

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CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

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PREPARED STATEMENT OF PAUL KEIPERT

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PREPARED STATEMENT OF JOAN KELLEY

On behalf of those individuals most in need of our protection, thank you for the opportunity to provide outside witness testimony to the Sub-Committee on Labor, Health & Human Services, Education and Related Agencies. I respectfully and urgently request the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill, to expressly prohibit the use of appropriations for any HHS program that supports activities attempting to downsize or close a Medicaid-licensed Intermediate Care Facility serving Individuals with Intellectual Disabilities (ICF/IID), unless the purpose of such action is to remedy proven, systemic abuse.

ICF/IID facilities ("institutions"), currently care for a majority of individuals with the most extreme, challenging behaviors, and profound disabilities. Such facilities, caring for our most vulnerable, operate under stricter Federal regulation than settings provided in the community. Our Supreme Court Justices recognized in the

1999 *Olmstead* ruling, the need for diverse settings and care levels, to honorably serve the full spectrum of the disability population.

Mounting tragedies resulting from forced facility closure are routinely disregarded by a number of federally funded entities. These entities include but are not limited to, AAIDD and its programs, National Council on Disability (NCD), CMS, and state-based Protection and Advocacy (P&A). Closure activities conducted by HHS funded entities include advocacy, lobbying, and class action lawsuits, which often result in putting defenseless individuals into harm's way. While AAIDD and others paint a picture of "Community for all", the weakest members of our society are often forced into ill-prepared community settings, and in many cases, with little or no oversight. Such HHS activities not only dishonor the Court's holding in *Olmstead*, they are an absurd misuse of Federal funding.

The 1999 Supreme Court *Olmstead* ruling is often misconstrued as a "mandate" for community placement only, leading to civil rights violations of this often, marginalized portion of the disability community. Premature and preventable deaths are routinely overlooked, and extensive abuse of those with no self-preservation skills is being ignored.

In his request for a Federal probe in to this mounting, appalling problem, your colleague, U.S. Senator Chris Murphy, described some of these tragic outcomes in a letter to OIG Inspector Daniel Levinson. To my knowledge, after 2 years, Senator Murphy has yet to receive a response from the Health and Human Services Office of Inspector General.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), while authorizing funding for AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced facility closure. Additionally, the DD Act clearly states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

Alarmingly, AAIDD programs routinely ignore the above provisions in law, by pursuing lawsuits and lobbying to eliminate specialized care settings. These settings include ICFs/IID, sheltered workshops, and day programs, yet in a general, marginalizing tone, are such settings are declared as "segregated."

Having raised a profoundly disabled grandson, my husband can testify first hand, that segregation is certainly not the case. Our grandson affected with profound autism, is now 24 years old. Yet due to a number of community system failures, he was placed at the Kansas Neurological Institute in 2008. Although KNI is a facility unfairly denigrated by AAIDD and other entities as "segregated", our loved one is not only well-cared for, he is provided more opportunities to interact in the community than many defenseless individuals, living in scattered, understaffed homes across the State. KNI retains dedicated staff, providing adequate, professional oversight on a centralized campus. This environment, necessary for the safety and care of those with the most medically involved and behaviorally dangerous conditions, is an environment not often secured, or easily secured, in the community.

*NCD*.—The biased and harmful tool kit "Deinstitutionalization: Unfinished Business" discriminately encourages the larger advocacy community to engage in efforts to evict people with I/DD from their homes. Such homes, caring for a majority of non-verbal, most challenging individuals, operate within a proven model of centralized care. The integrity of NCD is suspect, as they use Federal tax dollars to falsely describe "Willowbrook institutions", when most facilities have no such resemblance of institutions of decades long past.

*CMS*.—The new Community Settings Final Rule, while supporting higher functioning individuals, is unfortunately, discriminatory in nature for those with the most profound disabilities. It marginalizes those who most need oversight and protection, violating the civil rights of the weakest among us. The Rule ignores the unique needs for supervision, safety, and other provisions clarified by Supreme Court Justices in the *Olmstead* ruling.

*P&A*.—Disability Rights Center (DRC) is designated as the official Protection and Advocacy System for Kansas. While DRC claims that it "advocates for the rights of Kansans with disabilities under State or Federal laws (ADA, the Rehabilitation Act, Federal Medicaid Act, Kansas Act Against Discrimination, etc.)", in actuality, DRC violates Federal law and the Supreme Court *Olmstead* ruling by ignoring provisions within the Court's holding: "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal re-

quirement that community-based treatment be imposed on patients who do not desire it."

While claiming to address "disability rights needs . . . . to conduct abuse, neglect, and exploitation investigations, etc." DRC has not addressed systemic gaps in our abuse and neglect reporting system. In effect, DRC allows the continued harm to those they claim to protect. Additionally, DRC's misleading claims made before State legislators, regarding costs to serve our highest risk, highest need individuals, discriminates against those unable to speak or defend themselves.

When our most fragile citizens are removed from specialized care, tragedies are predictable. It is most disturbing that legal, protected rights of families and guardians, serving as primary decision-makers, are routinely ignored by the above mentioned entities, while they engage in unsound, facility closure policy-making.

The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization. The current trend by HHS funded agencies, in effect, not only disregards individual choice and need, jeopardizing the safety of those most in need of protection, it is contrary to Federal law.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony, and urge the Committee to take action, honoring requests therein.

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PREPARED STATEMENT OF DR. KAREN KELLY

Good day, Committee Members: I am submitting this written testimony urging the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse. I will use my own son as an example of the need for ICF/IID services on behalf of the Murray Parents Association, which represents the guardians of severely disabled residents at Murray Center, a State operated developmental center in Centralia, Illinois.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law, causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs. Such HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

Members of the Murray Parents Association and others who are part of the Murray Center Community are calling on the Subcommittee to PROHIBIT HHS agencies from using appropriations to limit individual and family/guardian choice. We argue that forced "deinstitutionalization" activities are contrary to Federal law and cause human harm. These deinstitutionalization activities, including advocacy, lob-

bying, class action lawsuits, and other tactics by some HHS-funded agencies that result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs. These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

I am both the mother of a severely autistic adult, Eric (age 41) and an experienced registered nurse with expertise in behavioral healthcare, healthcare administration, and autism. This effort to limit choice regarding care of developmentally disabled individuals is short-sighted and misguided, at best. The changes in the mental health system that began in the 1960s resulted in the closure/reduction of State psychiatric hospitals was supposed to provide support, treatment, and housing "in the community." Such services never evolved, leaving community hospitals swimming in debt for episodic care of the chronically mentally ill and cities trying to cope with the homeless, chronically mentally ill. Now so-called advocates for the developmentally disabled are using Federal funds to try to push vulnerable, severely disabled people into inadequate, small group homes that are understaffed with undertrained and underpaid nonprofessionals. They seek the support of Congress and State legislatures to achieve their misguided goals. Those who fail to learn from history are doomed to repeat its mistakes. Wholesale elimination of ICF/IID services would put thousands of severely disabled persons at risk in communities, not unlike populations of homeless chronically mentally ill individuals in nearly every city in the country.

My son Eric is severely impaired by autism and has lived at Murray Center since June 1999. He lived in a community-based ICF/IID for 4 years, but it could not meet his needs because of the severity of his disability. The State of Illinois recommended admission to Murray Center because there were not appropriate services for my son in the Metro East (an Illinois region just east of St. Louis, MO). There are still not appropriate community opportunities for him in the area.

Eric stopped talking around 30 months of age. He can feed and clothe himself, but needs help with basic hygiene: bathing, tooth-brushing, and toileting. He cannot use a knife or tie his shoes. He is 6'5" and weighs 250 pounds, a toddler in a linebacker's body. He communicates with a limited vocabulary in signed speech and gestures. His IQ measures around 38–40. He needs around the clock care to ensure his well-being, including nursing care, which community group homes do not provide.

Eric entered residential care a few months before his eighteenth birthday in 1991. The search for residential care began shortly after he turned 16. Applications went out to 80 agencies. Two responded: one in Texas that was caught up in an abuse scandal and the Hope School in Springfield, IL. Eric spent 4 years there; before he "aged out" of Hope School about 30 applications were sent out. Only one agency near our home indicated interest in him. This was his community-based ICF/IID residence for 4 years, until his placement failed and he moved to Murray Center because no other agency near the Metro-East would consider my 6'5" son.

Not long after he came to Murray Center, Eric had a bowel obstruction. He could not tell anyone he was in pain, but he took the hand of the nurse who gave him his morning medicines and put it on his abdomen. The RN assessed Eric, notified his physician, and sent him to the local hospital where he had surgery a few hour later once he was stable. If an RN had not been present, as in small community group homes, he would have suffered a rupture of the bowel with massive infection (sepsis) that could have been fatal.

Eric can be loving to family and friends, but has the potential to become easily frustrated with outbursts of aggression; this is characteristic of autism and is called a "meltdown." Unlike the temper tantrums of young children, autistic meltdowns have no apparent causative factor. Sometimes meltdowns can be thwarted through behavioral interventions; sometimes there is no way to mitigate such meltdowns, except to protect the autistic person from harm until the meltdown runs its course.

Because of his size, Eric can easily injure another person, especially with inadequate numbers of staff to supervise him. What will a community home do if he becomes aggressive? Call the police? In January 2012 a teen with autism was shot and killed by police in Calumet City IL in his parents' home when police, who had been trained to work with him, shot and killed him. National stories have reported the use of Tasers on autistic persons in the community. In my professional opinion as an experienced behavioral health nurse, moving a low functioning autistic person into a minimally staffed group home is akin placing toddlers in an understaffed day care center. Safety of both the residents and the staff are threatened when low functioning autistic persons are placed in programs that are inadequate to meet their unique needs.

Eric's stepdad and I visit with Eric in Centralia about every 2 weeks, taking him out for lunch or dinner, shopping, and other social experiences. Every 4 to 6 weeks, we bring him home to O'Fallon, about an hour east of Murray Center, for a weekend

visit where we try to engage him in family activities in the St. Louis community. For Eric, Murray Center is an appropriate and least-restrictive environment. He has matured and become more social at Murray.

Eric regressed with each transfer to a new living setting. He became more aggressive when he first moved to Hope School just before his 18th birthday. He was aggressive and tried to elope from Clinton Manor in New Baden for his first year there. He had many episodes of aggression that resulted in Eric being placed in restraints during his first couple of years at Murray Center. His aggressive behaviors have become almost nonexistent over the last decade. If he regresses and becomes aggressive when living in the community-based residence, what will happen? Will a single staff person be able to handle his outbursts? Will that staff person call the police for help? Will the police treat him like a "normal" adult or will they treat him like a toddler trapped in a large man's body?

What will happen to Eric if he is placed in a community-based facility that cannot meet his needs and there is no Murray Center for him? Would the State try to place in a facility far from his home, making it impossible for his family to see him every two weeks as we now do? What if the lack of a 24/7 presence of nurses results in another life-threatening health problem?

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. Along with the members of the Murray Parents Association and the Murray community, I support VOR's testimony.

Respectfully.

[This statement was submitted by Dr. Karen Kelly and the Murray Parents Association.]

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## PREPARED STATEMENT OF MEGAN KENNEDY

My name is Megan Kennedy and I'm from the State of Missouri. As Founder of The Megan Foundation, and Board Member of the Usher Syndrome Coalition, I write on behalf of the Usher syndrome community to respectfully request this committee prioritize research into the causes of Usher syndrome and into treatment options at the National Institutes of Health (NIH). As you prepare the fiscal year 2016 Labor, Health and Human Services, Education bill, we respectfully request that you include the following report language:

> The Committee commends NIH for including Usher syndrome on the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC) list in order to track the annual support level of this rare disease. The Committee urges NIH to prioritize Usher syndrome research at the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI) and develop a multidisciplinary research strategy among multiple NIH institutes, including the National Center for Advancing Translational Sciences (NCATS), the National Human Genome Research Institute (NHGRI), and the National Institute of Mental Health (NIMH). Because Usher syndrome is a rare genetic condition, the Committee urges NCATS to support fundamental basic science research on Usher syndrome and NHGRI to support research on the underlying genetic causes of Usher syndrome. Since children and adults with Usher syndrome are at risk for the development of mental and behavioral disorders, the Committee urges NIMH to support research to elucidate genomic risk factors that underlie mental disorders. The Committee urges additional focus from NIDCD, given Usher syndrome's involvement with vestibular dysfunction. The Committee requests an update in the fiscal year 2017 CJ on the planned and on-going activities related to this syndrome, including the manner in which various ICs coordinate on common goals and objectives.

Usher syndrome is the most common cause of combined deafness and blindness. In the United States, it is estimated that nearly 50,000 people have this rare genetic disorder. I am one of these people. Born with a hearing impairment of approximately 80 percent, it wasn't until I was 22 years old that I learned I had Usher syndrome Type 2a, and that I was already considered legally blind. Today, at age 30, I have a field of vision of only 10 degrees.

Hearing aids are incredible tools that I have used since I was 3 years old, but they cannot perfectly mimic normal hearing. Biology has developed a sophisticated system of hearing between the cochlea and the brain. The cochlea, a sound-transmitting device within our ears, works so seamlessly with our brains in interpreting signals that it can actually distinguish which sounds to focus on, and which sounds to ignore as background noise. This system has the ability to hone in on a conversation with a friend in a loud restaurant, for example, while minimizing the distracting noises of clattering plates and nearby conversations. Think of it as auto-adjusting. Hearing aids, while having come a long way, do not have the capability to separate foreground noise from background noise as naturally as this biological system, making the brain work much harder to distinguish between the two.

I have never experienced the luxury of normal hearing. The machines in my ears interrupt the seamless flow of hearing between the cochlea and brain by delaying the transmission of vibrations to be interpreted. All of my life, being a fluid part of conversations has been a laborious task. Not only do I have to manually distinguish between foreground and background noises, I also have to give my undivided attention to the direction a conversation is heading, as my brain catches up to interpret the delayed signals from my hearing aids. I cannot count the number of times I've received confused looks from others after saying something that was a topic of discussion five minutes earlier, or was never even a topic of discussion at all.

By the end of the day, I'm weary with fatigue as I take out my hearing aids to rest from my chaotic world of noises.

Normal vision is about 180 degrees in a peripheral field of vision. With only 10 degrees of vision, I see about 5 percent of what the rest of the world sees. When I open my eyes in the morning to look at my husband, I only see a small portion of his handsome face. I scan his facial features in sections: his eyes, his forehead, his mouth, his chin. Then I put together the pieces to make a picture of what he looks like at that moment. Sometimes it takes a minute before I realize his eyes are open, looking back at me, and he's greeting me with his beautiful smile.

I'm lucky that I'm still able to see the people and things I love, but soon even that will be gone. In the meantime, it is the constant scanning and putting together the pieces that make seeing an exhausting task to perform every day. Imagine a life where seeing is a draining action, rather than a liberating one. So many tasks in our daily lives become effortless with vision, such as reading the numbers on a measuring cup, walking up and down stairs, finding an app on the iPhone, or determining whether it's safe to cross the street. When vision is compromised, everything in life becomes compromised.

My vision loss is now to the point where my career has been compromised, and pursuing a life-long dream in architecture is no longer feasible.

I deserve to have a long and satisfying career, and I deserve to enjoy the simple pleasures of life without an exorbitant amount of effort to do so. I've worked harder than most people I know to be successful in the things I set out to achieve. I aspire to be an active part of this society, because the society we live in is full of opportunities to create the life we choose to live. Usher syndrome, however, doesn't allow me to create the life I choose to live.

People with Usher syndrome share the same range of intelligence and work ethic as any other slice of America. Yet they suffer from an 82 percent unemployment rate. People with Usher syndrome are born with the same emotional strength as any other American. Yet they have a suicide rate that is 2 ‡ times greater than the general population. People with Usher syndrome not only have the capacity to contribute to America's future, they thirst for it. They want to be active members of society. Yet our country spends an estimated $139 billion annually in direct and indirect costs for people with eye disorders and vision loss. That doesn't even include the costs associated with hearing impairment.

In my role on the Usher Syndrome Coalition's Board of Directors and as founder of The Megan Foundation, a Coalition member organization, I have spoken with and have met hundreds of people who are determined, focused, and working everyday to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells, which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Through the Usher Syndrome Coalition, we have brought the Usher community and researchers together by:

—Establishing an international registry of individuals with Usher syndrome, which is available for research or clinical trials at no cost. Our registry currently has individuals from each of the 50 States and 44 countries.

—Sponsoring an International Symposium on Usher Syndrome at Harvard Medical School in July 2014 to develop a roadmap for future research projects to bring us closer to viable clinical treatments.

—Sponsoring annual family conferences, webinars and monthly conferences that provide information and support to all of those living with Usher syndrome.

With this in place, we are bridging the gap between families in need and researchers who are working on developing treatments every day. Researchers like those in Oregon and Pennsylvania who are working on gene therapy treatments, one of which began clinical trials in 2013. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher syndrome using a drug therapy that holds promise for rescuing vision as well. Researchers in Iowa, California, Nebraska, Massachusetts, Florida, Texas, and many other States, who are collaborating with each other and with families through the Coalition to advance all kinds of Usher syndrome research.

But still this is not enough. We cannot help any of the tens of thousands who have Usher, or countless others that will be born in the future with this devastating genetic disorder without Federal support. There are dozens of different mutations that cause Usher syndrome, and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We are asking you to supply this last critical resource to help us find a cure.

Until very recently, there was no way of knowing how much money the National Institutes of Health (NIH) invested in Usher syndrome research. Through the efforts of the Usher Syndrome Coalition, this rare disease has been added as a new category in the NIH Categorical Spending list, the Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). Through the RCDC system, we now have visibility into the total dollars spent on Usher syndrome, as well as the specific grants that were funded. Usher syndrome research still needs a lot more investment, but this is a great start.

We do not ask that the committee throw dollars at the problem. Only that they ensure the appropriate funding is available. The researchers are there, waiting to discover what now is just a dream. All we are asking for is a chance; a chance for deaf children and adults who are going blind, a chance to see. With your help, those with Usher syndrome, including myself, can once again dare to dream.

[This statement was submitted by Megan Kennedy, Founder of The Megan Foundation, and Board Member of the Usher Syndrome Coalition.]

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PREPARED STATEMENT OF RALPH M. KENNEDY

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or ben-

efit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "given the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF THOMAS W. KIDD

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PREPARED STATEMENT OF MONICA KOVACS

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PREPARED STATEMENT OF TERRY LAFLEUR

My wife and I are parents of our 36 year daughter living in a public facility, Pinecrest Supports & Services Center in Pineville, La. We tried a community home where there way of dealing with her behavior was with psychotropic drugs. She aspirated and spent 2 weeks in Rapides General Hospital ICU. After she was released from the hospital, the owners of the community home called to let us know we could not bring her back there because of their liability. After a few months home Pinecrest called to let us know they could help. Since she moved there in 2000 she was taken off drugs and her behavior has greatly improved, she is doing very good at Pinecrest. Without this wonderful facility we feel our daughter would not have survived in any other community home. Not everyone can function in a community, all we and any parent want is the best choice for our children.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF CAROLINE A. LAHRMANN

I am writing to urge the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs. Let me give you a taste of the fear and destruction this "advocacy" work has caused in Ohio in the past 6 month:

Ohio families and guardians of loved ones with intellectual and developmental disabilities are outraged by the actions of Ohio's protection and advocacy agency, Disability Rights Ohio (DRO). DRO has threatened to sue the State over its ICF/IID program and its facility-based day services and workshops. Additionally CMS has implemented rule changes which harm these programs and leave their future in question.

Parents, guardians and family members have passionately urged government officials to not fall prey to DRO's fear-mongering. Elderly parents who know they do not have many years left have made tearful pleas to officials asking, "Who will care for my child if you close their ICF home?" Siblings have asked, "What will happen to my brother? My mother cannot care for him anymore. Do I have to give up my dreams too?" There have been sleepless nights, hand- wringing and days spent calling and meeting with government officials. Regular life has been put on hold for the Developmental Disabilities community in Ohio until some sanity is restored where the people drive the services and supports—not a "protection and advocacy" agency no one trusts.

As a parent with twins who are intellectually and developmentally disabled, these de- institutionalization activities are a direct threat to the health, safety and welfare of my children. My children rely on an ICF/IID home for life-sustaining nursing and behavioral support as well as daily integration into our community through an abundance of community-centered programs provided by their ICF home.

According to *Olmstead* and the ADA, DRO has no grounds on which to threaten the existence of the ICF program in Ohio and it is absurd for a federally funded agency to use its funding and what appears to be limitless power to strike fear in the hearts of intellectually and developmentally disabled citizens and their loving parents and guardians.

Parents of children who attend facility-based day services and workshops are equally concerned over DRO's actions. And CMS rule changes will deny funding to these much-loved programs.

DRO's threats of litigation have been the catalyst for Ohio's Governor to put forth budget proposals that will fulfill DRO's objectives by eliminating beds and forcing the closures of many ICF/IID homes and closing facility-based day services and workshops. Ohio families have fought back strongly against the Kasich administration's proposals which we perceive to be a direct attack on our loved ones. Families organized a petition campaign which attracted nearly 19,000 signatures in just 5 weeks. And we testified strongly to our State Assembly making sure legislators know, "DRO DOES NOT SPEAK FOR US."

DRO has used *Olmstead* and the ADA as a weapon against the Ohio citizens it was entrusted to serve. But, individuals with intellectual and developmental disabilities should not fear this law. This law was not put in place to harm our disabled citizens. *Olmstead* and the ADA expand opportunities and preserve choices for individuals with disabilities. This law DOES NOT drive people from so-called "institutional" settings. The U.S. Supreme Court stated,

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

I urge the Senate Appropriations Subcommittee on Labor, Health and Humans Services and Education and Related Agencies to live up to the true meaning of *Olmstead* and the ADA and refuse to fund programs such as Ohio's protection and advocacy agency that work in direct opposition to the best interests, health and welfare of our most fragile citizens.

Please do not send anymore federally-funded attack dogs to Ohio.

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## PREPARED STATEMENT OF THE LATINO COMMISSION ON AIDS

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Latino Commission on AIDS is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area we provide national capacity building and technical assistance to HIV service providers and other health and human service providers throughout the U.S., Puerto Rico and U.S. Virgin Islands. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

### *Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate

meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

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*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Guillermo Chacon, President, and Luis Scaccabarrozzi, MPH, Director of Health Policy & Advocacy, Latino Commission on AIDS.]

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[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

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PREPARED STATEMENT OF LIFELONG

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Lifelong is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. Chicken Soup Brigade, Lifelong's Food & Nutrition provides over 50,000 prepared meals and 15,000 bags of groceries to PLWHA in Western Washington State annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

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the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

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Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

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—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by state in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Paul Getzel, Director, Chicken Soup Brigade—Lifelong's Food & Nutrition Program.]

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## PREPARED STATEMENT OF SANDRA J. MAISTROS

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs,NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

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AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCDreleased a 300-page policy paper and related tool kit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF MAMA'S KITCHEN

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Mama's Kitchen is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 350,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

### *Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
—More ER visits[4] & increased morbidity and mortality[5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

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[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

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*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Alberto Cortés, Executive Director, Mama's Kitchen.]

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## PREPARED STATEMENT OF MANNA

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Ap-

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[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

propriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

MANNA (Metropolitan Area Neighborhood Nutrition Alliance) is the only organization in the greater Philadelphia that provides medically appropriate meals for people battling serious illnesses, and the only organization of its kind in the country that offers 21 meals a week—3 meals a day, 7 days a week—to all clients. In our service area, we provide 750,000 medically tailored, home delivered meals annually. Founded in 1990 to serve people living with HIV/AIDS, nearly 15,000 people have benefited from the 11 million meals that MANNA has delivered over our 25 year history.

MANNA is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

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*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

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—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. MANNA spearheaded a groundbreaking study comparing participants in our comprehensive medically-tailored FNS program vs. a control group within a local managed care organization. This study found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

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Studies show nutrition counseling improves quality of life.[9] MANNA clients overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

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[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Re-

Continued

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*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, is vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Sue Daugherty, RD, LDN, Chief Executive Officer, Metropolitan Area Neighborhood Nutrition Alliance.]

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## PREPARED STATEMENT OF MEADVOCACY.ORG

Dear Ladies and Gentlemen of the Committee: The Department of Health and Human Services is the U.S. Government's principal agency for protecting the health of all Americans and providing essential human services, especially for those who are least able to help themselves. Yet, in the past three decades, HHS, NIH and CDC have neglected and mistreated over a million severely disabled patients suffering from the disabling chronic disease myalgic encephalomyelitis (ME).

Thirty years of malfeasance, misfeasance, neglect, and incompetence by HHS has rendered ME patients frustrated and disgruntled. They remain invisible, misunderstood and extremely sick. Advances in the science of the disease have been mostly squashed by the gross lack of funding by NIH for this severely disabling disease. In addition, misinformation and badly outdated information published by the CDC, along with the lack of education about the disease in medical schools, have caused a dearth of palliative care for patients nationwide. Most importantly, after 30 years, we still are not any closer to finding a possible treatment or cure to help the millions of ME patients.

MEadvocacy.org is a growing grassroots movement of advocates and patients who are rising up and saying we have had enough of empty promises and lies. We want the right to life, liberty, and the pursuit of happiness that is afforded to us by the Declaration of Independence. We want the same chance at life and health as patients who suffer from other similarly burdened diseases. We are lawyers, laborers, teachers, students, fathers, mothers, and children. Our productive lives have been cut short by this debilitating disease and we have no hope of treatment or cure. We have had enough and are saying, "No More!"

*ME Incidence and Prevalence*

Myalgic encephalomyelitis, also known in the U.S. as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), is a seriously disabling neuro-immune disease. It sickens an estimated 850,000 to 2.5 million in the U.S. and 17 million worldwide. A majority of patients are disabled, un-

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sources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

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able to work, attend school or participate in activities of daily life. A quarter are so severely affected as to render them bedbound, unable to care for themselves.

*ME History, Criteria and Name*

ME has a long history, appearing worldwide in epidemic and endemic forms. A 1955 outbreak in London resulted in Dr. A. Melvin Ramsay (1) describing it as an infectious neuromuscular illness and coining the term "myalgic encephalomyelitis." Disregarding this, the CDC broadly redefined the disease and renamed it chronic fatigue syndrome (CFS) in response to 1985 cluster outbreaks of the disease in Incline Village, Nevada and Lyndonville, New York. This redefinition resulted in three decades of confused research findings rather than answers to the cause and treatment of this disease. In addition, the undignified name and poor criteria caused stigmatization and marginalization of patients.

HHS had been aware of these problems for years, yet stubbornly refused to act. It disregarded almost all advice from its own Chronic Fatigue Syndrome Advisory Committee (CFSAC)(2). It ignored specific requests by CFSAC, medical experts, patient advocates, patients and their families to adopt ME expert-authored, well-defined criteria for the disease. In direct opposition, HHS announced on September 23, 2013 a secretly negotiated contract with the Institute of Medicine (IOM) to redefine and re-brand this disease despite Dr. Nancy Lee, Director of the Office of Women's Health, stating earlier that year that Secretary Sebelius had specifically told her that the government was "not in the business of setting criteria for diseases." HHS disregarded the fact that historically it is the expert medical community, not the government, who delineate criteria for diseases. Case definitions are a clinical decision that should come from the clinical community.

The IOM report was published on February 10, 2015, and outlined new criteria that are again overly broad and unrestricted. They omit exclusionary criteria and even differential diagnostic suggestions to guide clinicians in making accurate diagnoses. Some experts believe the new definition will capture people with major depression, autoimmune diseases and cardiopulmonary disease. At the clinical level, the result will be tragic for patients who receive inappropriate advice and, as our history has already proven, it will be disastrous for the clarity of findings if this overly inclusive criteria is used for research. The new recommended name, "Systemic Exertion Intolerance Disease (SEID)", repeats the same error that the CDC made 30 years ago, which was attempting to describe the disease by one of its many symptoms.

*Disease Burden and Funding*

Some ME patients have died prematurely from complications of ME. Others have died at their own hands due to the severity and length of their suffering without proper palliative care, as well as dismissal and stigmatization by the medical community. If we do not act on behalf of these severely affected patients, we are complicit in their suffering and untimely deaths. The patients will not carry this burden quietly any longer and we are looking at Congress to require HHS to properly fulfill their duty to ME sufferers.

In 2009, Dr. Nancy Klimas, the director of AIDS research at the Miami Veterans Affairs Medical Center stated:

> My H.I.V patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses, (in 2009) I would rather have HIV. But CFS, which impacts a million people in the United States alone, has had a small fraction of the research dollars directed towards it. (http://consults.blogs.nytimes.com/2009/10/15)

In the intervening 6 years, nothing has changed. It is very clear that real change at HHS regarding this disease will not come about naturally. We have come to you, the Appropriation Committee, for help in addressing this dire need for oversight and investigation.

It is estimated that the burden to the economy for ME is between $17 to 24 billion, yet NIH funding for research has stagnated at a mere $5 million a year, less than funding for hay fever. HHS has placed funding for ME at the rock bottom of

their funding budget list(3). The yearly allocation for ME/CFS is a fraction of what other similarly burdened diseases receive.

| HHS/NIH funding data for 2014 | U.S. patient population | Funding per patient ($) |
|---|---|---|
| HIV/AIDS—$2 billion 978 million | 1,200,000 | 2,481 |
| M.S.—$102 million | 400,000 | 255 |
| Parkinson's—$139 million | 1,000,000 | 139 |
| Alzheimer's $564 million | 5,300,000 | 106 |
| ME/CFS—$5 million | 1,000,000 | 5 |

The great divide between NIH funding for ME and other diseases cannot be explained away. Simply advising and recommending that NIH increase funding for ME, has not worked. The Secretaries of Health and Human Services have not responded to most of the 77 recommendations made by the Chronic Fatigue Syndrome Advisory Committee during the past 10 years. The department did not heed the call by President Obama as a result of a call out at a townhall meeting by the wife of a patient. It has not listened to the many recommendations by this Appropriation Committee over the past 20 years. In order to fund ME on par with MS, a similarly serious disease, ME would need $250 million a year. Perhaps a sliding scale of allocation from other diseases related to immune, cognitive and nervous system dysfunctions could be utilized by this committee to find the additional funding needed for ME.

We cannot continue with the same path and expect a different result; that would be insanity. We need a different approach and a complete overhaul at all agency levels. We need an investigation by Congress into the mishandling and neglect of Myalgic Encephalomyelitis by HHS, NIH and CDC and active, ongoing Congressional oversight until HHS' negative bias is rectified.

The following are the recommendations and goals that we at MEadvocacy.org feel the Appropriations Committee needs to require that HHS meet, in order to bring Myalgic Encephalomyelitis back on par with other similarly burdened diseases:

—Fund biomedical research for ME commensurate with its severity and burden to patients and the economy. We are asking for specific funding in the amount of $250 million, the amount we believe is needed to bring ME on par with other similarly burdened diseases. HHS should clearly allocate funds to study patients from past ME cluster outbreaks as well as the study of the epidemiology of patients with severe ME. The additional funding needed for ME might be accomplished by means of a sliding scale of allocation from other diseases related to immune, cognitive and nervous system dysfunctions.

—Heed the ME stakeholders' request to adopt the diagnostic and research criteria authored by those experienced in the disease, namely the 2003 Canadian Consensus Criteria (CCC)(4), which has been adopted by the International Association of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME)(5). In a letter to the Secretary of HHS, 50 experts(6) in the disease declared their consensus agreement to adopt the CCC. This was endorsed by a letter signed by 171 advocates(7) as well as a petition(8) signed by over 6,000 patients. The 2011 revision known as the International Consensus Criteria (ICC) would be an alternatively acceptable criteria for adoption.

—Retain the historical name for this disease, myalgic encephalomyelitis, which has been coded since 1969 by the World Health Organization under neurological disease with the code G93.3. In addition, ME will appear in the 2015 U.S. ICD Codes as U.S. ICD–10–CM with the same coding.

Additionally, we request that the Appropriation Committee recommends HHS:

—Return ME to the National Institute of Allergy and Infectious Disease (NIAID) or place it in the National Institute of Neurological Disorders and Stroke (NINDS), which also manages similar neuroimmune diseases such as MS, fibromyalgia, and Lyme Disease. The Office of Research on Women's Health, where ME is currently housed, is entirely inappropriate for disease, which also strikes men and children.

—Provide opportunities for dissemination of information through the development of a curriculum for all U.S.- based medical schools, as well as physician continuing education, about ME as defined solely by disease experts, in order to provide the tools needed for physicians and other medical professionals to appropriately recognize and treat this disease. Currently, this would mean using either the 2003 Canadian Consensus Criteria or the 2011 International Consensus Criteria, not the overly broad criteria developed by the non-expert IOM

panel. In addition, the CCC (9) or ICC Primer(10) should be widely distributed and made available to clinicians, particularly primary care physicians, nationwide in order to facilitate the best care for their ME patients.

—Partner openly and transparently with stakeholders within 1 year to establish a comprehensive, aggressive and fully-funded cross-agency strategy and implementation plan, with well-defined objectives and milestones, and to develop a plan to monitor progress and provide for Congressional oversight.

"We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well-known, very severe medical conditions."—Dr. William Reeves, former CDC Chief of Viral Diseases Branch (2006 CDC Press Conference)

*Links:*

(1)—Http://mecfsforums.com/wiki/Articles__by__Dr.—A.—Melvin__Ramsay.
(2)—Http://www.hhs.gov/advcomcfs/.
(3)—Http://report.nih.gov/categorical__spending.aspx.
(4)—Http://www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pdf.
(5)—Http://www.iacfsme.org/OrganizationInformation/tabid/124/Default.aspx.
(6)—Https://dl.dropboxusercontent.com/u/89158245/Case%20Definition%20Letter%20Sept%2023%202013.pdf.
(7)—Https://thoughtsaboutme.files.wordpress.com/2013/10/sebelius__letter__advocates2.pd.
(8)—Https://secure.avaaz.org/en/petition/Stop__the__HHSIOM__contract__and__accept__the__CCC__definition__of__ME/?pv=4.
(9)—Http://www.name-us.org/DefintionsPages/DefinitionsArticles/ConsensusDocument%20Overview.pdf.
(10)—Http://www.name-us.org/DefintionsPages/DefinitionsArticles/2012__ICC%20primer.pdf.
(11)—Http://www.meadvocacy.org/.

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## Prepared Statement of Meals on Wheels America

Chairman Blunt and Ranking Member Murray: Thank you for the opportunity to present testimony to your Subcommittee concerning fiscal year 2016 appropriations for Older Americans Act Nutrition Programs administered by the Administration for Community Living/Administration on Aging within the U.S. Department of Health and Human Services. We are grateful for your past and continued support for these vital programs and urge you to adopt the funding levels provided in the President's fiscal year 2016 Budget Request to Congress. For the three Older Americans Act (OAA) Nutrition Programs authorized under Title III of the Act, that request is as follows:

—Congregate Nutrition Services (Title III, C–1)—$458 million
—Home-Delivered Nutrition Services (Title III, C–2)—$236 million
—Nutrition Services Incentive Program (Title III, NSIP)—$160 million

In addition, Meals on Wheels America supports the Administration's request for $20 million for Nutrition Innovation Demonstrations. If enacted, this funding would support evidence-based innovations and an opportunity to develop a perfected and scalable nutrition services model to optimize healthcare savings and quality of life for the seniors served.

At this critical juncture in our Nation's history, when both the need and demand are already substantial and will continue to climb exponentially, we implore you to give this request your utmost consideration due to the significant social and economic benefits that OAA Nutrition Programs offer. The nutritious meals, friendly visits, and safety and wellness checks these programs deliver each day are providing an efficient, effective and critical support service for our most vulnerable seniors, our families, our communities, and taxpayers as a whole. OAA Nutrition Programs (both congregate and home-delivered) enable seniors to live more nourished and independent lives longer in their own homes, reducing unnecessary visits to the emergency room and premature hospitalization and institutionalization. They are not only providing more than a meal to those who are fortunate to receive their services, but they are also an essential part of the solution to our Nation's fiscal and demographic challenges.

SERVING THE MOST VULNERABLE

For nearly 50 years in communities large and small, urban and rural, OAA Nutrition Programs have been successfully serving our country's most vulnerable, frail and isolated seniors. What started as a demonstration project has grown into a highly effective community-based, nationwide network of more than 5,000 local programs. While not all Meals on Wheels programs (whether congregate or home-delivered) receive OAA funds, the majority rely, in part, on the Federal dollars authorized under Title III of the Act as a foundation on which to leverage additional funding. This enables a very effective public-private partnership model which helps raise additional State and community-based resources to be directed toward seniors 60 years of age and older who are at significant risk of hunger and losing their ability to remain independent and live at home.

Data from the most recent Administration on Aging's State Program Reports (2012) and National Survey of OAA Participants (2013) demonstrates that the seniors receiving meals at home and in congregate settings, such as senior centers, need these services to remain healthier and independent. They are primarily women who are 75 and older and living alone. Additionally, these seniors have multiple chronic conditions, take six or more medications daily, are functionally impaired, and the single meal provided by the OAA Nutrition Program represents half or more of their total food intake in a day. Significant numbers live in rural areas, are living in poverty and belong to a minority group. In short, the individuals being served are high risk, potentially high cost to Medicare and Medicaid, and are in need of nutrition assistance.

Furthermore, findings from a just-released research study that Meals on Wheels America commissioned Brown University's Center for Gerontology and Healthcare Research to conduct found that those receiving and/or requesting Meals on Wheels services are significantly more vulnerable compared to a nationally representative sample of aging Americans.[1] Specifically, seniors on Meals on Wheels waiting lists were significantly more likely to:

—Report poorer self-rated health (71 percent vs. 26 percent)
—Screen positive for depression (28 percent vs. 14 percent) and anxiety (31 percent vs. 16 percent)
—Report recent falls (27 percent vs. 10 percent) and fear of falling that limited their ability to stay active (79 percent vs 42 percent)
—Require assistance with shopping for groceries (87 percent vs. 23 percent) and preparing food (69 percent vs. 20 percent)
—Have health and/or safety hazards both inside and outside the home (i.e., higher rates of tripping hazards, 24 percent vs. 10 percent, and home construction hazards, 13 percent vs. 7 percent)

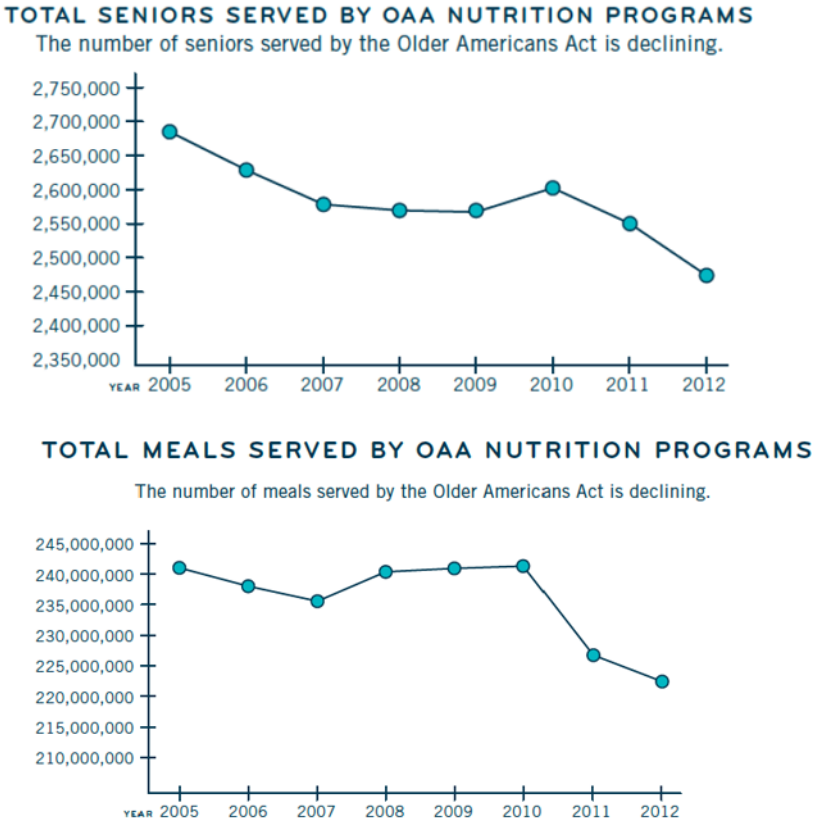
DEFINING THE MAGNITUDE OF THE PROBLEM

Despite the Meals on Wheels network's successes in effectively targeting those seniors at greatest risk, leveraging additional public and private resources, and leveraging two million volunteers nationwide, the Federal funding authorized through the OAA is failing to keep pace with inflation, the growth in the senior population, and the escalating senior hunger need. According to State of Senior Hunger in America 2012: An Annual Report, even then 9.3 million seniors (60+)—one in six—faced the threat of hunger. In just over a decade (2001 to 2012), the portion of seniors experiencing the threat of hunger has increased by 44 percent, while the number of seniors struggling increased by 98 percent (which also reflects the growing population of seniors). In 2012, the latest year for which we have data from the Administration on Aging, OAA funding supported the provision of meals to fewer than 2.5 million seniors. Year after year, the gap between those struggling with hunger and those receiving nutritious meals through the OAA continues to widen and waiting lists are mounting in every State. Members of our organization responding to a recent survey indicated an average waiting list of 135 people per program.

The graphs below, even prior to the 2013 cuts imposed by sequestration, illustrate this troubling trending decline.

[The graphics follows:]

[1] National Health and Aging Trends Study (NHATS), 2014.




*Source: Older Americans Act (OAA) Title III Programs data derived from the AGing Integrated Database (AGID) system, the AGID State Profiles. Full reports available at:* www.agidnet.acl.gov

PRESENTING THE ECONOMIC CASE

We all know that without proper nutrition, one's health deteriorates and inevitably fails. It is extremely costly not only in personal terms for the individuals who struggle, but also for our Nation in terms of increased healthcare costs. Beyond the real people and lives that OAA Nutrition Programs impact on a daily basis, however, there is increasing and irrefutable evidence that improving and bolstering funding for them will substantially reduce healthcare costs—both in the short- and long-term. On average, a program can deliver Meals on Wheels to a senior for an entire year for the same cost as just 1 day in the hospital or one week in a nursing home—costs that are often incurred by Medicare and Medicaid.

The recently released More Than a Meal study found that those who received daily-delivered meals (the traditional Meals on Wheels model of a daily, in-home-delivered meal, friendly visit and safety check), experienced the greatest improvements in health and quality of life indicators over the study period, compared to the other two groups (individuals who received frozen, weekly-delivered meals and those who were in the control group on waiting lists).

Specifically, between baseline and follow-up, seniors receiving daily-delivered meals were more likely to exhibit:

—Improvement in mental health (i.e., levels of anxiety)
—Improvement in self-rated health
—Reductions in the rate of falls
—Improvement in feelings of isolation and loneliness
—Decreases in worry about being able to remain in home

Those receiving daily-delivered meals reported greater benefits from their home-delivered meal experience compared to the group receiving frozen meals.

—Specifically, seniors receiving daily-delivered meals were more likely to attribute their meals to making them feel safer and report that their meals helped them to eat healthier foods than the group receiving frozen meals.

—In addition, those receiving daily-delivered meals were more likely to note that their meals resulted in more social contact and less loneliness than the group receiving frozen meals.

Finally, those seniors who lived alone and received daily-delivered meals were more likely to report decreases in worry about being able to remain in home, and improvements in feelings of isolation and loneliness over the study period, compared to the other two groups (individuals living alone, who either received frozen, weekly-delivered meals or were on waiting lists).

SCALING THE SOLUTION

It is clear that those who are in need of home-delivered meal services represent our Nation's most frail and vulnerable senior population, and a group with significant health and social support needs. The recent More Than a Meal study supports the wealth of past research, indicating that home-delivered meals improve the health and well-being of older adults, particularly those who receive daily-delivered meals and those who live alone. By lessening feelings of isolation and loneliness and reducing the rate of falls, the research suggests the traditional Meals on Wheels service delivery model has the greatest potential to decrease healthcare costs. When reviewing the reduction in falls alone, which adjusted for inflation equaled $34 billion in direct medical costs in 2013, further investments in OAA Nutrition Programs are an untapped solution and have the potential to produce billions of dollars in savings to the Mandatory side of the budget.

We certainly understand the difficult decisions you and your colleagues are tasked with in fiscal year 2016 and beyond. However, the evidence demonstrates that these programs are not only saving lives and taxpayer dollars every day, but they are effectively reaching our Nation's at risk seniors and have the capacity to serve significantly more if properly resourced. As such, we hope that you recognize the need to invest in Discretionary programs, like OAA Nutrition Programs, that help prevent and mitigate the effects of chronic diseases, improve quality of life, expedite recovery after an illness, injury, surgery or treatment, and reduce unnecessary Medicare and Medicaid expenses both today and in the future.

As your Subcommittee crafts and considers the fiscal year 2016 Labor-HHS-Education Appropriations Bill, we ask that you provide the funding levels included in the President's fiscal year 2016 Budget Request to Congress for all three nutrition programs authorized under the OAA—Congregate Nutrition Program, Home-Delivered Nutrition Program, and the Nutrition Services Incentive Program—as well as, support the need for Nutrition Innovation Demonstration funding. You have the ability to shorten or even eliminate waiting lists and increase the number of nutritious meals we can serve to seniors today. At the same time, you will be investing in a stronger fiscal path for our country by reducing future healthcare costs.

Again, we thank you for the opportunity to present this testimony to you, and for your continued support. We are also pleased to offer our assistance and expertise at any time throughout this process.

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## PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—Continue the commitment to the National Library of Medicine (NLM) by supporting the President's budget proposal which requests $394,090,000.

—Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and healthcare reform implementation.

INTRODUCTION

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the Subcommittee for the opportunity to submit testimony regarding fiscal year 2016 appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH). Working in

partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available to all who need it. As health sciences librarians who use NLM's programs and services every day, we can attest that these resources literally save lives making NLM an investment in good health.

*NLM Leverages NIH Investments in Biomedical Research*

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it seeks to improve our Nation's fiscal stability. We thank the Subcommittee for its long-standing commitment to strengthening NLM's budget. NLM's budget supports intramural services and programs that sustain the Nation's biomedical research enterprise and more—it builds, sustains, and augments NLM's suite of more than 200 databases which provide information access to health professionals, researchers, educators, and the public. NLM's budget also supports all aspects of library operations and programs, including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium.

In fiscal year 2016 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on the investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more accessible to researchers, clinicians, business innovators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM is a leader in Big Data and plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs), by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through expansion of its clinical trial registry and results database (ClinicalTrials.gov) in response to legislative requirements, and to the Nation's ability to prepare for and respond to disasters.

*Growing Demand for NLM's Basic Services*

NLM delivers more than a trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the Nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. Without NLM, our Nation's medical libraries would be unable to provide the quality information services that our Nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. PubMed, with more than 24 million citations to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 765,000 new citations were added in fiscal year 2015, and the database provided high quality medical information to about 2 million users each day. PubMed Central is NLM's digital archive which provides public access to the full-text versions of more than 3.3 million biomedical journal articles, including those produced by NIH-funded researchers. On a typical weekday more than one million users download 1.65 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 21 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

*Encourage NLM Partnerships*

NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NN/LM),

with over 6,300 members in communities nationwide, these activities educate medical librarians, health professionals and the general public about NLM's services and train them in the most effective use of these services. The NN/LM promotes educational outreach for public libraries, secondary schools, senior centers and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish. It has become a top destination for those seeking information on the Internet, attracting more than 1.6 million visitors daily. NLM has continued to make enhancements to MedlinePlus, with selected materials now available in forty other languages. New versions of MedlinePlus and MedlinePlus en español have been released and have been optimized for easier use on mobile phones and tablets; they also have all the content that is found on the MedlinePlus and MedlinePlus en español websites. Other products and services that benefit public health and wellness include the NIH MedlinePlus Magazine and NIH MedlinePlus Salud, available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility which enables clinical care organizations to implement links from their electronic health records systems to relevant patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

*Emergency Preparedness and Response*

Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization (DIS) program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the Subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur. In 2014, NLM released a new version of Chemical Hazards Emergency Medical Management (CHEMM) that provide first responders with tools to quickly make a series of complex decisions to minimize the risk of injury to their patients and themselves. CHEMM enables first responders and other healthcare providers to plan for, respond to, recover from, and mitigate the effects of mass-casualty incidents involving accidental or terrorist chemical releases.

*Health Information Technology and Bioinformatics*

For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the Nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies for free nationwide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems and link to relevant patient education materials.

*Dissemination of Clinical Trial Information*

As health sciences librarians who fulfill requests for information from clinicians, scientists, and patients, we applaud the NIH and NLM for their efforts to expand

and clarify the regulations for clinical trials registration and results submission, and for work to apply the ClinicalTrials.gov requirements to all NIH clinical trials. These efforts will enhance the transparency of clinical trial results, and provide patients with more information to make necessary healthcare decisions, including critical information about the safety of products and treatment options. Clinicians will have access to results information about efficacy, adverse effects, and safety; and biomedical researchers will have information on research design, safety, and scientific results that can inform future protocols and discoveries. We also support timely, easily understood, and accurate reporting of all clinical trials, especially those supported by Federal funding, regardless of agency and phase of the clinical trial, and information about studies that have been terminated due to adverse events, difficulties in research design making accrual difficult, or simply feasibility problems. Ultimately, expanding the requirements will create an incredible and vastly important database of clinical data and knowledge for clinicians, scientists, and patients who need access to cutting-edge information.

In addition to these efforts, beginning this spring, PubMed Health's curated collection of systematic reviews now enables PubMed users to go straight from a clinical trial to systematic reviews that have considered it. This allows users to see how a particular trial fits into the bigger picture of effectiveness research by helping them to look at evidence in context.

*Improving Public Access to Funded Research Results*

Earlier this year, the Department of Health and Human Services (DHHS) announced it plans and common policy approach to expanding public access to the results of scientific research funded by HHS agencies. Its operating divisions (Agency for Healthcare Research and Quality, Centers for Disease Control, Food and Drug Administration, and NIH) as well as the Assistant Secretary for Preparedness and Response will utilize NLM's PubMed Central as the common repository for its peer-reviewed publications and PubMed, a repository of citations, for the sharing of metadata. NLM's experience in developing these systems and related tools and engaging the health sciences library community in outreach will be essential to effective implementation of HSS-wide policies and improving compliance.

Thank you again for the opportunity to present our views. As health sciences librarians who use NLM's products and services and as intermediaries who provide services to researchers, clinicians, and the public, we value and rely upon the high quality invaluable support and leadership that NLM provides in support of our Nation's health professionals, educators, researchers, and the public. As the needs of these audiences continue to evolve, we are confident that NLM's vision and understanding of the role of information, data, and technology will continue to fuel the development of just-in-time resources and tools that will keep our Nation's health, biomedical, and scientific professionals at the forefront of healthcare, discovery, and innovation.

We look forward to continuing this dialogue and supporting the Subcommittee's efforts to secure the highest possible funding level for NLM in fiscal year 2016 and the years beyond to support the Library's mission and growing responsibilities. Information about NLM and its programs can be found at http://www.nlm.nih.gov.

*Organizational Bios*

The Medical Library Association (MLA) is a nonprofit, educational organization with 3,700 health sciences information individual and institutional members. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a network of partners to promote the importance of quality information for improved health to the healthcare community and the public.

The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management. AAHSL membership is composed of 166 academic health sciences libraries whose medical schools hold member or associate member status in the Association of American Medical Colleges.

PREPARED STATEMENT OF MEHARRY MEDICAL COLLEGE

SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—Funding for the Title VII Health Professions Training Programs, including:
  —$25 million for the Minority Centers of Excellence
  —$14 million for the Health Careers Opportunity Program
—$32 Billion for the National Institutes of Health and a Proportional Increase for the National Institute on Minority Health and Health Disparities.
  —$100 million for Research Centers for Minority Institutions.
—$65 million for the Department of Health and Human Services' Office of Minority Health.
—$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you. I am Dr. Anna Cherie Epps, President and CEO of Meharry Medical College in Nashville, Tennessee. I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next 10 years, we will need to be able to deliver more culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our Nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15 percent of the U.S. population while only 2–3 percent of the Nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: (1) serve in rural and urban medically underserved areas, (2) provide care for minorities and (3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 and fiscal year 2007 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially

disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2016, I recommend a funding level of $25 million for COEs.

*Health Careers Opportunity Program (HCOP)*.—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2016, I recommend a funding level of $14 million for HCOPs. Additionally, we have worked hard with the Obama Administration for them to understand this program. They have offered to "rebrand" HCOP. Until such time that the agency that administers the program, HRSA, and community agree on a path forward, we support the current funding of HCOP.

NATIONAL INSTITUTES OF HEALTH (NIH)

*National Institute on Minority Health and Health Disparities*.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities. For fiscal year 2016, I recommend $285 million for NIMHD.

*Research Centers at Minority Institutions*.—The Research Centers at Minority Institutions program (RCMI) is now housed at the National Institute on Minority Health and Health Disparities (NIMHD). RCMI has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, for fiscal year 2016, I recommend $100 million for RCMI.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

*Office of Minority Health*.—Specific programs at OMH include:

—Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,

—Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,

—Supporting conferences for high school and undergraduate students to interest them in healthcareers, and

—Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, but this role can only be fulfilled if this agency continues it grant making authority. For fiscal year 2016, I recommend a funding level of $65 million for the OMH.

DEPARTMENT OF EDUCATION

*Strengthening Historically Black Graduate Institutions Program*.—The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institu-

tional development activities. In fiscal year 2016, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1876.

Thank you, Mr. Chairman, for this opportunity.

[This statement was submitted by Anna Cherie Epps, Ph.D., President, Chief Executive Officer, Meharry Medical College.]

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## PREPARED STATEMENT OF ANA METTLER

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve

as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF MOREHOUSE SCHOOL OF MEDICINE

Mr. Chairman and members of the Subcommittee, my name is Dr. Valerie Montgomery-Rice, and I have the distinct privilege of serving as President of Morehouse School of Medicine (MSM) in Atlanta, Georgia. My testimony will highlight the sources of funding which allow Morehouse School of Medicine to serve underrepresented communities and address health disparities, workforce shortages, and chronic diseases impacting vulnerable populations. The agencies and programs which I will discuss include:

—Funding for Title VII Health Professions Training Programs, including:
  —$24.602 million for the Minority Centers of Excellence for Fiscal Year 2015.
  —$22.133 million for the Health Careers Opportunity Program for Fiscal Year 2015.
  —$33.345 million for the Area Health Education Centers for Fiscal Year 2015
—$32 billion for the National Institutes of Health
  —$291.778 million for the NIH's National Institute on Minority Health and Health Disparities.
—$65 million for the Department of Health and Human Services' Office of Minority Health.
—$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.

I previously served as dean of medicine at Meharry Medical College, and in all of my roles, I have seen firsthand the importance of minority health professions institutions and the challenges they face, especially in respect to their funding.

I want to take a moment to highlight the Historically Black Medical School's (HBMS) unique place in our society. An independent, historically black, primary health mission-centered institution like the Morehouse School of Medicine (MSM) is distinct in a world where health professionals tend to focus on more lucrative subspecialties. MSM ranks first among U.S. medical schools in terms of social mission, or the production of primary care physicians, minority doctors, and doctors practicing in underserved areas. While this conclusion might seem elementary, it is important to note that MSM was able to achieve this distinction with a graduating class of only 64. Since 1984, MSM has graduated more than 1,200 students and more than 71 percent have chosen to honor the institution's mission of serving where they are needed most: providing primary care to our underserved communities, both rural and urban.

Though the recent economic downturn has financially challenged all academic institutions, MSM and other HBMS are distinctly disadvantaged when compared to most of their peer institutions; given the societal mission, governmental and nongovernmental support finance the core curriculum and infrastructure of our institutions. Financially, MSM lacks many of the revenue streams one may find at nonminority peer institutions, including a wealthy donor base. Because MSM does so much public good, I've taken to calling us a "private institution with a public mission." For this reason and others, it is critical that Federal resources, along with the private, continue to invest in MSM and the future health professionals we train.

Mr. Chairman, our mission at MSM is "to improve the health and well-being of individuals and communities; increase the diversity of the health professional and scientific workforce; and address primary healthcare needs through programs in education, research, and service, with emphasis on people of color and the underserved urban and rural populations in Georgia and the Nation." Given this, I must point out that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example, while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your subcommittee can help us continue to carry out our mission, our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well-established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continues its commitment to minority health profession institutions and minority health professional training programs in order to produce the next generation of healthcare providers committed to addressing this unmet need.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved, are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Given the historic mission of institutions like MSM, to provide academic opportunities for minority and financially disadvantaged students and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The slow reinvestment in the Title VII Health Professions Training programs amounts to a loss of core funding at these institutions and has been financially devastating. Here are my recommendations for this subcommittee to make an investment, on which there will be a return:

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of additional categories. For fiscal year 1206, I recommend $25 million for COEs.

*Health Careers Opportunity Program*.—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Lately, HCOPs have come under increased scrutiny for their efforts to reach to elementary, middle, and high schools to cultivate future health professionals. While it is true that HCOPs partner with high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional, there are programs like the one MSM recently hosted which focused on undergraduates or the program which Meharry hosted based in their post-bachelorette program. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. For fiscal year 2016, I recommend funding of $14 million for HCOPs.

*Area Health Education Centers*.—AHECs are designed to encourage the establishment and maintenance of community based training programs in off-campus rural and underserved areas. At MSM, the AHEC funding focuses on exposing medical students and health professions students to primary care and practice in rural and underserved communities, with a special emphasis on primary care and interprofessional/interdisciplinary training for our health professions students. For fiscal year 2016, I recommend $35 million for AHEC.

NATIONAL INSTITUTES OF HEALTH (NIH)

*National Institute on Minority Health and Health Disparities*.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the Minority Centers of Excellence program. At MSM, the Research Endowment program has been transformed our institution because it aligns with the mission of promoting minority health and health disparities research, while at the same time the building capacity component has stabilized us financially. For fiscal year 2016, I recommend $285 million for NIMHD.

*Office of Minority Health*.—OMH was created in 1986 and is one of the most significant outcomes of the landmark 1985 Secretary's Task Force Report on Black and Minority Health. The Office is dedicated to improving the health of racial and ethnic minority populations through the development of health policies and programs that will help eliminate health disparities. Additionally, one of the most vital roles of OMH has been its strategic grant making authority, including its cooperative agreements with MSM and other HBMS. These cooperative agreements are based on the specific needs of the communities we serve. The requirements, which are published in the Federal Register, are the agency's connection with institutions that most mirror its purpose. There are those in the Administration that do not agree with the theory that OMH should grant funding, that the agency should be solely focused on strategies. Without these cooperative agreements, OMH loses much of its most effective outreach to the communities that need it the most. The OMH has the potential to play a critical role in addressing health disparities, and with the proper funding and continued emphasis on the cooperative agreements, this role can be enhanced. For fiscal year 2016, I recommend a funding level of $65 million for the OMH.

DEPARTMENT OF EDUCATION

*Strengthening Historically Black Graduate Institutions*.—The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MSM and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development, initiate endowment campaigns, and support numerous other institutional development activities. While this program provides significant funding, based off a competition, institutions must match fifty cents to every dollar. In fiscal year 2016, an appropriation of $65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Morehouse School of Medicine along with other minority health professions institutions will help this country to overcome health and healthcare disparities. These investments are not only important for the health of our Nation, but the elimination of health disparities will relieve our country of unnecessary health and economic burdens. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have since our founding day. Thank you, Mr. Chairman. I welcome the opportunity to answer questions for you now or in the subcommittee's record.

[This statement was submitted by Valerie Montgomery-Rice, M.D., President & Dean, Morehouse School of Medicine.]

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PREPARED STATEMENT OF MOVEABLE FEAST

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Moveable Feast is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 800,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results

that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RON) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]
—More ER visits[4] & increased morbidity and mortality[5]
—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000)

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30% lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

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[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[8] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Tom Bonderenko, Executive Director, Moveable Feast.]

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PREPARED STATEMENT OF PAUL MURPHY

My son currently resides in an ICF/IID facility. He lives in a home where he is supervised by a staff of caregivers and nurses. He needs constant professional supervision that the facility provides. My son is physically normal but has severe autism which makes him oblivious to possible dangers in his environment. It is crucial he has constant alert supervision to prevent him from being harmed by everyday hazards. He also requires multiple medications that must be administered on a precise schedule. The staff at the ICF/IID facility is equipped to provide these services. I searched for years to find an appropriate setting to care for my son. All the community services in my region were unable to care properly for him for one reason or another. Community services may suit some individuals properly but there is a special need for ICF/IID facilities to help supervise and support individuals such as my son.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Med-

icaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

The members of the National AHEC Organization (NAO) are pleased to submit this statement for the record recommending $35 million in fiscal year 2016 for the Area Health Education Center (AHEC) program authorized under Titles VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). The NAO is the professional organization representing AHECs. The AHEC Program is an established and effective national primary care training network built on committed partnerships of 53 medical schools and academic centers. Additionally, 253 AHEC centers within 48 States and tens of thousands of community practitioners are affiliated with the AHEC's national clinical training network.

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of healthcare services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments. The AHEC program would be the mechanism to recruit providers into primary health-careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. Area Health Education Centers are the workforce development, training and education machine for the Nation's healthcare safety-net programs. The AHEC program is focused on improving the quality, geographic distribution and diversity of the primary care healthcare workforce and eliminating the disparities in our Nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health-careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

The Area Health Education Center program is effective and provides vital services and national infrastructure. Nationwide, over 379,000 students have been introduced to health-career opportunities, and over 33,000 mostly minority and disadvantaged high school students received more than 20 hours each of health-career exposure. Over 44,000 health professions students received training at 17,530 community-based sites, and furthermore; over 482,000 health professionals received continuing education through AHECs. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal clinics and Public Health Departments.

### JUSTIFICATION FOR RECOMMENDATIONS

The AHEC network is an economic engine that fuels the recruitment, training, distribution, and retention of a national health workforce. AHEC stands for JOBS.

—AHECs are critical in the recruitment, training, and retention of the primary care workforce.

—Research has demonstrated that the community-training network is the most effective recruitment tool for the health professions and those who teach remain longer in underserved areas and communities.

—AHECs are in almost every county in the United States.

—With the aging and growing population, the demand for primary care workforce is far outpacing the supply.
—AHECs continue to educate and train current workforce, as well as recruiting and preparing future workforce
—In the past year, AHEC's had 731,515 active participants training in their programs
  —299,932 students were exposed to health-careers with the intent to pursue post-secondary education in primary healthcare professions through AHEC's pipeline programs
  —AHECs facilitated 40,591 rotations in clinical training to improve readiness, willingness, and ability of health professions trainees to serve in primary care, and rural and underserved communities
  —19,048 health professions students were placed in rural and underserved locations
    —10,643 were medical students
    —8,405 were associated health professions students
  —412,535 participants in continuing education programs learned how to address key issues in health professional shortage areas to improve quality of healthcare for medically underserved and health disparities populations
—Approximately 459,272 health professions students engaged in AHEC-supported programs between July 2013 and December 2014. Of these students engaged in AHEC-supported structured programs, 74 percent were from disadvantaged backgrounds, 54 percent were from rural backgrounds, and 27 percent were under-represented minorities (URM).
—The AHEC network's outcomes are the backbone of the Nation's community-based health professions training, with a focus on training primary care workforce.
—Continued funding for the AHEC program is necessary as demonstrated by (1) a growing unmet need for primary care doctors in rural areas, and (2) the use of the national network of AHEC programs to carry out administrative priorities.

1. The National Health Service Corps (NHSC), has been mentioned as a program that addresses the priority of increasing diversity in the health professions workforce in underserved and rural areas and addresses the end of the pipeline. The AHEC program engages in pre-pipeline, pipeline, and post-pipeline activities that works to move individuals through a health-careers pathway and beyond, with a special focus on primary care doctors.
2. The national network of the AHEC program has been tasked with:
  —Training 13,000+ providers nationwide in OIF/OEF/OND Veteran's behavioral and mental health, substance abuse, traumatic brain injury and post-traumatic stress, for those not utilizing the VA system
  —Working with the Food and Drug Administration to educate healthcare professionals nationwide on proper opioid prescribing habits to address the epidemic of prescription drug abuse
  —HRSA has encouraged functional linkage between Bureau of Primary Care and Bureau of Health Professions Programs. AHECs have partnerships with over 1,000 Community Health Centers nationally to recruit, train, and retain health professionals who have the cultural and linguistic skills to serve in HRSA designated underserved areas
  —Affordable Care Act activities such as increasing the enrollment of individuals and educating providers nationwide on health insurance exchanges

[This statement was submitted by Rob Trachtenberg, Executive Director, National AHEC Organization.]

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## PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

### EXECUTIVE SUMMARY

NAEVR requests fiscal year 2016 NIH funding of at least $32 billion, waiving it from sequester cuts and Budget Control Act caps and improving upon the President's fiscal year 2016 funding proposal of $31 billion. This build upon actions in fiscal year 2014 and 2015 by Congress to restore the $1.7 billion in fiscal year 2013 sequester cuts by enabling at least a 5 percent increase in the NIH budget, reflecting both modest growth and an inflationary increase. The latter is crucial, as NIH has lost 22 percent of its purchasing power since fiscal year 2003, in terms of constant dollars.

—Cuts and a lack of inflationary increases have significantly limited NIH's ability to sustain current research capacity and encourage new areas of science. This comes at a time when past investment in basic and clinical research has resulted in new diagnostics, treatments, and prevention strategies that save lives and improve quality of life.
—NIH is an economic driver. In fiscal year 2011, NIH-funded research supported 432,000 jobs across the U.S. and generated more than $62 billion in new economic activity. Every $1 of NIH funding generates $2.21 in local economic growth.
—The U.S. must capitalize on previous NIH investment to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy.

NAEVR requests National Eye Institute (NEI) funding at $730 million, which would fully restore the $36 million in fiscal year 2013 sequester cuts and enable both modest growth and an inflationary increase, the latter being crucial as the NEI has lost 25 percent of its purchasing power since fiscal year 2003.

—Despite Congressional actions in fiscal year 2014 and 2015 to restore sequester cuts, the NEI's operating budget is still $25 million below the fiscal year 2012 level-the equivalent of 60 grants, any one of which could have held the promise to save sight and restore vision. The President's fiscal year 2016 proposed NEI funding of $695 million would still be $7 million below pre-sequester funding.
—NEI's fiscal year 2015 operating budget of $676 million is still less than 0.5 percent of the $145 billion annual cost of vision disorders, which will grow to a $717 billion annual cost by year 2050, in inflation-adjusted dollars.

AMERICANS FEAR VISION LOSS, WHICH IS A GROWING PUBLIC HEALTH PROBLEM

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as age-related macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020, driven by:

—The aging of the population-the "Silver Tsunami" of the 78 million baby boomers who will turn age 65 this decade and experience increased risk for eye disease.
—The disproportionate risk/incidence of eye disease in Hispanic and African American communities, which increasingly account for a larger share of the U.S. population.
—Vision loss as a co-morbid condition of chronic disease, such as diabetes, which is at epidemic levels due to the increased incidence of obesity.

In September 2014, NAEVR's educational foundation, the Alliance for Eye and Vision Research (AEVR), released results of a new poll entitled The Public's Attitudes about the Health and Economic Impact of Vision Loss and Eye Disease, which was commissioned by Research!America and conducted by Zogby Analytics with a grant from Research to Prevent Blindness (RPB), a private vision funding foundation which conducted the first-ever poll of the public's attitudes about vision loss in 1965. The 2014 poll-the most rigorous conducted to-date of attitudes about vision and vision loss among ethnic and racial groups including non-Hispanic Whites, African Americans, Hispanics, and Asian Americans-found, in part, that:

—A significant number of Americans across all racial lines rate losing their eyesight as having the greatest impact on their daily life, affecting independence, productivity, and quality of life.
—African Americans, when asked what disease or ailment is the worst that could happen, ranked blindness first, followed by HIV/AIDS. Hispanics and Asians ranked cancer first and blindness second, while non-Hispanic Whites ranked Alzheimer's disease first, followed by blindness.
—America's minority populations are united in the view that not only is eye and vision research very important and needs to be a national priority, but many feel that the current annual Federal funding of $2.10 per-person, per-year is not enough and should be increased.

In June 2014, Prevent Blindness (PB) released a report entitled The Future of Vision: Forecasting the Prevalence and Costs of Vision Problems, which it commissioned from the University of Chicago's National Opinion Research Center (NORC). This report estimates the current annual cost (inclusive of direct and indirect costs) of vision disorders at $145 billion, an increase of $6 billion from the $139 billion estimate in PB's 2013 study entitled Cost of Vision Problems: The Economic Burden of Vision Loss and Eye Disorders in the United States, which also concluded that direct medical costs associated with vision disorders are the fifth highest-only less than heart disease, cancers, emotional disorders, and pulmonary conditions. PB's

2014 study projects that the total annual cost of vision disorders, which includes government, insurance, and patient costs, will grow to $373.2 billion in 2050 when expressed in 2014 dollars-which is $717 billion when adjusted for inflation. Of the $373.2 billion estimated 2050 costs, $154 billion or 41 percent will be borne by the Federal Government as the Baby-Boom generation ages into the Medicare program.

PB's 2014 report also concludes that the prevalence of vision disorders and costs will shift to conditions that are more common at older ages and for minorities:

—The age 90-plus population will see the highest rates of growth in prevalence and costs by 2050, since it will be the fastest growing segment of the U.S. population, reflecting the aging over the next 40 years of the Baby-Boom generation.

—The prevalence of eye diseases is going to increase by 60 to 80 percent by 2050, with cataract being most prevalent in the growing older population and with prevalence of diabetic retinopathy and glaucoma also increasing, driven by greater incidence in the African American and Hispanic populations.

### NEI'S BUDGET IS NOT KEEPING PACE AS THE BURDEN OF EYE DISEASE AND VISION IMPAIRMENT GROWS

In fiscal year 2015, NEI's operating budget is still $25 million below the fiscal year 2012 level due to a combination of the fiscal year 2013 sequester cut, lack of inflationary increases, and a reduction in NEI's appropriation due to the transfer back to the NIH Office of AIDS Research (OAR) for funding of the successfully completed NEI-sponsored Studies of the Ocular Complications of AIDS (SOCA). Although OAR's funding to NEI was not committed indefinitely, its return to NIH Central in the amounts of $5.6 million (fiscal year 2013), $6.9 million (fiscal year 2014), and $7.4 million (fiscal year 2015) has essentially cut NEI's budget further, resulting in a new baseline upon which any future funding increases are based. Even though the President's budget would increase NEI funding to $695 million, its budget would still be $7 million below the fiscal year 2012 pre-sequester level.

NEI's fiscal year 2015 operating net budget of $676 million, as well as the President's fiscal year 2016 proposed NEI budget of $695 million, are each less than 0.5 percent of the $145 billion annual vision disorder cost burden. The U.S. is spending only $2.10 per-person, per-year for vision research at the NEI, while the 2013 PB report estimates that the cost of treating low vision and blindness is at least $6,690 per-person, per-year.

The very health of the vision research community is also at stake. The convergence of factors that have reduced NEI funding has affected both young and seasoned investigators and threatened the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding.

In 2009, Congress spoke volumes in passing S. Res 209 and H. Res. 366, which designated 2010–2020 as The Decade of Vision and recognized NEI's 40th anniversary as the lead institute in funding research to save sight and restore vision. With the fiscal year 2016 LHHS spending bill, Congress can act upon its past resolutions regarding vision and ensure that NEI is funded at $730 million to meet these challenges.

### $730 MILLION FISCAL YEAR 2016 FUNDING ENABLES NEI TO PURSUE ITS AUDACIOUS GOAL OF RESTORING VISION

NEI has lost 25 percent of its purchasing power since fiscal year 2003, and the $25 million that its budget is down from the fiscal year 2012 level is the equivalent of 60 grants it cannot fund-any one of which could have held the promise to save sight and restore vision. Although these goals would have seemed unattainable just a few short years ago, the NEI is pursuing vision restoration through its Audacious Goal Initiative (AGI) which focuses on regenerating neurons and neural connections in the eye and visual system. In February 2014, NEI Director Dr. Paul Sieving stated the following about the AGI:

> "The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10–15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

The AGI builds upon discoveries from past investment in biomedical research, such as gene sequencing, gene therapy, and stem cell therapies, and combines these with new discoveries-such as imaging technologies that enable researchers to noninvasively view in real-time biological processes occurring in the retina at a cellular level-to develop new therapies for degenerative retinal disorders.

These are ambitious goals that require increased-not decreased-funding. Our Nation's investment in vision health is an investment in its overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

In summary, NAEVR requests fiscal year 2016 NIH funding of at least $32 billion and NEI funding of $730 million to maintain the momentum of research.

ABOUT NAEVR

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyeresearch.org.

[This statement was submitted by James Jorkasky, Executive Director, National Alliance for Eye and Vision Research.]

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PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR PUBLIC CHARTER SCHOOLS

Mr. Chairman and Members of the Subcommittee, I am pleased to present the views of the National Alliance for Public Charter Schools (National Alliance) regarding fiscal year 2016 appropriations. The National Alliance is the leading national organization committed to advancing the quality, growth, and sustainability of public charter schools.

In what continues to be a very tight fiscal environment, with sequestration caps still in place and many urgent needs and priorities competing for Federal support, the National Alliance appreciates the work that Congress has done to help meet the needs of the burgeoning and successful charter schools movement. We truly appreciate the bipartisan support that public charter schools have received, including the increase for the Charter Schools Program (CSP) in the final 2015 appropriation and the additional increase included in the President's 2016 budget request. I appreciate this opportunity to describe the growth of the charter school movement, the successful student outcomes achieved by charter schools, and the reasons why we believe it would be appropriate—even urgent—for the CSP to receive a significant appropriations increase for 2016.

THE GROWTH AND PERFORMANCE OF PUBLIC CHARTER SCHOOLS

In the 2014–2015 school year, almost 2.9 million children are attending more than 6,700 public charter schools in 42 States and the District of Columbia. Alabama is the most recent State to authorize charter schools, passing a law in March 2015. The growth in the charter movement during the 23 years since the first school opened in 1992 has been absolutely phenomenal. Public charter schools are now a significant presence (more than 10 percent of enrollment) in some 150 communities, and enroll more than 30 percent of students in twelve school districts. Charter schools have become a prominent component of the public school landscape in many communities because they offer students and parents high-quality educational options, have the flexibility to adopt innovative curricula and practices, and are held accountable for their performance. Charter schools often address particular themes or instructional areas, such as science, technology, engineering, and math (STEM), performing arts, language immersion, project-based learning, and many others.

Charter schools have also been at the forefront of serving disadvantaged and other special-needs populations since the movement began. Nationally, public charter schools enroll higher percentages of minority students and students from low-income families than do traditional public schools (and particularly high percentages in certain communities, such as New York City), and their enrollment of English language learners and students with disabilities is comparable to that of other schools.

Through their agreements with authorized public chartering agencies, charter schools are held accountable for results, and the penalty for repeated failure to educate students to State standards is closure. The data show that this model—greater flexibility in exchange for accountability for student outcomes—is working. A 2015 review of 2006–07 through 2011–12 data by the Center for Research on Outcomes in Education at Stanford University, found that charter school students are outperforming their peers in traditional public schools and closing the achievement gaps

between student subgroups. Nearly half (43 percent) of urban charter schools post larger learning gains than traditional public schools in math. In reading, 38 percent of charter schools outperform traditional school peers, while 46 percent show equivalent learning gains. The academic gains charter students received equated to 40 additional learning days in math and 28 additional days in reading relative to their peers in traditional public schools.

These results are especially impressive for students from specific demographic backgrounds: black students from low-income families enrolled in charter schools gained 59 instructional days in math and 44 days in reading compared to their peers. Hispanic English language learners gained 72 days in math and 79 days in reading by attending a public charter school. Students with special needs showed learning gains equivalent to nine additional instructional days in math and 13 in reading.

THE NEED FOR ADDITIONAL RESOURCES

Although the number of charter schools has increased rapidly, the movement has not been able to expand quickly enough to meet strong parent and student demand. Last year, the National Alliance found that there were more than a million names on charter school waiting lists nationally in school year 2013–2014. Accounting for the fact that many students apply to more than one school, we estimated that more than 586,000 students wanted to attend a charter school but could not do so simply because there were not enough spaces. The number of names on the waiting lists has grown annually: from 2008–2009 through 2013–2014 it increased by a staggering 186 percent. The message is clear—there is a great unmet demand for seats in charter schools, and public officials at all levels should be doing more to meet that demand.

Toward that end, I cannot overemphasize the importance of Federal support, through the CSP, in helping charter schools get started and in enabling the replication and expansion of successful charter school models. Unfortunately, while 43 States and DC now have charter school laws, States and localities have underfunded their charter schools (relative to traditional public schools) and have not provided the seed money needed to plan and start new schools. It is inconceivable that the movement would have grown as quickly as it did without the CSP, particularly through the State Educational Agency (SEA) grants. And in recent years, the Replication and Expansion grants have been an essential tool for enabling our most effective models and schools to serve additional students, often in economically distressed areas where traditional public schools are failing.

Facilities are another area in which Federal support is critical. State and local formulas and programs often do not provide charter schools with the same support for capital expenses as is available to traditional schools. In those cases, charter school operators typically have to scramble to find acceptable facilities. The CSP State Facilities Incentive Grants and the Credit Enhancement for Charter Schools program help to make up the difference. We look forward to working with the Committee on ensuring that both of these grant programs are meeting the needs of the charter school community.

THE FISCAL YEAR 2016 BUDGET

As the Subcommittee begins its work on the appropriation for 2016, I encourage you to make funding for the CSP a key priority. As I have described, the Nation needs more schools that can effectively serve diverse populations, particularly in neighborhoods that have not had high-quality options. And we must do more to meet the needs of parents and students who want charter schools but cannot gain access to them.

The National Alliance is pleased that the Administration's budget request includes $375 million for the program, of which at least $100 million would go for Replication and Expansion Grants, up to $10 million for State Facilities Incentive Grants, at least $13 million for Credit Enhancement, at least $11 million for National Activities, and the remainder for Grants to SEAs and the "non-SEA" competition. We commend the Administration for including $375 million for CSP in the budget request and ask that Congress support these funding levels for these important programs. In addition, we look forward to discussing our recommendations for report language to support authorizer and charter school quality, and other issues related to the program.

Again, thank you for the opportunity to present the views of the National Alliance and the charter school community on the fiscal year 2016 appropriations. If my organization can be of any assistance to the Subcommittee, please do not hesitate to contact me.

[This statement was submitted by Nina Rees, President and CEO, National Alliance for Public Charter Schools.]

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## PREPARED STATEMENT OF THE NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the Nation's chief state health agency staff who have programmatic responsibility for administering HIV and hepatitis healthcare, prevention, education and supportive service programs funded by State and Federal Governments. On behalf of NASTAD, we urge your support for increased funding for Federal HIV and hepatitis programs in the fiscal year 2016 Labor-Health-Education Appropriations bill, and thank you for your consideration of the following critical funding needs for HIV and hepatitis programs in fiscal year 2016:

| Agency | Program | NASTAD Funding Request ($ million) |
|---|---|---|
| Health Resources and Services Administration | Ryan White Part B Base | 437.5 |
| Health Resources and Services Administration | Ryan White Part B ADAP | 943.3 |
| Centers for Disease Control and Prevention | Division of HIV Prevention | 832.7 |
| Centers for Disease Control and Prevention | Division of Viral Hepatitis | 62.8 |

The Affordable Care Act (ACA) is radically changing the U.S. healthcare system. The ACA provides opportunities to increase access for many people living with HIV and/or hepatitis to the care and prevention services needed to help end these twin epidemics. However, access to insurance alone does not replace the key role of State public health programs to monitor diseases within their borders. Public health will remain a critical player in meeting the needs of the hardest to reach, most vulnerable populations (e.g., men who have sex with men [MSM], youth, persons who inject drugs) from actively identifying and locating persons at risk, to ensuring linkage to and retention in medical care in a manner that is responsive to the needs of people living with HIV and/or hepatitis.

Domestic prevention efforts must match the commitment to the care and treatment of people who are living with HIV. To be successful, we must expand traditional efforts (e.g., outreach and screening for HIV/STDs) and scale-up proven new biomedical prevention modalities such as pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP), while reimaging how the compendium of effective prevention tools can work in tandem to curb incidence in the United States. We must also prioritize funding and efforts to the populations most disproportionately impacted by HIV in the United States—men who have sex with men (MSM), especially young MSM of color. Among the services necessary to improve health outcomes are the needs for linkage to, and retention in care, and access to medications that suppress viral load, reducing HIV transmission, which make HIV more difficult to transmit—ultimately leading to fewer new infections. The Centers for Disease Control and Prevention (CDC)'s prevention programs and the Ryan White Program are crucial to preventing new infections and improving health outcomes.

### HIV/AIDS CARE AND TREATMENT PROGRAMS

The Health Resources and Services Administration (HRSA) administers the $2.3 billion Ryan White Program that provides health and support services to more than 500,000 people living with HIV (PLWH). NASTAD requests a minimum increase of $65.8 million in fiscal year 2016 for State Ryan White Part B grants, including an increase of $22.8 million for Part B and $43 million for AIDS Drug Assistance Programs (ADAPs). The Ryan White Part B Program funds State health departments to provide care, treatment and support services for low-income uninsured and underinsured individuals living with HIV. With these funds States and territories provide access to HIV clinicians, life-saving and life-extending therapies and a full range of vital coverage completion services to ensure adherence to complex treatment regimens. The State ADAPs provide medications to low-income PLWH who have limited or no coverage from private insurance, Medicare and/or Medicaid.

Throughout and following the ACA implementation, health departments will require capacity-building support in order to create new infrastructure and leverage existing systems to ensure continuous, high quality care for PLWH. The Ryan White Program will continue to serve PLWH in order to ensure that clients do not experience gaps in coverage or access to treatment.

HIV/AIDS PREVENTION AND SURVEILLANCE PROGRAMS

NASTAD requests an increase of $77 million in fiscal year 2016 for CDC's Division of HIV Prevention. The flagship HIV prevention program, HIV Prevention by Health Departments, funds State and local health departments to provide the foundation for HIV prevention and control nationwide. Health departments are the cornerstone implementers of Federal public health policy and are essential to lowering HIV infections. HIV prevention activities and services are targeted to communities where HIV is most heavily concentrated, particularly among racial and ethnic minorities and gay men/MSM of all races and ethnicities.

The number of new HIV infections must decrease to address in order to see meaningful improvements in individual and community level health outcomes, particularly among disproportionately impacted populations. It is increasingly clear that early detection, linkage to and retention in care, and adherence to treatment will suppress individual and community viral loads and reduce the incidence of HIV. Unfortunately, only thirty percent of people living with HIV have an undetectable viral load. Addressing interventions along the HIV care continuum is our newest and most effective tool to get to zero new HIV infections; however, health departments need additional support to successfully implement these strategies.

Robust surveillance systems are essential for high-impact prevention, including using surveillance data for program planning and response, strategically directing resources to populations and geographic areas and linking and retaining individuals in care. Additional resources will allow improvements in core surveillance and expand surveillance for HIV incidence, behavioral risk and receipt of point of care information, including CD4 and viral load reporting. This will, in turn, contribute to improved testing and linkage to care, retention and re-engagement in care, and reducing risk behaviors.

NASTAD requests that the Committee allow States and localities the discretion to use Federal funds to support cost-effective and scientifically proven, syringe services programs (SSPs). Overwhelming scientific evidence has shown SSPs and access to sterile syringes are an evidenced-based and cost-effective means of lowering HIV and hepatitis infection rates, reducing use of illegal drugs and helping connect people to HIV and hepatitis medical treatment, including substance abuse treatment.

VIRAL HEPATITIS PREVENTION PROGRAMS

NASTAD requests an increase of $31.5 million in fiscal year 2016 for the CDC's Division of Viral Hepatitis (DVH). This increase will better enable State and local health departments to provide the basic, core public health services to combat hepatitis, increase surveillance, testing and education efforts nationwide and effectively implement the recommendations set by the IOM's Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C, the Action Plan for Viral Hepatitis, and the CDC and United States Preventive Services Task Force (USPSTF) viral hepatitis testing recommendations for populations with risk factors, including baby boomers. NASTAD requests that CDC dedicate at least $10.5 million for the viral hepatitis prevention coordinators (VHPC) program to support and expand programs in all existing jurisdictions. The IOM report and the Viral Hepatitis Action Plan, set prevention goals, established program priorities and assigned responsibilities for actions to HHS operating divisions, including CDC. In turn, CDC has provided funds to State and local health departments to coordinate prevention and surveillance efforts via the VHPC. For over a decade, the VHPC program has been and remains the only national program dedicated to the prevention and control of the hepatitis epidemics. The CDC has estimated that up to 5.3 million people are living with hepatitis B (HBV) and/or hepatitis C (HCV) in the United States and as much as 75 percent are not aware of their infection. Additionally, recent alarming epidemiologic reports indicate a rise in HCV infection among young people throughout the country. Some jurisdictions have noted that the number of people ages 15 to 29 being diagnosed with HCV infection now exceeds the number of people diagnosed in all other age groups combined—a trend that is following the prescription drug overdose epidemic and increasing use of heroin in rural and suburban areas. NASTAD encourages the committee to prioritize disproportionately impacted populations and increase funding for primary prevention efforts.

As you contemplate the fiscal year 2016 Labor-Health-Education Appropriations bill, we ask that you consider all of these critical funding needs. We thank the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations. Our response to the HIV and hepatitis epidemics in the United States defines us as a society, as public health agencies, and as individuals living in this country. There is no time to waste in our Nation's fight against these epidemics.

[This statement was submitted by Murray Penner, Executive Director, National Alliance of State and Territorial AIDS Directors.]

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PREPARED STATEMENT OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS

Chairman Blunt and members of the Subcommittee, I am Mary Giliberti, Executive Director of NAMI (the National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming fiscal year 2016 bill. NAMI is the Nation's largest grassroots advocacy organization representing persons living with serious mental illnesses and their families. Through our 1,100 affiliates in all 50 States, we support education, outreach, advocacy and research on behalf of persons with mental illnesses such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and major mental illnesses affecting children.

An estimated 11.5 million American adults live with a seriously disabling mental illness, such as schizophrenia, bipolar disorder, and major depression. Based on estimates for 2010, mental disorders accounted for 21.3 percent of all years lived with disability in the United States. Among the top 20 causes of years lived with disability, five were mental disorders: major depressive disorder (8.3 percent of the total), anxiety disorders (5.1 percent), schizophrenia (2.2 percent), bipolar disorder (1.6 percent) and dysthymia (1.5 percent). Suicide is the 10th leading cause of death for adults in the U.S. and the third leading cause of death for adolescents, accounting for the loss of more than 34,000 American lives each year, more than double the number of lives lost to homicide. The social and economic costs associated with these conditions are tremendous. A cautious estimate places the direct and indirect financial costs associated with mental illness in the U.S. at well over $300 billion annually, and it ranks as the third most costly medical condition in terms of overall healthcare expenditure, behind only heart conditions and traumatic injury.

Moreover, these costs are not only financial, but also human in terms of lost productivity, lives lost to suicide and broken families. Investment in mental illness research and services are—in NAMI's view—the highest priority for our Nation and this Subcommittee.

*National Institute of Mental Health (NIMH) Research Funding*

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports a $32 billion overall allocation for the National Institutes of Health (NIH). This increase is needed to prevent the United States from further falling behind China, India and other emerging nations in terms of investments in scientific research. As you know, the President is requesting a $56 million increase for the National Institute for Mental Health (NIMH) for fiscal year 2016, boosting funding for the agency to $1.489 billion. NAMI urges the Subcommittee to fund investments beyond this amount with an overall higher allocation for the entire NIH.

NAMI also supports the President's BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) and the request for a $70 million boost, up to $135 million. The BRAIN Initiative is a multi-agency collaborative with a number of foundations designed to unleash new technologies and undertake basic mapping of circuits and neurons in the most complex organ in the human body.

*Supporting the NIMH 2015 Strategic Plan*

NAMI supports the new 5-year NIMH Strategic Plan and its four overarching goals:

—Leveraging progress in genomics, imaging, and cognitive science to define the biology of complex behaviors,
—Building on the concept of mental disorders as neurodevelopmental disorders to chart trajectories and determine optimal times for interventions,
—Using discoveries to focus on new treatments (and eventually cures) based on precision medicine and moving trials into community settings, and
—Increasing the public health impact of NIMH research through improved services that improve access and quality of care.

*Accelerating the Pace of Psychiatric Drug Discovery*

In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect; failing to relieve symptoms in a significant proportion of patients; or, resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate

novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to identify quickly candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

*Advancing Services and Intervention Research*

NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH funded research is demonstrating progress advancing the health of people with serious mental illness. NIMH needs to advance this research to large-scale clinical trials aimed at reducing premature mortality with people living with serious mental illness.

*Investing in Early Psychosis Prediction and Prevention (EP3)*

As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illnesses such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays in seeking care—up to 2 years in some cases. Such delays result in periods of increased risk for adverse outcomes, including suicides, incarceration, homelessness and in a small number of cases, violence.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through the North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched the Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing promise in detecting risk States for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced FEP.

*Advancing Precision Medicine*

NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria (RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms. Through continued development, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

*Funding for Programs at SAMHSA's Center for Mental Health Services (CMHS)*

As noted above, the costs of untreated mental illness to our Nation are enormous—as high as $300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that across the Nation States and localities devote enormous resources addressing the human and financial costs of untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of "spending money in all the wrong places" is tragic given that we have a vast array of proven evidence-based interventions that we know work such as assertive community treatment (ACT), supported employment, family psycho-education and supportive housing.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental illness. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the increases in funding for the MHBG that this Subcommittee has made in recent years, boosting funding from $420 million in fiscal year 2010, up to its current level of $482.5 million in fiscal year 2015. This increase

has been important to helping States fills gaps in services that have occurred as States cut more than $4 billion from State mental health budgets since the recession began in 2008.

NAMI also supports the 5 percent set aside in the in the MHBG that this Subcommittee enacted in fiscal year 2014 for early intervention in psychosis. As noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment approach, combining evidence-based services into an effective, coordinated package. CSC emphasizes shared decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In 2014, CMHS issued guidance to the States specifying that funding as part of the 5 percent set aside must be used for those who have developed the symptoms of early serious mental illness, not for "preventive intervention for those at high risk of serious mental illness." NAMI supports this guidance and we recommend that the Subcommittee continue this 5 percent set aside for FEP in fiscal year 2016 and beyond. It is critically important for Congress to continue supporting the establishment of evidence-based FEP programs in all 50 States.

NAMI also recommends the following priorities for CMHS for fiscal year 2016:

—Continuation of the Children's Mental Health program at $117 million,

—$10 million in new funding in the President's request for Crisis Systems, an initiative to support States and communities in developing mental health crisis-response systems with ongoing outpatient services and supports,

—A $2 million increase for suicide prevention activities at CMHS, including funding for the Garrett Lee Smith Memorial Act.

—$15 million in funding for States and localities as part of the Assisted Outpatient Treatment (AOT) pilot program as authorized by Congress in Section 224 of Public Law 113–93). We strongly believe that this funding should be used to study the effectiveness of a variety of approaches to engaging people with serious mental illness in treatment, including voluntary approaches for engaging people before they reach the point of requiring court-based interventions.

*Addressing Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care*

The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illnesses and substance use disorders are screened and treated at 126 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to reject the President's proposal to cut this program by $23 million in fiscal year 2016 and fund the PBHCI at $50 million.

*Addressing the Needs of Homeless Individuals Living with Serious Mental Illness*

On any given night, according to 2013 data, 610,042 people are homeless, and 15 percent of these individuals are defined as long-term or chronically homeless. Years of reliable data and research demonstrate that, for single individuals with complex needs due to serious mental illness, the most successful intervention for ending and preventing homelessness is linking housing to appropriate support services. Although there is a need for more affordable housing, funding the supportive services is even more difficult. SAMHSA homeless programs fill a gap created by a preference of HUD to fund housing rental assistance and capital needs. HHS must take responsibility to fund the critically important services that are necessary for programs to be effective. Unfortunately, in 2014 SAMHSA was not able to award any new community-based services grants. The current fiscal year 2015 funding level of SAMHSA homeless programs is $74 million, divided between CMHS and CSAT. NAMI supports an increase for this joint program up to $100 million, equally divided between CMHS and CSAT.

NAMI also supports funding for the PATH program (Projects for Assistance in Transition from Homelessness) that allocates funds by formula to States to serve homeless people with serious mental illness. Eligible services include outreach, screening and diagnosis, habilitation and rehabilitation, community mental health services, substance abuse treatment, case management, residential supervision, and housing. PATH supported programs reached over 192,000 people in fiscal year 2014. Of these, 65 percent were unsheltered at the time of engagement, 42 percent were not engaged in mental illness treatment and 53 percent had co-occurring substance

use disorders. NAMI recommends at least $75 million for the PATH program for fiscal year 2016 (the authorized amount). In fiscal year 2015, the PATH program is funded at $64.6 million.

*Conclusion*

Chairman Blunt, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's fiscal year 2016 bill. NAMI's consumer and family membership thanks you for your leadership on these important national priorities.

[This statement was submitted by Mary Giliberti, Executive Director, National Alliance on Mental Illness.]

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## PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals affected by alopecia areata as you work to craft the fiscal year 2016 L-HHS Appropriations Bill.

### ABOUT ALOPECIA AREATA

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2.1 percent of the population, including more than 6.5 million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

### ABOUT THE FOUNDATION

NAAF, headquartered in San Rafael, California, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and prestigious Research Advisory Councils. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Registry, Biobank and Clinical Trials Network which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (Award Number HHSN268200682279C); NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

### DEIDRE'S STORY

It has been 15 years since I first found the bald patch on my head that would completely change the course of my life. As a student at Florida State University during my junior year I found a perfectly round bald patch while blow-drying my very thick long hair—my pride and joy! Little did I know then the significant effect alopecia areata would have on my life.

I followed the typical patient profile for this disease. I started with one patch the size of a 50 cent piece, which later evolved into patches of varying sizes all over my head, and then to total loss of all scalp hair, which progressed to the most severe form of the disease: total loss of all body hair including my scalp, eyebrows, eyelashes, etc. Recently, my hair has inexplicably started to grow back in a very patchy and strange fashion on my head, while most of my body still remains hairless; a perfect example of the completely unpredictable course of this disease, which can cause significant emotional turmoil and distress for the sufferer.

As a professional woman, this disease has had a severe impact on my life. I have to present a confident image to the outside world. Living in constant fear of being discovered as a bald woman, being thought to be sick, bizarre, or worse has always been on the forefront of my mind.

The exorbitant cost for treatments such as cortisone injections, extremely painful with questionable efficacy, has been an issue for me along with the expensive cranial prosthetics. Over the course of the years these have cost me thousands of dollars. If a lawyer like myself has financial difficulty when it comes to paying for treatments and prosthetics (which are not covered by insurance due to lack of CMS coverage benefits for those with alopecia areata), can you imagine the plight facing those patients that live on limited or fixed income?

The fact that there is so little known about the causes or possible treatments/cure for this disease only adds to the pain and suffering. This is a disease that alters the way you see yourself and the way the outside world treats you, and also causes significant and often debilitating emotional distress. The fact that there is little that can currently be done adds to that pain and suffering. Patients face a bleak outlook. For me, it has been a constant battle. I have not lived a single moment in the 5,475 days since that I have not looked in the mirror and wanted to scream or cry, not a single day that I haven't thought that I am damaged, abnormal, or ugly because of my hair loss, not a single day that I haven't worried about how a client, colleague, friend, or love-interest might see and judge me. Many will say to me that "it is only hair" or "at least it's not cancer." These comments only frustrate and upset me more. The feelings of being ostracized as an outcast can become deafening, even for a confident, intelligent professional. I shudder to think how others who don't possess my strength of character handle the stresses of this disease.

It is only with additional funding for research that we might hope to improve the lives of the millions in the U.S. living with alopecia areata. Few have even heard of the disease. That fact alone creates additional stresses and difficulties for those of us with the disease, constantly having to explain what is "wrong" with us. Increased research into viable treatment options and a potential cure could significantly impact millions of lives, from small children to adults, facing the constant battle that comes from a total loss of self image and confidence.

I thank you on behalf of myself and of the entire alopecia areata community for consideration of NAAF's requests.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into alopecia areata, skin, and autoimmune disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

—The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) less than in fiscal year 2003.

—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is dou-

ble the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a modest alopecia areata research portfolio, and the Foundation works closely with NIH to advance critical activities. NIH projects, in coordination with the Foundation's TDP, have the potential to identify biomarkers and develop therapeutic targets. In fact, researchers at Columbia University Medical Center (CUMC) have identified the immune cells responsible for destroying hair follicles in people with alopecia areata and have tested an FDA-approved drug that eliminated these immune cells and restored hair growth in a small number of patients. This huge breakthrough lead to NIAMS providing a research grant to the researchers at Columbia to continue this work. In this regard, please provide NIH with meaningful funding increases to facilitate growth in the alopecia areata research portfolio.

One exciting emerging opportunity is the new Accelerating Medicines Partnership (AMP) that was recently announced by NIH. This effort is outcomes-oriented and based on a public private-partnership model. Industry, patient organizations, and researchers work together to conduct research with the goals of improving treatments and diagnostic tools. Rheumatoid arthritis is one of the diseases being examined in the first round of study, which should generate opportunities for alopecia areata due to the similarities between the conditions. Please support AMP and encourage NIH to expand activities in this area, particularly when there is research overlap between conditions

ADDITIONAL ACTIVITIES

FDA nominated alopecia areata as a potential condition for specific review through the Patient-Focused Drug Development Initiative (PFDDI). This is because many of the impacts of alopecia areata have to be reported by patients and cannot be measured biologically. While we appreciate that FDA falls under the guise of the Agriculture Appropriations Subcommittee, we ask that you work with your colleagues on the Appropriations Committee to support this important program. Further, FDA should be encouraged to review all originally-nominated conditions in a timely manner so the PFDDI can continue to move forward.

Additionally, Congressman Jared Huffman (D–CA–2nd) is working with the community on introducing a bill that will allow for Medicaid to cover a significant portion of the cost of a cranial prostheses when a doctor deems it medically necessary. The disease can be incredibly debilitating not only physically and psychologically but financially as well. This bill is designed to help lessen the burden placed upon those effected by the disease. Please consider cosponsoring the bill when it is introduced.

Thank you for your time and your consideration of the community's requests.

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CLINICAL NURSE SPECIALISTS

The National Association of Clinical Nurse Specialists (NACNS) is the voice of more than 70,000 clinical nurse specialists (CNSs). CNSs are licensed registered nurses who have graduate preparation (master's or doctorate) in nursing as a clinical nurse specialist. They have unique and advanced level competencies that meet the increased needs of improving quality and reducing costs in today's healthcare system. CNSs provide direct patient care, including assessment, diagnosis, and management of patient healthcare issues. They are leaders of change in health organizations, developers of scientific evidence-based programs to prevent avoidable complications, and coaches of those with chronic diseases to prevent hospital readmissions. CNSs are facilitators of multidisciplinary teams in acute and chronic care facilities to improve the quality and safety of care, including preventing hospital acquired infections, reducing length of stays, and preventing hospital readmissions.

The NACNS urges the subcommittee to fund the Title VIII Nursing Workforce Development Programs at $244 million in fiscal year 2016.

According to the Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow 19.4 percent from 2012 to 2022, outpacing the 11 percent average for most other occupations. BLS also projects that this growth will result in

1,052,600 job openings, representing one of the largest numeric increases for all occupations. With technological advancements driving growth in treatments, preventive care being emphasized more, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year, these are the factors fueling this projected increase in new RN jobs. A particularly alarming element of the probable RN job openings is the anticipated loss of nursing expertise due to the need to replace some 525,700 jobs vacated by RNs who are expected to leave the profession and/or retire from the labor force by 2022.

BLS notes that the healthcare sector is a critically important industrial complex for the Nation. It is at the center of the economic recovery with the number of jobs climbing steadily. Growing even when the recession began in December 2007, healthcare jobs are up nationwide. Nearly five million workers are in hospital settings, which often are the largest employer in a State. Healthcare has been a stimulus program generating employment and income, and nursing is the predominant occupation in the healthcare industry with more than 4.265 million active, licensed RNs in the United States in 2015.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, healthcare in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. NACNS applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

The current Federal funding falls short of the healthcare inequities facing our Nation today. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a more than 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

NACNS believes that the deepening health inequities, inflated costs, and poor quality of healthcare outcomes in this country will not be reversed until the concurrent shortages of nurses, advanced practice registered nurses, and qualified nurse educators are addressed. Your support will help ensure that future nurses exist who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the healthcare reality facing the Nation today, an under resourced nurse education and its adverse effect in healthcare generally will be difficult to avoid.

In closing, NACNS urges the subcommittee to maintain the Title VIII Nursing Workforce Development Programs by funding them at a level of $244 million in fiscal year 2016.

[This statement was submitted by Peggy Barksdale, MSN, RN, OCNS-C, CNS-BC, President, National Association of Clinical Nurse Specialists.]

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

### INTRODUCTION

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee: on behalf of our Nation's health centers, we wish to thank you for the opportunity to submit testimony for the record as the committee begins its work on the fiscal year 2016 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

### HEALTH CENTERS-GENERAL BACKGROUND

Health centers are community-owned and operated non-profit entities providing primary medical, dental, and behavioral healthcare as well as pharmacy and a variety of enabling and support services. This year marks a momentous occasion in health center history as we celebrate 50 years since the first health centers opened their doors in Boston and the Mississippi Delta. Today, what began as a small demonstration project has evolved into the largest and most successful primary healthcare system in the United States. Now, there are nearly 1,300 health centers operating in more than 9,000 urban and rural communities nationwide, serving as the "healthcare home" for more than 22 million patients including nearly 7 million children and more than 268,000 veterans. Health centers operate in all 50 States and nearly every Congressional district.

By statute and mission, health centers are located in medically underserved areas (or serve medically underserved populations) and are governed by patient-majority boards to ensure they are responsive to the needs of each individual community they serve. Health centers offer comprehensive care to all residents of the community who seek their care, regardless of ability to pay or insurance status and offer services on a sliding fee scale. Health centers' unique model of care has enabled us to save the entire health system approximately $24 billion annually. Health center care reduces preventable hospitalizations and emergency department (ED) use, as well as the need for more expensive specialty care. The services provided at health centers save $1,263 per patient per year compared to expenditures for non-health center users.

In addition to reducing costs, health centers also serve as small businesses and economic drivers in their communities. Health centers employ 156,000 individuals and generate an estimated $26.5 billion in needed economic activity for communities that need it the most.

FISCAL YEAR 2015 FUNDING BACKGROUND

In fiscal year 2015, health centers received a total of $5.1 billion in total Federal funding. This includes $1.49 billion in discretionary funding provided by the Health Resources and Services Administration (HRSA) and $3.6 billion in mandatory funding for health centers through the final year of the Health Center Fund. We want to thank the members of this Subcommittee for their strong support of health centers within the Consolidated and Further Continuing Appropriations Act of 2015 to ensure health center funding reaches communities in need.

HEALTH CENTER FUNDING CLIFF AND FISCAL YEAR 2016 FUNDING REQUEST

On September 30, 2015, unless Congress acts, the Health Center Fund will expire. We refer to this as the "health center funding cliff." The Health Center Fund is one portion of the two Federal funding streams available to health centers, and in fiscal year 2015 the fund represents approximately 70 percent of the total funding made available to health centers by Congress. Failure to continue this funding would prove to be devastating to the program. A recent report issued by NACHC, entitled Community Health Centers: Past, Present and Future: Building on 50 Years of Success, reveals the funding cliff would cause 7.4 million patients to lose access to care at their local health center. Nearly 57,000 clinicians and staff would also lose their jobs. These reductions would take place in the first year alone and would be compounded in future years. In this scenario, every health center in more than 9,200 communities nationwide would be affected, and the funding cut would force health centers to close sites, reduce staff, or discontinue services. HHS Secretary Burwell emphasized these consequences in recent testimony, where she warned that in addition to the job losses, the cliff would lead to more than 2,000 health center site closures.

With these potential consequences in mind, that Health Centers are respectfully requesting Congress and this Subcommittee work to ensure funding for the Health Centers Program remains whole and does not sustain any funding reductions in fiscal year 2016. Continued funding for the Health Centers Program at the fiscal year 2015 program level of $5.1 billion will preserve and continue the high quality cost-effective primary care offered today at health centers across the country. If the Subcommittee chooses to keep discretionary funding level with the fiscal year 2015 discretionary allocation of $1.49 billion for Health Centers in fiscal year 2016, we would request you work collaboratively with the Senate HELP and Finance Committees to avert the $3.6 billion shortfall related to the expiration of the Health Center Fund.

There have been clear signs over the last year that Congress wants to address the funding cliff. 250 House members and 66 Senators signed letters to Congressional leaders highlighting the important role of health centers and calling for a bipartisan solution to this precipitous drop in funding. The Senate letter was led by you, Chairman Blunt and we especially want to thank you for your leadership on this issue. Legislatively, the House has acted to address the Health Center Funding cliff by extending the Health Center Fund for an additional 2 years as part of H.R. 2, the Medicare and CHIP Reauthorization Act of 2015. We view H.R. 2 as one of the very few opportunities to address the funding cliff this year without complicating or severely impacting the discretionary appropriations process due to the budget caps. If the Senate does not act to swiftly pass H.R. 2, access to healthcare for millions of people—including 4.3 million women and 2.5 million children—will be lost in a few short months. We strongly urge you to stand with the House and vote in support of H.R. 2.

CONCLUSION

We understand this Subcommittee must make difficult budgetary decisions as you work within the funding limits set for the subcommittee's bill. As the fiscal year 2016 appropriations process moves forward, we urge you to keep the potential impact of the funding cliff in mind. Not only is access to healthcare for current health center patients at risk, but those 62 million Americans who still lack regular access to primary care and may be seeking care at health centers will certainly have no place to go. Without access to their local health center, many individuals located in medically underserved communities will seek care in emergency departments and hospitals, often waiting until they are sicker get treatment. This will mean poorer health for these patients and much higher costs to the system.

With our unique model of care, Health Centers can help address these primary care demands in a cost effective manner. However, Health Centers cannot continue to deliver results without a sound financial base and continued future certainty. We are extremely grateful for your past support and ask for the Subcommittee's continued support for the Health Center program. We look forward to working with you and thank you for your consideration.

[This statement was submitted by Daniel R. Hawkins, Jr., Senior Vice President, Public Policy and Research, National Association of Community Health Centers.]

## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

The National Association of County and City Health Officials (NACCHO) is the voice of the 2,800 local health departments across the country. City, county, metropolitan, district, and tribal health departments work to ensure the public's health and safety. On behalf of local health departments, NACCHO submits the following requests:

*Public Health Emergency Preparedness—Centers for Disease Control and Prevention (CDC)*

NACCHO urges the Subcommittee to provide $675 million for the Public Health Emergency Preparedness (PHEP) cooperative agreements in fiscal year 2016. Recently, health departments have responded to the threat of infectious diseases like Ebola and measles and more severe and frequent weather events. Emergency Federal funding to respond to the unexpected threat of Ebola is much appreciated. However, sustained funding to support local preparedness and response capacity is needed to make sure that every community is prepared for disaster. A majority of local health departments rely solely on Federal funding for emergency preparedness. PHEP protects communities by providing funding to strengthen local and State public health departments' capacity and capability to effectively respond to public health emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies.

Hospital Preparedness Program—Assistant Secretary for Preparedness and Response (ASPR)

The experience of responding to Ebola shows the importance of seamless public health and hospital collaboration. NACCHO urges Congress to begin restoring funding to the Hospital Preparedness Program (HPP) by increasing it to $300 million in fiscal year 2016. HPP is vital because this program provides grant funding to build healthcare coalitions that enhance regional and local hospital preparedness and improve overall surge capacity. NACCHO also urges Congress to request information from ASPR on how State HPP funding is distributed, including how much is allocated to local health departments and on what basis or formula each State allocates funds.

*Medical Reserve Corps—ASPR*

In 2002, the Medical Reserve Corps (MRC) was created after the terrorist attacks of 9/11 to establish a way for medical, public health, and other volunteers to address local health and preparedness needs. These highly skilled volunteers include doctors, dentists, nurses, pharmacists, and other community members. The program is comprised of 200,000 volunteers enrolled in 1,000 units in all 50 States and territories. Two-thirds of MRC units are coordinated by local health departments. NACCHO opposes the President's proposed cut to MRC and requests $11 million in funding in fiscal year 2016 to restore the program's funding to that of fiscal year 2014.

*Section 317 Immunization Program—CDC*

Immunizations continue to be one of the most cost-effective public health interventions. In an effort to prevent and control the spread of infectious diseases, the promotion of vaccinations is needed more now than ever. During the 2014 measles outbreak the United States experienced a record number of cases, with 644 cases from 27 States, according to CDC. The rapid spread of this disease illustrates the need for a strong public health immunization infrastructure to prevent disease in both children and adults. The 317 Immunization Program funds vaccine purchase for at-need populations and immunization program operations, including support for implementing billing systems for immunization services at public health clinics to sustain high levels of vaccine coverage. NACCHO opposes the President's $50 million cut in fiscal year 2016 and supports the $8 million included in the President's budget to build health department capacity for billing.

*Foundational Capacities—CDC*

Foundational capacities is a new program to strengthen public health practice at State and local health departments and build core capacity in alignment with national accreditation standards. As healthcare and public health agencies become more interconnected, it is essential that local health departments have the necessary capacity to engage in population health improvement. Therefore, NACCHO supports the President's request of $8 million for the Foundational Capacities Program.

*Chronic Disease—CDC*

NACCHO appreciates efforts made by the Subcommittee to ensure that chronic disease funding reaches the local level, where behavior and environments that prevent chronic disease are implemented. NACCHO encourages continuation of this approach.

*Partnerships to Improve Community Health*.—NACCHO urges the Subcommittee to provide $80 million to support the Partnerships to Improve Community Health program in fiscal year 2016. Grantees lead efforts to reduce tobacco use, increase physical activity and expand access to nutrition in order to reduce the prevalence of chronic diseases, such as heart disease and diabetes, through collaboration with community partners and businesses. These efforts complement the other CDC chronic disease programs listed below.

*Heart Disease and Stroke Prevention*.—NACCHO urges the Subcommittee to continue to support Heart Disease and Stroke Prevention at $130 million in fiscal year 2016. The Heart Disease and Stroke Prevention program supports evidence-based programs to reduce disease. It requires States to fund local health departments to target at risk populations and promote healthy eating and exercise and reduce sodium intake, which can lead to high blood pressure and heart disease.

*Diabetes Prevention*.—NACCHO urges the Subcommittee to continue support for Diabetes Prevention at $150 million in fiscal year 2016. Diabetes affects more than 20 million people and can cause serious health complications including heart disease, blindness, kidney failure, and amputations. New funding in fiscal year 2015 to 21 States and four cities requires States to fund local health departments to target at risk populations and implement evidence-based approaches to support diabetes self-management education and lifestyle change.

*Prevention and Public Health Fund (HHS)*

In fiscal year 2016, NACCHO requests $1 billion for the Prevention and Public Health Fund (PPHF). The PPHF supports core public health programs such as immunization, chronic disease prevention, lead poisoning prevention, and early and rapid detection of diseases and injury.

In conclusion, thank you for your attention to these recommendations for programs that protect the public's health and safety.

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to submit this testimony in support of fiscal year 2016 funding for the Foster Grandparent Program (FGP), the oldest and largest of the three programs known collectively as the National Senior Volunteer Corps, or "Senior Corps," which are authorized by Title II of the Domestic Volunteer Service Act (DVSA) of 1973, as amended and administered by the Corporation for National and Community Service (CNCS). This year the Foster Grandparent Program is celebrating its 50 year anniversary. I respectfully request that the Subcommittee provide at least $107,702,000 for FGP

in fiscal year 2016. The National Association of Foster Grandparent Program Directors (NAFGPD) is a membership-supported professional organization who administers Foster Grandparent Programs nationwide, as well as local sponsoring agencies and others who value and support the work of FGP.

Mr. Chairman, I would like to begin by thanking you and the distinguished Members of the Subcommittee for your steadfast support of the Foster Grandparent Program. No matter what the circumstances, this Subcommittee has always been there to protect the integrity and mission of our program. Our volunteers and the children they serve across the country are the beneficiaries of your commitment to FGP, and for that we thank you. However, your help and support are still needed today. The Administration's fiscal year 2016 Budget Request would reduce funding for FGP by $1,550,000 million. The FGP has seen a 10 percent reduction in funding over the past 5 years. Even with this reduced level of funding, we continue to serve at-risk youth and seniors across the Nation. However, if our funding continues to be cut, it will greatly impact those individuals who we serve.

For 50 years, the Foster Grandparent Program has made efficient use of Federal dollars to make real changes in children's lives. FGP has thousands of supporting organizations in communities across the country. The program has never been accused of mismanagement or waste, and has garnered respect from both Republicans and Democrats alike.

A 2006 national performance measurement survey of the Foster Grandparent program found that 81 percent of children served demonstrated improved academic performance; 90 percent demonstrated increased self-image; 56 percent improved school attendance and 59 percent were reported to have a reduction in risky behavior.

Foster Grandparent Programs represent the best in Federal partnerships with local communities, with Federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Foster Grandparent Programs have forged partnerships with thousands of community organizations that value and support the Foster Grandparents' service. FGP serves local communities in a high quality, efficient and cost-effective manner, saving local communities money by helping our older volunteers stay independent and healthy and out of expensive in-home or institutional care. The value local communities place on FGP and its multifaceted services is evidenced by the large amount of cash and in-kind donations contributed by communities to support FGP.

The relationships between FGP volunteers and the children they serve is so extremely special. FGP has been creating meaningful, life-changing bonds between seniors and children for almost 50 years. This has been incredibly effective for these children, and will continue to be as long as FGP is continued to be funded at its current level.

Mr. Chairman, in closing I would like reiterate NAFGPD's opposition to the funding cut to the Foster Grandparents Program the President Obama included in his fiscal year 2016 budget request because it would result in fewer hours of service given to children who have special or exceptional needs, who are at academic, social, or financial disadvantage. I ask your Subcommittee to maintain level funding for this very important program. I want to thank you again for the Subcommittee's support and leadership for Foster Grandparent Programs over the years. NAFGPD believes that you and your colleagues in Congress appreciate what our senior volunteers accomplish every day in communities across the country.

*FGP: An Overview*.—The Foster Grandparent Program was established in 1965 and was the first federally funded, organized program to engage older volunteers in significant service to others. From the 20 original programs based totally in institutions for children with severe mental and physical disabilities, FGP now comprises 313 programs in every State and the District of Columbia, Puerto Rico, and the Virgin Islands. These programs are now primarily in community-based child caring agencies or organizations, where most special needs children can be found today, and are administered locally through a non-profit organization or agency and Advisory Council comprised of community citizens dedicated to FGP and its mission.

*FGP: The Volunteers*.—In fiscal year 2014, 25,190 FGP volunteers, of whom 760 were veterans, contributed 23 million hours of service. Foster Grandparents served 189,100 children and youth with exceptional needs, including mentoring 110,300 children. 2,700 of these children served were from military families. The value of this service is over $500 million and represents more than a four-fold return on the Federal dollars invested in FGP. The program gives Americans 55 years of age or older, who are living on incomes at or less than 200 percent of the poverty level, the opportunity to serve 15 to 40 hours every week. FGP provides intensive preservice orientation and at least 48 hours of ongoing training every year to keep volunteers current and informed on how to work with children who have special needs. Through their service, our FGP volunteers say they feel and stay healthier, that

they feel needed and productive. Most importantly, they leave to the next generation a legacy of skills, perspective and knowledge that has been learned through experience.

*FGP: The Children*.—FGP also provides person-to-person service to children and youth under the age of 21 who have special or exceptional needs, many of whom face serious, often life-threatening challenges. With the changing dynamics in family life today, many children with disabilities and special needs lack a consistent, stable adult role model in their lives. The Foster Grandparent is very often the only person in a child's life who is there every day, who accepts the child, encourages him/her no matter how many mistakes the child makes, and focuses on the child's successes.

[This statement was submitted by Kristen Tracy, President, National Association of Foster Grandparent Program Directors.]

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF NUTRITION AND AGING SERVICES PROGRAMS

Chairman Blunt, Ranking Member Murray: On behalf of the National Association of Nutrition and Aging Services Programs (NANASP), an 1,100-member nonpartisan, nonprofit, membership organization for national advocates for senior health and well-being, we thank you for the opportunity to offer testimony in support of the Department of Health and Human Services' proposed increase of $59.9 million for Older Americans Act Title III(C) senior nutrition programs.

Older Americans Act congregate and home-delivered meals programs are provided in every State and congressional district in this Nation. Approximately 2.4 million seniors in 2014 received these services. As the Administration for Community Living (ACL) Congressional Justification States, studies have found that 50 percent of all persons age 85 and over need help with instrumental activities of daily living, including obtaining and preparing food. Older Americans Act nutrition programs address these concerns. Thus, these meal recipients are able to remain independent in their homes and communities and are not forced into hospitals or nursing homes due to an inability to maintain a proper diet.

In addition, for participants in the congregate program in particular, the nutrition programs provide a daily opportunity for socialization, preventing isolation and promoting health and wellness. For home-delivered meals recipients, their delivery driver may be the only person they see all day—this wellness check is also key to their health.

In fiscal year 2014 and fiscal year 2015, Older Americans Act Title III(C) programs received appropriations in the amount of $814.6 million. Though we are thankful that this represents an increase from fiscal year 2013, unfortunately, this does not keep pace with the rising cost of food, inflation, and the growing numbers of older adults. In fact, year over year, the number of older adults receiving meals is shrinking even as the need is growing.

The President's fiscal year 2016 funding request includes:

—$39.9 million for congregate and home-delivered meals

—$20 million for evidence-based demonstration grants

The additional $39.9 million for congregate and home-delivered meals would allow ACL to maintain the total number of meals projected to be provided in fiscal year 2015. This does not keep up with the growing demand for services, but it would at least prevent further reductions in services. As we saw in fiscal year 2013 when sequestration was in effect, our programs had lengthy wait lists and some sites even closed for lack of funding. One program created its first wait list in over 90 years of operation. We cannot afford to continue to backslide, especially as another round of sequestration looms on the horizon.

Further, these services are designed to target those in the "greatest social and economic need," according to the Older Americans Act and to actual practice in the field. According to ACL studies, approximately two-thirds of home-delivered meal recipients have annual incomes of $20,000 or less. Sixty-two percent of these recipients report that these meals represent at least half their food intake each day. And yet, the Government Accountability Office found that only about 9 percent of low-income older adults are even receiving meals services. For a small investment, more at-risk older adults could receive nutritious meals.

NANASP also supports evidence-based demonstration grants for senior nutrition programs. It is important that programs be as modern as possible and that all funds that these programs have are spent effectively and wisely. Many programs are already using innovative and cost-effective practices; they just need to be expanded and replicated at the national level. Further, it is important to ensure that programs are ready to meet the demands of the boomer population aging into services

as caregivers and recipients who are accustomed to different ways of interacting with providers, such as "apps," Facebook, and websites.

Investing in these programs would be cost-effective because many common chronic conditions such as hypertension, heart disease, diabetes, and osteoporosis can be effectively prevented and treated with proper nutrition. The Academy of Nutrition and Dietetics estimates that 87 percent of older adults have hypertension, high cholesterol, diabetes, or some combination of all of these. These seniors need healthy meals, access to lifestyle programs, and nutrition education and counseling to avoid serious medical care.

Data from ACL's National Survey of Older Americans Act Participants shows that congregate and home-delivered meals recipients are significantly less healthy than older adults in general. About 57 percent of congregate and 72 percent of home-delivered recipients have five or more chronic conditions. About 32 percent of congregate and 51 percent of home-delivered recipients take over six medications per day and some take as many as 30 medications.

Older adults who are not receiving proper meals can also become malnourished and undernourished. This makes it harder for them to recover from surgery and disease, makes it more difficult for their wounds to heal, increases their risk for infections and falls, and decreases their strength that they need to take care of themselves. Malnourished older adults are more likely to have poor health outcomes and to be readmitted to the hospital—their health costs can be 300 percent greater than those who are not malnourished on entry to the healthcare system.

Access to Older Americans Act meals is essential to keeping these older adults out of costly nursing facilities and hospitals. A senior can be fed for a year for about $1,300. This $1,300 is the same as the cost of a week in a nursing home or 1 day in the hospital. The cost savings to Medicare and Medicaid that this creates cannot be over-emphasized. One study estimates that for every dollar invested in the Older Americans Act nutrition programs, Medicaid saves $50.

For over 40 years, the Older Americans Act nutrition programs have been serving older adults who are frail, isolated, and in great need of assistance. With more than 10,000 seniors turning 65 every day, now is the time to provide a greater investment in these proven and cost-effective programs.

Thank you for your past and future support.

[This statement was submitted by Ann Cooper, Chair, and Robert Blancato, Executive Director, National Association of Nutrition and Aging Services Programs.]

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF RSVP DIRECTORS

I am Betty Ruth, President of the National Association of RSVP Directors (NARSVPD). On behalf of NARSVPD, I appreciate the opportunity to submit testimony about the funding level for the RSVP program that is included in the Administration's fiscal year 2016 budget proposal.

RSVP is a senior volunteer program administered by the Corporation for National and Community Service (CNCS). It provides opportunities for people 55 and over to make a difference in their communities through volunteer service. RSVP offers maximum flexibility and choice to its volunteers. It matches the personal interests and skills of older Americans with opportunities to help solve community problems. It offers supplemental insurance while volunteers are serving, pre-service orientation, and on-the-job training from the agency or organization where volunteers are placed. RSVP volunteers get no stipend but are eligible for reimbursement for meals and mileage, as long as program budgets allow for it.

RSVP is not means tested and recruits volunteers without regard to income. Most serve between 10 and 40 hours a week, but there is no set schedule. Because they are retired, volunteers can meet needs that occur during the 8-5 workweek, when offices are open for medical appointments, tax aid, meal delivery and other basic human needs categories. Who, other than RSVP volunteers are readily available to take on those tasks?

RSVP is cost-effective. The average annual cost per volunteer is $202. Independent Sector values an hour of volunteer service at $22. Using this multiple, RSVP volunteers provide about $900 million worth of service to the Nation each year. RSVP grantees must provide a match. The required non-Federal share is a minimum 10 percent of the total grant in year 1, 20 percent in year 2, and 30 percent in year 3 and all subsequent years. Grants are awarded for a period of up to 3 years.

RSVP volunteers improve the lives of their neighbors and friends every day by meeting the needs of their communities. They help them prepare their tax returns, provide needed transportation services, offer respite to caregivers, deliver health

and nutrition services, support veterans and military families, volunteer in parks, participate in disaster prevention and relief activities, and many other activities. The key point is that RSVP is flexible and volunteers can be recruited and deployed to meet a wide variety of community challenges.

For example:

—At the Athens-Limestone County, Alabama RSVP, more than 350 volunteers provide transportation to veterans needing assistance to medical visits and food shopping. RSVP volunteers serve as school tutors assisting K—6th grade at-risk students to improve math and reading skills during the school year. Twenty-five IRS certified RSVP volunteers provide income tax assistance annually to more than 2000 low income and elderly taxpayers and 247 veterans and helped secure refunds of almost $2.3 million. Returns are e-filed at no cost to the needy taxpayers. Without this service many taxpayers would unable to afford filing their tax returns. Locally this is a boost to the economy. RSVP volunteers provide weekly respite for caregivers of mentally and physically challenged family members. RSVP volunteers continually provide transportation for the isolated needy elderly and deliver meals to the homebound elderly.

—In Mississippi, the RSVP of Harrison County partners with many nonprofit organizations including Shepherd of the Gulf to address homelessness. Hundreds of Gulf Coast's homeless, many of them veterans, camp out in the woods. RSVP volunteers venture into the woods to distribute blankets, food, household items, and other supplies to this population of homeless campers. For many of these people, RSVP volunteers are their only communication outside of the woods. RSVP volunteers promote community participation and donations from Gulfport citizens, and sponsor annual events this often-invisible population, including Picnic in the Park, Thanksgiving in the Woods, and Campers' Christmas. They distribute food, clothing, and other items.

—In response to the need to address the food insecurity rate facing the Baltimore region, Baltimore City RSVP and Baltimore County RSVP partnered to create the Baltimore RSVP Hunger Corps. In the Baltimore region the food insecurity rate for the region is 15.9 percent. In the Baltimore RSVP Hunger Corps volunteers are solely dedicated to service that 1) increases the availability of nutritious food to impoverished families; 2) increases the capacity of organizations working to decrease food insecurity; 3) educates the public on nutrition and healthy eating behaviors and; 4) improves access to nutritious food. Over 100 RSVP volunteers have served in the Baltimore region with partner organizations such as the Maryland Food Bank and First Corinthians Church. More than 5500 individuals or families received food assistance such as food packages or emergency food assistance in 2014. Additionally, over 39,000 seniors received meals. These dedicated senior volunteers served nearly 10,000 hours.

RSVP expands the capacity of non-profit agencies and local and county governments.

—RSVP of North Central Washington, a program of the Chelan Douglas Community Action Council, serves six counties in North Central Washington. RSVP volunteers work with local faith-based organizations to provide weekend food to hungry school-age students in the Wenatchee and East Wenatchee area. Starting with two congregations matched with two local elementary schools, the Packing Friendship program, with the support of RSVP, has grown to 18 congregations serving 18 elementary schools, providing food to approximately 325 students each week. Participating congregations collect food donations from their members and volunteers pack bags of food for needy students in local elementary schools. RSVP has facilitated the recruitment of congregations, matching congregations with local elementary schools, and recruiting volunteers to participate in the program. The program has created new sources of food for the community, new volunteers, and new collaborations between RSVP, local faith-based organizations, and local schools.

—The Southeast Missouri Area Agency on Aging RSVP partnered with the Cape Girardeau Parks and Recreational Department on the 2014 Annual Friends of the Parks Day. More than 1,700 volunteers removed three tons of debris in 12 areas of the town. They helped clean and beautify the community by planting trees and flowers, picking up trash, cleaning trails and creeks, removing graffiti, recycling, and conserving natural resources. RSVP/VIC provided 76 RSVP Volunteers to assist with this beautification project. Cape Girardeau is one of the most highly impoverished areas of the State of Missouri. RSVP volunteers also address food security and hunger issues for more than 1,600 individuals.

RSVP efficiently deploys 232,000 volunteers in more 625 programs that support the efforts of 38,000 community organizations across the Nation. In fiscal year 2014, RSVP volunteers delivered an estimated 40.4 million hours of service in their com-

munities. Working through such networks as Area Agencies on Aging, city and county governments, local United Way organizations, social service agencies, faith-based organizations, and many others, RSVP volunteers served 329,000 veterans in activities such as transportation and employment service referrals; mentored more than 78,000 children; provided independent living services to 797,000 adults, primarily frail seniors; provided respite services to nearly 20,300 family or informal caregivers; engaged 20,100 veterans who served as RSVP volunteers and leveraged an additional 18,500 volunteers to support RSVP activities such as delivering meals to those in need and tutoring at-risk children.

RSVP helps seniors to live independently in two ways: volunteering helps keep seniors vibrant and RSVP volunteers help meet the needs of seniors to keep them in their homes.

—RSVP of Clay, Effingham, Moultrie, and Shelby Counties, sponsored by CEFS Economic Opportunity Corporation in Illinois has 85,044 individuals aged 65 and above, many of whom are living alone. Many of these individuals are disabled or have health issues that prevent them from driving or preparing meals on their own. RSVP partnered with 12 area organizations to provide meals and companion services to more than 600 at- risk seniors. Five days each week, 215 RSVP volunteers delivered meals and visited with 613 frail, elderly clients. The result of this intervention is 55 percent or 337 seniors reported that they had increase social support due to the service of RSVP volunteers and 100 percent of the seniors said the extra meals were necessary for them to stay independent.

Keeping seniors productively engaged and out of adult day care saves them and their families substantial expense. The cost of a semi-private room in a nursing home (national annual median rate) is $75,555. The national annual median rate for a private room is $83,950. (See Genworth Financial, Cost of Care Survey 2013). In many States, it costs more to put one senior in a nursing home than it does to support an entire RSVP program for a whole year. The average Federal RSVP grant is about $75,000.

RSVP has the largest rural footprint of any CNCS program and is an important source of disaster relief services in many communities.

—In Rhode Island, The East Bay RSVP service area runs along Narragansett Bay and the Atlantic Ocean. It is imperative to have trained volunteers in this service area should disaster strike. More than 30 volunteers have been trained in disaster preparedness in coordination with the American Red Cross. These volunteers are ready to serve in shelters in case of a disaster, food distribution, and donation management. They also work to assist neighborhood crime watches, disaster preparedness efforts and emergency response assistance.

—In the year following the 2013 tornado, more than 90 volunteers from RSVP of Central Oklahoma have contributed 4,515 hours to nine nonprofit and State organizations working in the recovery effort. RSVP volunteers answered disaster hotlines, performed follow-up calls to families affected by the disaster, served food and provided companionship at day shelters, provided survivors with rides to medical appointments, and collected and distributed donated goods to disaster survivors. During the coming year, volunteers with the RSVP of Central Oklahoma will continue to participate in disaster recovery projects, and will prepare and distribute disaster-ready kits to families and elderly persons in Oklahoma's tornado-prone communities. Believing that public/private partnerships strengthen community impact, the Shell Company of the Americas contributed $50,000 to support the vital disaster recovery and preparedness services being provided by the RSVP of Central Oklahoma.

RSVP programs like the one in Manhattan, Kansas also support veterans and military families.

—It organizes volunteers into a Cookie Brigade to bake and deliver homemade cookies to the USO twice a month with an average of over 13,000 cookies delivered annually. Volunteers make cards to welcome more than 200 new soldiers a month to the Fort Riley Military Post. Volunteers knit/crochet hats, booties, and blankets for babies delivered at the Irwin Army Community Hospital. RSVP and the Kiwanis Club of Manhattan have teamed up to encourage local residents to fly the American Flag on five major holidays: Memorial Day, Flag Day, Independence Day, Labor Day, and Veterans Day.

RSVP is a "destination" for retiring "baby boomers." 10,000 Baby Boomers are retiring every day and will do so for the next 20 years. RSVP is the only national program able to place large numbers of senior volunteers in high quality volunteer positions.

The National Association of RSVP Directors (NARSVPD) seeks an fiscal year 2016 funding level of $63 million for RSVP. This is $15 million above the President's request and would restore funding for RSVP to the level it enjoyed in fiscal year 2010

and would provide for an additional 75,000 volunteers. NARSVPD also proposes that this increase be allocated to strengthen existing RSVP programs.

For additional information, contact: Betty Ruth, President, NARSVPD or Gene Sofer, Washington Representative.

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PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE HEAD INJURY ADMINISTRATORS

Dear Chairman Roy Blunt and Ranking Member Patty Murray: On behalf of the National Association of State Head Injury Administrators (NASHIA), thank you for the opportunity to submit testimony regarding the fiscal year 2016 appropriations for programs authorized by the Traumatic Brain Injury (TBI) Act within the Department of Health and Human Services (HHS). We were pleased that Congress passed the TBI Act Reauthorization Act of 2014 to continue the ability to fund programs to expand capacity within States for TBI rehabilitation and community services, as well as prevention, public education and other assistance provided by the Centers for Disease Control and Prevention's National Center for Injury Prevention and Control.

The legislation also removed Health Resources and Services Administration (HRSA) language from the sections authorizing appropriations for the State Grant and the Protection and Advocacy (P&A) Grant programs to give the Secretary of the HHS the authority to place these programs within the Administration as she sees fit.

NASHIA supported this language change and furthermore, recommends transferring the HRSA TBI State Grant and P&A programs to the Administration for Community Living (ACL) to maximize resources to support the array of services and supports needed following a brain injury across the lifespan for these reasons:

—To integrate TBI into the HHS long-term services initiatives, which also rely on Aging and Disability Resource Centers (ADRCs) as the entry point into these systems;

—To promote collaboration with the Administration on Aging (AoA) on falls related TBIs among older adults, a major cause of TBI;

—To include TBI in the veterans initiatives between HHS and Department of Veterans Affairs to support Home and Community-Based Services (HCBS) for veterans and returning servicemembers coordinated by the ACL's Office of Disability and Aging Policy's Office of Integrated Programs;

—To coordinate and enhance services for individuals with TBI who could benefit from the ACL's Administration on Intellectual/Developmental Disabilities (AIDD) initiatives to improve education, transition services, employment outcomes and self-advocacy for children and youth;

—To include TBI in the Office of Disability and Aging Policy's Office of Integrated Policy initiatives (i.e. Lifespan Respite Care Program, Participant Direction Program, Evidenced-Based Care Transitions, and Transportation Research and Demonstration Program);

—To include families providing caregiving services to their family members with TBI in the Lifespan Respite Care Program, and

—To further collaborate with other programs transferred to the ACL through the Workforce Innovation and Opportunity Act including the Assistive Technology, Independent Living and NIDRR TBI Model Systems programs.

In keeping with the Olmstead decision, States are taking advantage of Federal initiatives and opportunities to expand community long-term services options. Unfortunately, most States focus on the traditional populations of I/DD, physical disabilities, aging and mental health and are omitting TBI in their long-term care initiatives. This leaves individuals with TBI with little options, other than nursing facilities or other segregated living programs, for assistance with activities of daily living and residential or housing needs. We believe that aligning the Federal TBI State Grant Program with these other programs will help address these concerns.

The TBI Act programs are the only programs providing Federal assistance to help States with developing an array of rehabilitation, home and community-based services and other short-term and long-term supports specific to the cognitive and behavioral needs of individuals with TBI and their families. Since 1997, HRSA has awarded grants to 48 States, District of Columbia and one Territory, although not concurrently, to develop and improve services and systems to address the short-term and long-term needs. These grants have been time limited and are relatively small. Only 20 States currently receive Federal grant funding. Therefore, we believe is imperative to position the program within ACL that will foster collaboration and co-

ordination of resources to assist all States and Territories, whether receiving grant funding or not.

NASHIA is well aware that Federal funds are becoming increasingly difficult to obtain, let alone being increased, therefore NASHIA is recommending relocating the program because:

—The number of Americans who sustain a TBI is increasing, especially among older adults and young children, and among our men and women in uniform as a result of the wars in Iraq and Afghanistan.

—All States have enacted legislation to develop return to play guidelines with regard to sports-related concussions among our youth. Through these efforts, children and youth are now being identified and screened for potential assistance. However, after the age of 21, few will have resources available to them once they are no longer eligible for children's services.

—State budgets have not been able to keep up with the demand for services.

In closing, NASHIA is a non-profit organization representing and assisting State governmental officials who administer an array of short-term and long-term rehabilitation and community services and supports for individuals with TBI and their families. Over the past 30 years, States have initiated efforts to develop capacity for offering information and referral services, service coordination, rehabilitation, in-home support, personal care, counseling, transportation, housing, vocational and other support services for persons with TBI and their families. These services vary in size and scope across the country and even within a State. Twenty-four States have enacted legislation to assess fines or surcharges to traffic related offenses or other criminal offenses and/or assessed additional fees to motor vehicle registration or drivers license to generate funding for TBI programs and services, generally referred to as trust fund programs.

States have also implemented TBI Home and Community-Based Medicaid Waiver Programs (27 waiver programs) with twelve States having the advantage of administering both a trust fund and waiver program. These programs are administered by State public health, Vocational Rehabilitation, mental health, Medicaid, intellectual disabilities, education or social services agencies within the States.

Thank you.

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## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE LONG-TERM CARE OMBUDSMAN PROGRAMS

I am pleased to present this testimony on behalf of residents and tenants residing in Kansas long-term care facilities in collaboration with the National Association of State Long-Term Care Ombudsman Programs (NASOP). Thank you for your past support of the Long-Term Care Ombudsman Program (LTCOP) and all the vulnerable citizens that it serves. This statement and the following funding recommendations are submitted for the fiscal year 2016 for the Long-Term Care Ombudsman Programs administered through the Administration for Community Living (ACL).

First, we request $5 million to support the work of the LTCOP under the Elder Justice Act. This appropriation would allow States to hire additional staff and leverage that staff to recruit additional volunteers to help support the investigation of complaints of abuse, neglect, and exploitation of residents of nursing home and assisted living facilities. To date, no EJC funds have been provided for the LTCOP.

Second, we request $20 million to support 333 additional Ombudsman (salaried staff) at an estimated $60,000 average annual salary/fringe benefits and necessary staff training. The requests adds new ombudsman positions specifically dedicated to providing Ombudsman services to residents of assisted living facilities and other community-based long-term care delivery systems, which currently suffer from a significant lack of personnel resources around the country.

Third, we request $16.83 million authorized under Title VII of the Older Americans Act for LTCOPs to restore funding back to the fiscal year 2011 level. Programs in every district and State are suffering from recent cuts. These funds would help in a partial way to restore our reduced ability to visit residents in nursing homes.

The primary function of the LTCOP in the Federal OAA is to identify, investigate, and resolve complaints that relate to action, inaction or decisions that may adversely affect the health, safety, welfare, and rights of residents of long-term care facilities. Ombudsman representatives work with the consent and at the direction of residents in the resolution of their problems. They visit residents living in nursing homes and residential care homes. Ombudsman representatives ask them about problems or concerns they have and if they need or want our help to resolve these issues. Ombudsman representatives act as their advocates. We strongly believe that our work not only improves the quality of life for millions of long-term care facility

residents, but also saves Medicare and Medicaid resources by avoiding unnecessary costs associated with poor quality care.

Nationally, in fiscal year 2013, nearly 12,000 volunteers, including 8,290 individuals certified to investigate complaints, and 1,233 staff (full-time equivalent) served in the LTCOP. Ombudsmen investigated and worked to resolve 190,592 complaints made by 123,666 individuals. Ombudsmen were able to resolve or partially resolve 73 percent, or almost three out of every four complaints investigated. In addition, ombudsmen provided information or consultation on rights, care and related services approximately 500,000 times.

Kansas's LTCOP is responsible for advocating for 35,836 residents and tenants residing within 814 long-term care facilities. The Kansas Office of State Long-Term Care Ombudsman consists of the State Long-Term Care Ombudsman; 8 Local Long-Term Care Ombudsman; numerous volunteers, and an Administrative Assistant. Since 2008, our program has experienced a 15 percent reduction in funding resulting in the loss of two full-time positions as well as the resources to adequately run our program. In Federal fiscal year 2014, Kansas's LTCOP received 1,918 complaints by or on behalf of 1,594 residents and tenants; and provided 5,673 consultations, education sessions, visits, and other activities. Our office advocates for 35,836 residents/tenants in 814 facilities and we do this with just a few staff. We are grateful for the staffing that we do have, but feel that our efforts are just a drop in the bucket. According to two national studies from the Institute of Medicine and the Bader Report, the national recommendation for States to follow is 1 long-term care ombudsman for 2,000 beds or people. With the current number of long-term care ombudsman staff in Kansas, our ombudsmen are serving 4,480 beds or people. Kansas would need a total of 18 local long-term care ombudsmen to fully meet this Federal recommendation. This would ensure that all individuals residing in long-term care would have immediate access to an advocate who can represent their interests.

We understand that this Subcommittee faces a strained financial situation, but a continued commitment to Ombudsman programs advocating for the healthcare needs and safety of millions of older adults living in nursing homes and assisted living facilities across the Nation should remain a high priority. Since 1978, the LTCOP has been a core program of the OAA. It is the only program in the OAA that specifically serves residents of nursing homes and assisted living facilities. We all appreciate and value the importance of living in one's own home. The OAA provides critically needed home and community based services that often delay institutionalization. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. These residents are usually frail and extremely vulnerable and rely on the advocacy services of the LTCOP.

Demand for our services and advocacy is growing. The number of complex and very troubling cases that long-term care ombudsmen investigate has been steadily increasing. In addition, there continues to be a disturbing increase in the frequency and severity of citations for egregious regulatory violations by long-term care providers. These violations put facility residents in immediate jeopardy of harm. This trend suggests a frightening decline in the quality of long-term care services. Ombudsmen are needed now more than ever in nursing homes, board and care facilities, and in assisted living communities. As well, the demand placed on the program by the need to assist residents who are relocating from long-term care facilities that are downsizing or closing their doors continues to complicate ombudsman programs' daily operations.

Administrators in many long-term care facilities have recognized the value and benefit of having ombudsmen assist with staff training and consultation and this form of outreach has also placed an increasing strain on available advocacy resources. In order to improve advocacy and services available to residents of long-term care facilities, the Kansas Office of the State Long-Term Care Ombudsman and NASOP supports the aforementioned funding levels.

Overall, Ombudsmen offer valuable consumer protections to residents and provide a voice for those unable to speak for themselves. Every day in America, 10,000 more persons reach the age of 65 years. With a rapidly growing older population, LTCOPs can continue to enhance the quality of life, improve the level of care, protect the individual's rights and promote the dignity of Americans across the Nation. NASOP, formed in 1985 as a non-profit organization, is composed of State long-term care ombudsmen representing their State programs created by the Older Americans Act (OAA).

Thank you for your ongoing support.

[This statement was submitted by Barbara Hickert, Kansas State Long-Term Care Ombudsman.]

PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

CDC'S DIVISION OF STD PREVENTION FUNDING HISTORY

| Fiscal Year | ($ million) |
|---|---|
| 2016 Recommendation* | 212* |
| 2016 President's Budget | 157.3 |
| Funding Level: | |
| 2015 | 157.3 |
| 2014 | 157.7 |
| 2013 | 154.9 |
| 2012 | 163 |

*$54.7 million increase.

On behalf of the members of the National Coalition of STD Directors, who represent sexually transmitted disease (STD) programs in all 65 directly-funded project areas of the Centers for Disease Control and Prevention (CDC)—all fifty States, eight cities and seven U.S. territories— I am writing to request an additional $54.7 million for the Division of STD Prevention in fiscal year 2016 funding. The Division of STD Prevention is part of the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention at the CDC.

STDs remain major epidemics in the United States. Each year, there are almost 20 million new cases of STDs, approximately half of which go undiagnosed and untreated, giving the United States the highest STD rate in the industrialized world. These new STDs cost the U.S. healthcare system $16 billion every year—and cost individuals even more in immediate and life-long health consequences, including infertility, higher risk of acquiring HIV, and certain cancers.

The CDC's Division of STD Prevention (DSTDP) guides national efforts to prevent and control STDs and invests most of its resources in State, territorial, and large city health departments. CDC/DSTDP needs additional Federal resources to reverse the alarming and costly trends of STDs. In fiscal year 2016 funding, please support an increase of $54.7 million to support the prevention of STDs and their complications and to ensure those on the front lines of STD prevention have funding to prepare for the immerging threat of drug-resistant gonorrhea, respond to the rising rates of syphilis, and other outbreaks.

The current public health infrastructure has been continually strained by budget reductions both at the Federal and State level and is currently unable to prepare as necessary for the arrival of untreatable gonorrhea as well as responding to growing epidemics and the needs of diverse populations. STD programs have been doing more with less for years and it can no longer continue. The system cannot respond to additional demands and threats with the same level of funding; additional funding is desperately needed.

*Gonorrhea Resistance*

Gonorrhea is the second most commonly reported communicable disease in the United States. Gonorrhea has developed resistance to every class of antibiotics recommended for its treatment; we are now on our last line of defense to treat this disease that is a major cause of pelvic inflammatory disease, ectopic pregnancy, infertility and can facilitate HIV transmission. Given the current trajectory of this disease, the question is not if gonorrhea will develop resistance to all drugs designed to treat it, but when.

While this issue poses grave concerns for all sexually-active people, drug-resistant gonorrhea will hit certain populations harder than others including men who have sex with men (MSM), blacks, and young people:

—Men who have sex with men (MSM) already have the highest rates of gonorrhea resistance across the country.

—The rate of gonorrhea among blacks is 14.9 times the rate of gonorrhea among whites.

—Young people aged 24 and younger account for 58 percent of the new gonorrhea cases every year.

Untreated gonorrhea is a disaster for public health and HIV prevention. In 2013, the CDC released Antibiotic Resistance Threats in the United States, 2013, its first-ever snapshot of the burden and threats posed by the antibiotic-resistant germs having the most impact on human health and in this report named drug-resistant gonorrhea one of three "urgent" threats, the highest level in this report. If drug-resistant gonorrhea becomes widespread not only would it dramatically increase gonorrhea rates, the broader public health impact during a 10-year period would be dev-

astating. It is estimated that it would lead to 75,000 additional cases of pelvic inflammatory disease (a major cause of infertility), 15,000 cases of epididymitis, and hundreds of additional HIV cases.

The direct medical costs of drug-resistant gonorrhea are estimated to be $235 million 10 years after onset of drug resistance. In reality, however, the real costs of gonorrhea resistance are likely to be much higher—this estimate does not account for increased susceptibility monitoring, additional provider education, case management, and the need for additional courses of antibiotics and follow-up.

We acknowledge the political and budgetary climate in which Congress finds itself. But the reality is that soon we will have yet another un-treatable STD on our hands. Investments made now can help respond to future public health emergencies and delay a costly untreatable gonorrhea epidemic. The best way to address growing gonorrhea resistance now, before its arrival on our shores, is to decrease the disease burden of gonorrhea.

Overall gonorrhea rates were stable from 2012 to 2013; however, for the first time since 2000, the rate of reported gonorrhea cases among men was higher than the rate among women. In fact, during 2009—2013, the gonorrhea rate among men increased 20.3 percent while the rate among women decreased two percent. Regional differences also exist; during 2012—2013, the rate of reported gonorrhea cases in the Western United States, where gonorrhea resistance has been the highest, increased among both men (17.3 percent) and among women (11.8 percent). The most salient example is a startling 393 percent increase in gonorrhea cases in Utah in the last 4 years

This request outlines what State and local health departments, as well as on-the-ground partners, need to effectively respond to the growing resistance of gonorrhea to the last drug shown to treat it. It outlines the needs in five distinct areas:

—Proper Diagnosis and Treatment: $11.38 million

While we may not be able to completely avoid the arrival of drug-resistant gonorrhea, we can decrease the burden of gonorrhea currently seen in our country, thereby reducing the response needed when resistant strains are identified. Scaled up screening programs are needed, as well as ensuring the recently-updated CDC screening and treatment guidelines for gonorrhea are being followed by private providers.

—Surveillance and Increased Lab Capacity: $6.1 million

CDC currently conducts surveillance for gonorrhea resistance through the Gonococcal Isolate Surveillance Project (GISP), a sentinel surveillance that collects data from a group of STD clinics around the country. GISP has successfully detects trends in resistance, provides prevalence data and directly informs CDC treatment recommendations for gonorrhea. Using the current GISP system as a model, this funding would establish "mini-GISP" models across the country to ensure we receive not only more gonorrhea resistance data but also data in real time. This funding will also increase lab capacity across the country, a key weakness in our response to multi-drug resistant gonorrhea.

—Disease Intervention Specialists: $19.5 million

Disease Intervention Specialists (DIS) are a workforce that is the underpinning of all STD and HIV health department programs. Vital to health departments across the country, DIS personnel conduct voluntary interviews with patients to obtain the names and contact information of their sexual partner(s) and then use that information to contact a patient's sexual partner(s) and inform them of their potential exposure to an STD or HIV. To get a better handle on the gonorrhea disease burden ahead of multi-drug resistant gonorrhea, State and local health departments need additional DIS to identify partners of possible exposure to gonorrhea and link them to care.

—Evidence-Based Interventions: $10 million

As treatment resistance draws closer, we need to reduce our existing gonorrhea disease burden. Especially given the asymptomatic nature of many gonorrhea infections, the more gonorrhea there is in a community, the more likely it is to spread, and that fact will only be compounded with the arrival of treatment-resistant strains. Funded is need to scale-up existing evidence-based interventions, particularly for populations most at risk, as well as developing additional interventions.

—Education and Awareness: $6.5 million

Additional funding is needed to increase STD education and awareness efforts across the country. The public must be better educated on the reality of the rise of multi-drug resistant gonorrhea and what it means for the current and future treatment of gonorrhea.

*Increasing Syphilis Rates, Increasing Congenital Syphilis, and Ocular Spyhilis*

Data release by the CDC late last year showed that rates for primary and secondary syphilis, which is the most infectious stages of syphilis, increased by an alarming 10 percent in 2013, the year of most recent data, on top of an 11 percent increase in 2012. This second year of double digit increases of syphilis rates is completely also significantly intersects with our HIV epidemic. This continues to affect populations already disproportionally impacted by all STDs, including HIV, most notably gay men and other men who have sex with men (MSM).

The rate of primary and secondary syphilis in 2013 is the highest recorded rate since 1996. In addition, the 10 percent increase in syphilis rates in 2013 was the result of increases in men, mainly MSM; no overall increase was seen in women in 2013. Syphilis and HIV co-infection among MSM is very common, with 52 percent of MSM with primary and secondary syphilis co-infected with HIV.

Congenital syphilis rates also increased 3.6 percent in 2013, the first increase in congenital syphilis since 2008. This disease can cause infant death, developmental delays, and seizures when a pregnant woman has syphilis and it is not treated before delivering.

Also of concern is the fact that since December 2014, at least 15 cases of ocular syphilis from California and Washington have been reported to the CDC. At least five other States have suspect cases under investigation. The majority of cases have been among MSM with HIV; and a few cases have occurred among HIV-uninfected persons including heterosexual men and women. Several of the cases have resulted in significant sequelae including blindness. The cause of these cases is still developing; while the organism the causes syphilis can affect the eye, it is not yet known if certain strains are more likely to cause ocular infections.

What is known, however, is that syphilis of all types is on the rise and we need new tools to fight it. This request also includes an additional $1.2 million to invest in new approaches to address syphilis.

*Disease Intervention Specialists: Outbreak Response Workforce*

The importance of DIS to controlling disease outbreaks of all kinds cannot be overstated, as evidenced by their key role in the control of Ebola. This workforce infrastructure is vital to responding not only to emergencies such as this, but to contain our STD, including HIV, epidemics across the country. These individuals are the unsung heroes of public health; few have heard of them, but we desperately rely on them when many types of emergencies occur.

This infrastructure is housed in State and Federal health departments and is often funded by Federal dollars through grants from the Division of STD Prevention at the CDC. The functions of DIS are not going to be fulfilled by the private sector, but will need to be continued to be funded by the discretionary funding appropriated by this Committee.

DIS positions are often low paying and incredibly demanding. That, coupled with reductions in investments in the public health system, has eroded the DIS workforce over time. Additional resources are desperately needed to bolster DIS staffing— efforts on which NCSD has been leading for years. Limited funds at both the State and local levels do not allow for DIS to follow up on all of the almost two million cases of STDs, including HIV, that are reported annually. Additional funds are desperately needed to allow for more DIS to perform contact tracing to stop the spread of STDs. We need to ensure this workforce continues if we ever hope to control STDs, including HIV, but also so we can adequately and effectively respond to public health emergencies, including Ebola.

To allow for STD public health programs to respond to gonorrhea resistance, increasing syphilis, and prepare for outbreaks of all kinds, please support an increase of $54.7 million for the Division of STD Prevention in fiscal year 2016.

For more information about this funding request or STD prevention in general, please contact the National Coalition of STD Director's Director of Policy and Communications, Stephanie Arnold Pang.

[This statement was submitted by William Smith, Executive Director, National Coalition of STD Directors.]

PREPARED STATEMENT OF THE NATIONAL COUNCIL FOR DIVERSITY IN THE HEALTH PROFESSIONS

SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

$300 million for the Title VII Health Professions Training Programs, including:
—$25 million for the Minority Centers of Excellence
—$14 million for the Health Careers Opportunity Program

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wanda Lipscomb, President of the National Council for Diversity in the Health Professions (NCDHP) and the Director of the Center of Excellence for Culture Diversity in Medical Education at Michigan State University. NCDHP, established in 2006, is a consortium of our Nation's majority and minority institutions that once house the Health Resources and Services (HRSA) Minority Centers of Excellence (COE) and Health Careers Opportunities Programs (HCOP) when there was more funding. These institutions are committed to diversity in the health professions. In my professional life, I have seen firsthand the importance of health professions institutions promoting diversity and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help NCDHP continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like the NCDHP members, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 fiscal year 2007, and fiscal year 2008. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

We have been pleased to see efforts to revitalize both COE and HCOP in recent fiscal years, but it is important to fully fund the programs at least at the fiscal year 2004 level so that more diversity is achieved in our health professions.

Earlier this year with the passage of health reform, the Congress showed the importance of the many of the Title VII programs, including the Minority Centers of Excellence (COE) and Health Careers Opportunities Program (HCOP), by reauthorizing the programs.

*Minority Centers of Excellence*.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2016, I recommend a funding level of $25 million for COEs.

*Health Careers Opportunity Program (HCOP)*.—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. For fiscal year 2016, I recommend a funding level of $14 million for HCOPs.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, NCDHP member institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. NCDHP seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman.

[This statement was submitted by Wanda Lipscomb, Ph.D., President, National Council For Diversity In The Health Professions.]

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## PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration's (SSA's) fiscal year 2016 Appropriation.

NCSSMA is a membership organization of approximately 3,200 SSA managers and supervisors who provide leadership in nearly 1,250 community-based field offices and teleservice centers throughout the country. We are the front-line service providers for SSA in communities all over the Nation. Since the founding of our organization over 45 years ago, NCSSMA has considered a stable SSA, which delivers quality and timely community-based service to the American public, our top priority. We also consider it paramount to be good stewards of the taxpayers' monies and the Social Security programs we administer.

NCSSMA respectfully requests that Congress consider full funding of the President's fiscal year 2016 budget request, which includes $12.513 billion for SSA's Limitation on Administrative Expenses (LAE) account. This level of funding will allow SSA to improve and modernize customer service, enhance program integrity efforts, deter and detect fraud and errors, and continue to address high volumes of work.

NCSSMA appreciates the fiscal year 2015 LAE account funding of $11.806 billion provided for SSA. Increased resources, particularly in SSA's field offices and teleservice centers, have a positive impact on delivering vital services to the American public and in fulfilling the agency's stewardship responsibilities. From the end of 2010 to the end of fiscal year 2013, SSA field offices decreased by 3,452 employees and teleservice centers lost 931 employees. SSA's fiscal year 2014 appropriation allowed the agency to undertake appreciable hiring for the first time since fiscal year

2010. As indicated in the chart below, the fiscal year 2014 hiring and the anticipated fiscal year 2015 replacements for staff attrition are urgently needed to help recover from several years of staffing reductions. While we appreciate the fiscal year 2014 and fiscal year 2015 appropriations for SSA, adequate and sustained funding is needed to maintain staffing levels and to ensure new employees receive the training necessary to become fully productive, which takes on average 3 years.

SSA STAFF ATTRITION END OF FISCAL YEAR 2010-END OF FISCAL YEAR 2014

| Component | Fiscal Year | | | Net staff difference* | Percent of staff losses* ($) |
|---|---|---|---|---|---|
| | 2010 | 2013 | 2014 | | |
| All SSA | 70,202 | 62,199 | 65,102 | −5,100 | −7.26 |
| Field Offices | 31,331 | 27,879 | 29,682 | −1,649 | −5.26 |
| TSCs | 5,206 | 4,275 | 4,535 | −671 | −12.90 |
| ODAR | 10,055 | 9,510 | 9,266 | −789 | −7.85 |
| PSCs | 11,868 | 9,957 | 10,674 | −1,194 | −10.10 |

*Net Staff Difference and Percent of Staff Losses are from End of Fiscal Year 2010 to End of Fiscal Year 2014.

The dramatic growth in SSA workloads, along with the attrition in our offices over the last several years, has emphasized how imperative it is that the necessary resources are received to maintain service levels vital to the nearly 65 million Social Security beneficiaries and Supplemental Security Income (SSI) recipients. Despite agency strategic planning, expansion of online services, significant productivity gains, and the best efforts of management and employees, SSA still faces many challenges providing the service the American public has earned and deserves.

As a result of the significant staffing losses, SSA experienced a marked deterioration in our services from fiscal year 2012 through fiscal year 2014. The scope of the deterioration in field office and teleservice center services is illustrated in the examples provided below.

*Availability of an Appointment with a Field Office*

—Beginning of fiscal year 2012: 74 percent of customers could get an appointment within 2 weeks. Less than 1 percent waited over a month for an appointment.
—End of fiscal year 2014: 28 percent of customers could get an appointment within 2 weeks. 47 percent waited over a month for an appointment.

*Waiting Times in Field Offices*

—Fiscal Year 2012: 18.8 minutes; and 4.8 percent or 2.15 million customers waited over an hour to be served.
—Fiscal Year 2014: 28.2 minutes (50 percent increase) and 13.3 percent or 5.42 million customers waited over an hour to be served (152 percent increase).

*Field Office Telephone Service (Earliest data available Fiscal Year 2012)*

—Fiscal Year 2012: Busy Rate: 7.4 percent; Answer Rate: 82.9 percent*
—Fiscal Year 2014: Busy Rate: 20.1 percent; Answer Rate: 67.3 percent*

*Note—Answer rate is 100 percent minus the busy rate and rate of caller hang up because they did not want to remain on hold any longer.

*800 Number Telephone Service*

—Fiscal Year 2012: Busy Rate: 4.6 percent; Time on Hold: 4 minutes, 14 seconds; Answer Rate: unavailable
—Fiscal Year 2014: Busy Rate: 13.5 percent; Time on Hold: 22 minutes, 3 seconds; Answer Rate: 53.8 percent

With the improved appropriations and new staff brought on in fiscal year 2014 and fiscal year 2015, SSA is beginning to see substantive progress in addressing service deteriorations.

In order to maintain this progress with service improvement, we fully support the President's budget request of $12.513 billion for SSA's LAE account in fiscal year 2016. While this would be a much-appreciated increase of $707 million over the fiscal year 2015 level of funding, it is important to note that the fiscal year 2016 budget request includes inflationary increases of over $355 million in fixed costs, including rent, guards, postage, and employee salaries and benefits. NCSSMA respectfully requests that Congress consider full funding of the President's budget request for SSA to ensure adequate levels of service to the American public. Full funding is critical to maintain staffing in SSA's front-line components, cover inflationary increases, continue efforts to reduce disability backlogs, increase deficit-reducing program integrity work, and to address the significantly increased hearings backlog. The hear-

ings backlog is currently at an all-time high, with over 1 million people waiting for a hearing.

The President's fiscal year 2016 budget request includes $1.439 billion dedicated to processing program integrity workloads, which is consistent with the Budget Control Act of 2011. Program integrity initiatives save taxpayer dollars and contribute to reducing the Federal budget and deficit. To address program integrity, the President's fiscal year 2016 SSA budget request includes funds for the two most cost-effective tools to reduce improper payments—medical continuing disability reviews (CDRs) and SSI redeterminations.

In fiscal year 2015 SSA projections indicate the agency will complete 790,000 medical CDRs, which is an increase of 50 percent, and 2.255 million SSI redeterminations. The fiscal year 2016 budget request calls for SSA to process 908,000 medical CDRs and 2.622 million SSI redeterminations. In order to process this large increase in volume of medical CDRs and SSI redeterminations, the field offices and disability determination services (DDS) will need to maintain adequate staffing levels or there could be delays in processing initial disability claims and reconsiderations and degradation of other services field offices provide.

Again, SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. With the current fiscal challenges confronting SSA, we encourage Congress to consider changes to the Social Security and SSI programs that have the potential to increase administrative efficiency and lower operational costs.

It is critical SSA receives adequate, yet flexible funding for the LAE account to respond to requests for assistance from the American public, and to fulfill our stewardship responsibilities. SSA TSCs, hearing offices, program service centers (PSCs), DDS, and the nearly 1,250 field offices are in grave need of adequate resources to address their growing workloads. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve and will be unable to process program integrity workloads, which save taxpayer dollars and reduce the Federal budget and deficit.

We realize the fiscal year 2016 funding level of $12.513 billion for SSA's LAE account requested above is not insignificant, particularly in this difficult Federal budget environment. However, Social Security serves as the largest most vital component of the social safety net of America and is facing unprecedented challenges. The American public expects and deserves SSA's assistance.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the critical and necessary service they deserve from the Social Security Administration.

[This statement was submitted by Richard E. Warsinskey, President, National Council of Social Security Management Associations.]

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## PREPARED STATEMENT OF THE NATIONAL COUNCIL OF STATE DIRECTORS OF ADULT EDUCATION

The National Council of State Directors of Adult Education offers this testimony Submitted to the Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies to Address Funding Levels in the Department of Education for Adult Education and Family Literacy

The National Council of State Directors of Adult Education (NCSDAE) appreciates the opportunity to submit testimony about the funding level proposed in the Administration's fiscal year 2016 Budget.

Adult education serves adults, 16 years of age and older, who are no longer in school or are functioning below the high school completion level. Services include teaching foundation skills like reading, math, and English coupled with college and career readiness skills that lead to adult secondary education and the transition to post-secondary education. Public schools, community colleges, and community-based organizations provide programs at the local level.

NCSDAE believes that funding for Adult Education in fiscal year 2016 should be at $622.3 million, the level authorized in the Workforce Innovation and Opportunity Act (WIOA) in 2014. Just last year, Congress passed WIOA by overwhelmingly bipartisan votes in both the House (415–6) and Senate (97–3). The law established Adult Education as one of the four key programs in the workforce system because it recognized the crucial role Adult Education plays in educating our population, teaching English and civics, and preparing adults for occupational training and to enter the workforce or improve their employment status.

Such improvements as the law anticipates cannot be fully realized without sufficient resources.

The President's request of $569 million is approximately $53 million below the level Congress authorized ($622.3) in WIOA and is insufficient to the challenges facing Adult Education. These challenges include:

—Only 1.7 million of the 93 million who could benefit can access adult education services.

—One million school age children drop out of school each year adding to that number.

—Thirty percent (30 percent) of foreign born speak English "not very well" or "not at all." Fourteen million are limited English proficient.

—Only 678,000 can currently access adult education services

—Over 40 percent of the 2.3 million incarcerated adults have not finished high school.

—The primary indicator of a child's success in school is the education level of the parent; especially the mother.

—In the most recent (2010) NCSDAE survey, there were waiting lists in adult education programs in every State but one.

The challenges of attempting to provide access to adult education services are overwhelming.

Without access, those undereducated, under prepared adults cannot qualify for jobs with family sustaining incomes that require not only a high school equivalency, but also some college—preferably a one or 2 year certificate in a high demand occupation.

Adults without a high school diploma or functioning below a high school level, cannot qualify for either community college programs or high demand occupations.

According to the National Assessment of Adult Literacy, more than 93 million Americans, about 60 percent the workforce, lack literacy at a level needed to enroll in postsecondary education or job training that current and future jobs now require. In the decade just ended, 24 of the 30 fastest-growing occupations required workers with postsecondary education or training. About 40 percent of job openings will soon require such skills.

Thirty-two States need more adults with college degrees to reach international competitiveness. States cannot close the gap with traditional college students. They must rely on the re-entry pipeline—getting older adults back into the education system and on track to attaining college degrees.

High schools cannot provide business and industry the workers they needs.

—There are approximately 150 million adults in the workforce

—The public schools graduate approximately three million young people every year which equates to only 2 percent of the current workforce.

—Projected 10 years out, public schools can provide only 20 percent of the 2025 workforce. The other 80 percent are adults in the workforce or preparing to enter the workforce today.

Most of America's workforce of tomorrow is already in the workforce. They are beyond the reach of the high schools and postsecondary education. Adult education is the best way to re-engage them.

Further, the Census Bureau projects that between 2000 and 2015, net international immigration will account for more than half of our Nation's population growth, increasing even more the demand for adult English-language programs for adults.

By neglecting the adult population in need of education, we also harm the prospects of the next generation—57 percent of children whose parents don't have a college education live in low-income families, and are less likely themselves to get a good education qualify for family-sustaining jobs.

One in four working families in our country is low income, and postsecondary education or job training can be a ticket to the middle class for low-wage workers seeking better jobs.

The reality is that our adult education programs—for which Federal funding is the core support—are reaching fewer than 2 million adults a year, just the tip of the iceberg. For all intents and purposes, Adult Education State Grants have been essentially frozen since fiscal year 2002. Adjusted for inflation, this is a reduction of 25 percent. Enrollment has decreased most sharply among the low-income populations that most need adult education and workforce skills services. Waiting lists exist in almost every State.

A robust adult education system is essential if we are to achieve our Nation's economic goals. It will be impossible to create a workforce skilled enough to compete in the global 21st Century economy if we focus only on secondary schools and postsecondary institutions. Adult education must also be supported.

Education levels correlate highly to employment and income levels, but significant underinvestment in adult education and workforce skills development is eroding America's global competitiveness.

Other nations are fast outstripping America in boosting the educational levels of their young and working age adults. They are showing consistent decade-to-decade progress in enhancing the education levels of their adult populations, while the U.S. is losing ground.

According to the results of The Program for International Assessment of Adult Competencies (PIAAC) conducted under the auspices of the Organization for Economic Cooperation and Development (OECD) and published in 2013, "the U.S. average on the literacy and numeracy scales is mediocre at best . . . ." PIAAC also reports that:

—U.S. adults scored below the international average in all three domains [literacy, numeracy, and problem solving in technology-rich environments]

—U.S. adults with more than a high school education have literacy skills similar to their peers in other countries. . . . However, U.S. adults with less than a high school diploma scored lower than their peers internationally, especially in literacy and numeracy . . . . In fact, the gap in average scores between adults with the highest and lowest levels of educational attainment was greater in the United States than in any other participating country, for both literacy and numeracy.

In short say the authors of the Report, "These PIAAC results confirm that skills do make a difference and suggest that we can have a substantial impact on economic success and the quality of life in the United States by enhancing skill levels across all groups within the adult population."

Unfortunately, in the past decade overall adult education enrollment has declined even as need for services has expanded rapidly.

*Investing in Adult Education makes sense*.—According to "The Return on Investment from Adult Education and Training," a policy paper issued by the McGraw-Hill Research Foundation (2011), "A preemptive focus on adult education actually saves governments money by reducing: Societal healthcare, public assistance, and incarceration costs."

The Report also noted that, "Adult education also improves and expands the Nation's available pool of human capital by helping motivated but undereducated people achieve gainful employment in today's increasingly high-tech and global job market, and at a far lower cost per learner when compared to either K–12 or higher education. As a result, adult education and career training is potentially one of the most cost-effective tools the Nation has to recover its economic health in the aftermath of the "Great Recession."

Properly funding the adult education system would yield substantial fiscal and social benefits, adding to GDP growth, personal incomes, increased revenues, and savings on incarceration and healthcare:

—$848 billion—increase in personal income in the U.S. over a working lifetime if all adults aged 25 to 64 with some college but no degree acquired at least an associate degree.

—$900,000 per person—how much more an adult holding a bachelor's degree would contribute to the tax coffers of Federal, State, and local governments during a working lifetime compared to an adult with only a high school diploma.

—$2.5 billion annually—the net fiscal contributions to the Federal Government and State and local governments if 4 million dropouts a year earn a high school diploma.

—Up to $1.4 billion per year in savings in reduced costs from crime if the high school completion rate increased by just 1 percent for all men aged 20 to 60.

—Up to $238 billion annually in healthcare expenditures can be saved by improving adult literacy.

—$191 billion—increase in personal income in the U.S. over a working lifetime if all adults aged 25–64 without a high school diploma acquired a high school diploma or equivalent.

We are well aware of the pressures that the Committee faces in this challenging budgetary environment. Nevertheless, we urge you to fund Adult Education at the level authorized in the Workforce Innovation and Opportunity Act (2014) so that the ambitious goals of that law may be realized and that Americans embark or continue on pathways that lead to good jobs and good wages.

We must invest adequately in our Adult Education system to remain economically competitive.

For additional information, please contact: Dr. Lennox McLendon, Senior Advisor, and Gene Sofer, Director of Government Relations.

PREPARED STATEMENT OF THE NATIONAL ENERGY ASSISTANCE DIRECTORS' ASSOCIATION

The members of National Energy Assistance Directors' Association (NEADA), representing the State directors of the Low Income Home Energy Assistance Program (LIHEAP) would like to first take this opportunity to thank the members of the Subcommittee for considering our funding request for fiscal year 2016.

LIHEAP is the primary source of heating and cooling assistance for some of the poorest families in the United States. In fiscal year 2015, the number of households receiving heating assistance is expected to remain at about 6.7 million households or about 19 percent of those eligible to receive assistance, with an average grant size of about $425. In addition, the program is expected to reach about 1 million households for cooling assistance, the same level that received assistance in fiscal year 2014.

Program funding for LIHEAP has been significantly cut from $5.1 billion in fiscal year 2010 to the current level of $3.3 billion. As a result, States have had to reduce the number of households receiving assistance from 8 million to the current level of 6.7 million. Program cuts have had a severe impact on the ability of States to help some of the Nation's poorest households pay their home energy bills.

For fiscal year 2016 we are requesting the Committee restore program funding to the fiscal year 2011 level of $4.7 billion. The funding request would allow States to increase program services to the level provided in fiscal year 2011 and allow us to increase the number of households served by 1.3 million to 8 million and the percentage of households served from about 19 percent in fiscal year 2015 to about 22 percent and fund about 50 percent of the cost of home heating for eligible households.

In addition, the lack of a final program appropriation prior to the beginning of the fiscal year creates significant administrative problems for States in setting their program eligibility guidelines. We are concerned that States will be hampered in their ability to administer their programs efficiently due to the lack of advanced funding. In order to address this concern, we are requesting advance appropriations of $4.7 billion for fiscal year 2017.

*LIHEAP in the President's Budget*

The President's Budget would maintain the overall funding level for LIHEAP at 2015 levels but would add two new provisions that would reduce State flexibility and grant amounts by requiring a minimum set-aside of 10 percent of each State's grant for weatherization and set-aside $200 million from the overall State grant to implement a new competitive grant program that would test "innovative strategies to serve LIHEAP households, including reducing energy use, supporting fuel switching, reducing energy bills, and smoothing energy costs to avoid large spikes during some parts of the year."

Our concern is the negative impact these provisions would have on State grants and State flexibility in administering LIHEAP.

*Weatherization*.—Current law allows States to set aside up to 15 percent of their allocation for Weatherization and up to 25 percent with a waiver. The Administration's proposal would require a minimum set-aside of 10 percent and allow States to set-aside up to 40 percent without a waiver.

We are recommending that the Committee reject both proposals. The current law provides States with sufficient flexibility to design their weatherization programs in context of other resource that might be available for this purpose, allowing States to strike the proper balance between bill payment assistance and efficiency. In addition, we believe that increasing the ceiling for Weatherization within the block grant would undermine the primary purpose of LIHEAP which is to help poor families pay their home energy bills.

*Competitive Grant Program*.—The proposed program would be funded by reducing the formula grant program by $200 million. The funding level for the block grant has been cut significantly in the last few years from $5.1 billion in fiscal year 2010 to the current level of $3.4 billion. We do not believe the program has any flexibility to absorb additional cuts without corresponding cuts to program services. If approved, the States would have no choice but to reduce the number of grants by about 47,000 households to pay for this initiative.

The Administration has also proposed to establish a contingency fund providing additional funds to respond to increases in the number of low-income households, spikes in the price of natural gas, electricity, or oil, and extreme cold at the beginning of winter. We support this additional program authority. It would help to address State concern about winter heating and cooling conditions that we have no control over and have the potential to undermine the effectiveness of the program's

purchasing power at very short notice. The need for such a contingency fund was made abundantly clear during the winter of 2014 as propane prices nearly doubled, forcing State LIHEAP offices to increase propane benefits in order to keep poor families alive during the harsh winter months.

*What is the Impact of Declining Federal Funds?*

Surveys of families receiving Federal assistance have been consistent over the years. Poor families struggle to pay their home energy bills. When they fall behind, they risk shut-off of energy services or they are not able to afford the purchase of delivered fuels. In fiscal year 2011, NEADA conducted a survey of approximately 1,800 households that received LIHEAP benefits. The results show that LIHEAP households are among the most vulnerable in the country.

—40 percent have someone age 60 or older
—72 percent have a family member with a serious medical condition
—26 percent use medical equipment that requires electricity
—37 percent went without medical or dental care
—34 percent did not fill a prescription or took less than their full dose of prescribed medication
—19 percent became sick because the home was too cold
—85 percent of people with a medical condition are seniors

Many LIHEAP recipients were unable to pay their energy bills:

—49 percent skipped paying or paid less than their entire home energy bill,
—37 percent received a notice or threat to disconnect or discontinue their electricity or home heating fuel,
—11 percent had their electric or natural gas service shut off in the past year due to nonpayment, 24 percent were unable to use their main source of heat in the past year because their fuel was shut off, they could not pay for fuel delivery, or their heating system was broken and they could not afford to fix it, and
—17 percent were unable to use their air conditioner in the past year because their electricity was shut off or their air conditioner was broken and they could not afford to fix it.

LIHEAP's impact in many cases goes beyond providing bill payment assistance by playing a crucial role in maintaining family stability. It enables elderly citizens to live independently and ensures that young children have safe, warm homes to live in. Although the circumstances that lead each client to seek LIHEAP assistance are different, LIHEAP links these stories by enabling people to cope with difficult circumstances with dignity.

*The Need for LIHEAP*

Households reported enormous challenges despite the fact that they received LIHEAP. However, they reported that LIHEAP was extremely important. About 64 percent reported that they would have kept their home at unsafe or unhealthy temperatures and/or had their electricity or home heating fuel discontinued if it had not been for LIHEAP. Almost 98 percent said that LIHEAP was very or somewhat important in helping them to meet their needs. In addition, 53 percent of those who did not have their electricity or home heating fuel discontinued said that they would have if it had not been for LIHEAP.

The members of NEADA recognize the difficult budget decisions that you face as you consider funding levels for LIHEAP for fiscal year 2016 and advance funding for fiscal year 2017. We appreciate your interest and continued support for LIHEAP. Please feel free to call upon us if we can provide you with additional information.

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## PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE HEALTH ASSOCIATION

### SUMMARY

Requesting $327 million in funding for fiscal year 2016 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership organization representing the Nation's safety-net family planning providers—nurse practitioners, nurses, physicians, administrators and other key healthcare professionals. Many of NFPRHA's members receive Federal funding from Medicaid and through Title X of the Federal Public Health Service Act, the only federally funded, dedicated, family planning program for the low income and uninsured. These critical components of

the Nation's public health safety net are essential resources for those providing access to high-quality services in communities across the country. As the Committee works on the fiscal year 2016 appropriations bill, NFPRHA respectfully requests that you make a significant investment in Title X by including $327 million to restore the capacity of the program to serve those in need.

NFPRHA was pleased to see that the administration acknowledged Title X's integral role in healthcare delivery by including a $13.5 million increase to $300 million for Title X in the president's fiscal year 2016 proposal; however, even that amount is insufficient to meet the well-documented demand for publicly funded family planning services. Even as more individuals benefit from insurance coverage through the Affordable Care Act (ACA), the Title X network continues to play an essential role in our Nation's service delivery framework. "Churning," confidentiality, and other issues will all play a role in keeping some individuals uninsured, underinsured, or unable to use the coverage they have for the full range of their family planning needs. More importantly, Title X-funded health centers provide healthcare access within communities for all patients regardless of payer source. If the Massachusetts health reform experience were to prove representative of what could be expected by nationwide health reform, there will be a strong increase in demand for services within the already-strained safety net. At present, six in ten women describe family planning centers as their usual source of medical care. According to a report by the Centers for Disease Control and Prevention (CDC), as health reform in Massachusetts expanded coverage for most people living in the State, Title X family planning health centers continued to have high volumes of patients, both insured and uninsured, and remained providers of choice for many.

The failure of States to expand Medicaid eligibility for all adults up to 138 percent of the Federal poverty level (an income of $16,243 a year for an individual in 2015)—along with new barriers to coverage being sought by some expansion States, such as premiums and other cost-sharing requirements—compounds the demand being placed on the Title X safety net. Currently, 22 States have not expanded their Medicaid eligibility under the ACA. Of those, only 1 State (WI) have full-benefit Medicaid eligibility for childless adults. For working parents, 18 of the 22 States have Medicaid eligibility equal to or less than 75 percent of FPL (an income of $8,828 a year); 13 have eligibility at or below 50 percent (an income of $5,885 a year). Four States have eligibility set at less than 25 percent of FPL—that means individuals making more than $2,943 are too "rich" for Medicaid.

Furthermore, the Supreme Court's recent decision in Burwell v. Hobby Lobby Stores, Inc., undermining the ACA's historic contraceptive coverage requirement, potentially adds strain on Title X to assume the cost of care for individuals who legally should have their contraception paid for by their insurance. That strain will be magnified should the Court rule in King v. Burwell this summer that premium tax credits should not be made available in States with an exchange managed by the Federal Government. The RAND Corporation estimates that enrollment in ACA-compliant plans sold within and outside of the exchanges would decline by 9.6 million in Federal exchange States, a 70 percent decrease, and unsubsidized premiums would increase 47 percent.

Similar to other publicly funded health programs, Title X has unfortunately suffered budget cuts despite patient need. Between fiscal year 2010–fiscal year 2013, the Title X family planning program was cut $39.2 million (−12.3 percent). Federal data show a strong correlation between Federal funding cuts and the most dramatic reduction of patients served. During the same period, 667,000 patients were lost from the program, with no indication that they were absorbed into other safety-net healthcare systems. While Congress restored $8.2 million over the fiscal year 2013 post-sequester level in fiscal year 2014, that amount only brought Title X resources back to a level matching its funding a decade a prior (e.g. fiscal year 2005 funding levels), and the fiscal year 2015 appropriation subsequently only provided that same level funding.

As appropriators grapple with how best to distribute limited Federal resources, NFPRHA encourages the Committees continue to prioritize investments in programs, including Title X, that are proven to save critical taxpayer dollars. Every $1 invested in publicly funded family planning services saves $7.09 in Medicaid costs associated with unplanned births. Additionally, services provided in Title X-supported centers alone yielded $5.3 billion of the $10.5 billion in total savings for publicly funded family planning in 2010.

Moreover, appropriators should invest in programs, such as Title X, that focus on outcomes and increasing service efficiency. Title X has long set the standard for high quality family planning and sexual health service provision and recently doubled down on its efforts to lead the field by advancing best practices for clinical care. In April 2014, the program issued "Providing Quality Family Planning Services—

Recommendations of CDC and the U.S. Office of Population Affairs," that outlines the most up-to-date clinical recommendations for all providers of family planning care, including Title X-funded providers, to help define patient-centered, high quality care in a family planning visit. Such efforts reinforce the network's dual role as safety-net providers and centers of excellence for family planning and sexual healthcare.

Lastly, Title X supports critical infrastructure and technology necessary for modern service delivery that are not reimbursable under Medicaid and commercial insurance. Resources for electronic health record implementation for safety-net providers—just as for others in the safety net—are necessary to help achieve the ACA goal of having a nationwide health information technology infrastructure and more coordinated models of care. Increased Title X funding is essential to help address the gap caused by the oversight in Federal planning that led to most family planning health providers' ineligibility for the electronic health records (EHR) incentives available under the HITECH Act.

For these reasons, NFPRHA urges the Committee to make a significant investment in the Nation's safety-net family planning health services and requests funding for Title X at $327 million in fiscal year 2016.

[This statement was submitted by Clare Coleman, President & CEO, National Family Planning & Reproductive Health Association.]

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## PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Chairman Blunt, Ranking Member Murray and other members of the Subcommittee, thank you for allowing the National Head Start Association (NHSA) to submit testimony on behalf of funding for Head Start and Early Head Start in fiscal year 2016. This year marks the 50th year that Head Start centers have been creating opportunities for at-risk children and families to achieve success in life by providing critical early education, health, nutrition, parent engagement and family support services. NHSA respectfully urges the Subcommittee to continue its enduring bipartisan support by allocating $10,117,706,000 for Head Start and Early Head Start in fiscal year 2016, in line with the President's Budget.

### IMPACT OF THE FISCAL YEAR 2013 SEQUESTER

The Head Start and Early Head Start community remains appreciative of your leadership in ensuring that the fiscal year 2014 Omnibus Appropriations legislation not only helped restore the damaging cuts from sequestration, but also made investments in ongoing quality improvement that enabled Head Start providers to keep pace with rapidly rising operating costs. Our community was equally pleased that Congress retained this level of investment in the fiscal year 2015 CROmnibus. That said, the impact of the sequester was severe and, despite appropriations being restored, programs are still recovering. Services were reduced by 1,342,015 days, Head Start Centers closed, transportation services were cut, and teachers were furloughed and laid off. Head Start grantees continue to struggle to regain trust and support in some communities where centers were closed and partnerships ended. The long lasting impact of sequestration has been truly devastating and something that must be avoided in the years to come.

### RECOMMENDATIONS FOR FISCAL YEAR 2016

In fiscal year 2016, we urge the Subcommittee to continue and build on investments made in fiscal year 2014 and fiscal year 2015 by allocating $10,117,706,000 for Head Start and Early Head Start. This funding will allow us to continue services to nearly 959,828 children and their families from birth through age five, continue supporting the recently awarded Early Head Start expansion grants and child care partnerships, support our critical workforce and enable a special focus on improving program quality. Specifically, we propose a $1.228 billion allocation for Quality Improvement funds which, as outlined in the Head Start Act of 2007, may be used for increasing the duration of instruction time, staff training, improving community-wide planning, improving classroom environments, strengthening transportation safety, and increasing hours of program operation. We also urge the Subcommittee to join us in asking the Administration to honor its promise to release, this spring, a long-overdue revised set of Head Start Program Performance Standards, aligned to the Head Start Act of 2007.

SUPPORTING THE WORKFORCE

It is well known that one of the hallmarks of excellence in any early learning program is the caliber of its teachers. More than 70 percent of Head Start teachers have a bachelor's degree or higher in early learning or related fields, which significantly exceeds the 50 percent minimum mandated by Congress in the 2007 reauthorization and enables the program to have one of the best-trained workforces in the country. However, the average salary for these degreed teachers is $30,086—lower than what schools pay teachers, and much lower than salaries for many other jobs with comparable education requirements.

Examples of programs losing their best staff to higher paying schools or other providers are plentiful across the country. In New York, one Head Start social/emotional education mentor-coach reported seeing several "gifted teachers, assistants and aides leave our classrooms after short stays due to the pressure to provide for their own families." Many of the staff that do choose to stay with Head Start struggle to make ends meet—such as the Oregon teachers who have depended on a local food bank to help feed their own children or the Mississippi staff that work evening jobs just to be able to pay their electricity bills. Focusing increased investment toward workforce quality improvements will help enable programs to hold on to dedicated teachers, and provide a solid foundation for the good of our students and families. To that end, NHSA supports the Administration's request of $284,482,375 for workforce investments in order to help programs retain staff and keep up with a rising cost of living in our country.

*Ongoing Quality Improvements*

Recognizing the need for programs to retain staff, improve facilities, expand transportation services, and increase program duration, we recommend providing $1.228 billion to the Quality Improvement fund. Investing in the Quality Improvement fund, rather than mandating funds to be used to expand hours of service as the President's budget does, enables programs to determine areas of greatest need for their individual program and improve services in their own community. This is especially true for rural programs and we believe that it will still accomplish the Administration's goal of increasing the duration of instruction time to meet the needs of working families. We encourage the funds, as well as all other funds in the Head Start base, to be disseminated in accordance with such process described in the Head Start Act, specifically including no less than 4.5 percent of the funds be made available to Migrant and Seasonal Head Start programs and no less than 3 percent for American Indian/Alaska Native Head Start programs.

*Early Head Start Expansion and Child Care Partnerships*

We are thrilled that the first round of Early Head Start-Child Care Partnership grants have been awarded, resulting in an additional 30,000 vulnerable infants and toddlers now able to access high quality early learning. We encourage the Subcommittee to include $500,000,000 in fiscal year 2016 to continue to support this emerging program. Given the challenges expressed by providers in the field and the collective desire to expand access to high-quality programs immediately, we encourage the Administration to keep the option of these funds being available for straight Early Head Start expansion as well. Mandating or incentivizing one model of service, such as the child care partnership, would eliminate the opportunity for many providers to compete for these funds, especially in rural and frontier communities that have few available partner options. The grants, whether for expansion, conversion, or partnerships, should be awarded based on how effectively the model design fits the needs of the community in question, versus an adherence to a partnership model that may be inappropriate to that locality.

*Head Start is a High Yield Investment*

NHSA believes that the budget caps now in place limit opportunities to make high-yield investments in non-defense discretionary spending. Every President and Congress over the past 50 years has supported Head Start on a bipartisan basis. While we have no reason to believe that this support will wane in coming years, we do recognize the constraints the caps put on the Subcommittee. Every dollar invested by the Federal Government should seek a high yield impact and be used accountably. Studies show that for every one dollar invested in a Head Start child, society earns at least $7 back through increased earnings, employment, and family

stability;[1] as well as decreased welfare dependency,[2] healthcare costs,[3] crime costs,[4] grade retention,[5] and special education.[6] These are the very results taxpayers demand for their investments.

Again, the Head Start community understands the pressure the Subcommittee faces and is grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, as a top priority. With a strong concern about the possibility of a fiscal year 2016 sequester in mind, we urge the Subcommittee to build on the bipartisan investments made in Head Start and Early Head Start to increase access, improve quality, and ensure the prosperity of our next generation—especially in this 15th year of our Nation's commitment to providing our Nation's most vulnerable children and families an opportunity to succeed through Head Start. Thank you for your time and consideration.

[This statement was submitted by Yasmina Vinci, Executive Director, National Head Start Association.]

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## PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA) has over 35 years of experience providing public policy leadership that supports children's well-being and tribal self-determination in child welfare and children's mental health systems. Thank you for the opportunity to provide fiscal year 2016 budget recommendations for child welfare and children's mental health programs administered by the Department of Health and Human Services (DHHS).

### CHILD WELFARE RECOMMENDATIONS

A recent report from the Attorney General's Advisory Committee on American Indian/Alaska Native (AI/AN) Children Exposed to Violence provided the following recommendation:

> Congress and the executive branch shall direct sufficient funds to AI/AN tribes to bring funding for tribal criminal and civil justice systems and tribal protection systems into parity with the rest of the United States (U.S. Department of Justice [USDOJ], 2014, p. 51).

Tribes, like States, rely on the Federal Government for the majority of their child welfare funding. Child safety and family stability are tribal governments' highest priorities, yet their programs remain drastically underfunded by the Federal Government. This underfunding has contributed to the increased risk for child maltreatment of AI/AN children and has stymied efforts to heal victims of child maltreatment and rehabilitate their families. Congress must prioritize the safety and well-

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[1] Ludwig, J. and Phillips, D. (2007). The Benefits and Costs of Head Start. Social Policy Report. 21 (3: 4); Deming, D. (2009). Early childhood intervention and life-cycle skill development: Evidence from Head Start. American Economic Journal: Applied Economics, 1(3): 111–134; Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California; Deming, D. (2009, July). Early childhood intervention and life-cycle skill development: Evidence from Head Start, p. 112.

[2] Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

[3] Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06–WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? The American Economic Review, 85 (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. Economic Inquiry, 48 (3), 587–602.

[4] Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. American Economic Review, 92 (4): 999–1012.

[5] Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. American Economic Review, 92 (4): 999–1012.

[6] NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services. Office of Shared Accountability, Montgomery County Public Schools.

being of these children and families in the budget process. NICWA provides the following recommendations:

| Agency | Program | President's fiscal year 2016 budget | Fiscal year 2016 recommendation |
|---|---|---|---|
| DHHS ACF/CB | Promoting Safe and Stable Families-Disc. (tribal) | $89.7m ($31.8m) | $89.7m ($31.8m) |
| DHHS ACF/CB | Child Abuse Discretionary Activities (tribal) | $48.7m (unknown) | $48.7m (unknown) |
| DHHS ACF/CB | Community-Based Child Abuse Prevention (tribal) | $39.7m ($416k) | $60m ($600k) |
| DHHS ACF/CB | Child Welfare Services (tribal) | $268.7m ($6.3m) | $280m (–$7.1m) |
| DHHS ACF/CB | Payments for Foster Care and Permanency | +$27m for tribal start-up funds | +$27m for tribal start-up funds |
| DHHS HRSA | Maternal Infant & Early Childhood Home Visiting Program (tribal) | $500m ($15m) | $500m ($15m) |

PRIORITY RECOMMENDATIONS

*Payments for Foster Care and Permanency*
*DHHS, Administration for Children and Families*

*Budget Recommendation*.—Increase this program's funding by $27 million to specifically support tribal Title IV-E program start-up for tribes with approved Title IV-E plans.

The Fostering Connections to Success and Increasing Adoptions Act (2008) provided tribal governments with historic new opportunities to access foster care and permanency funding and technical assistance under the Title IV-E program—an area of child welfare services where tribes are woefully underfunded.

As described in a recent GAO report (2015) more tribes are not running Title IV-E programs because Title IV-E does not provide the funding or support needed by many tribes to actually begin implementation of the program. Essential to Title IV-E implementation is the ability to provide a substantial non-Federal match and support initial caregiver payments and program costs with tribal funds. Yet, tribes interested in operating IV-E do not have the same access to general revenue as States. Also essential to Title IV-E implementation is the staffing and infrastructure necessary to support expanded services, additional requirements, and new accounting systems. Tribes—who have been chronically underfunded and only reassumed control over their child welfare services in 1978—do not have the same child welfare infrastructure or capacity as States.

The President's fiscal year 2016 budget requests an increase of $27 million to the Payments for Adoption and Permanency Program to allow for tribes that have approved Title IV-E plans to apply for start-up funding. For tribes to successfully access Title IV-E and children to have safe and supported foster homes this program must be funded.

*Promoting Safe and Stable Families (Social Security Act Title IV-B, Subpart 2)*
*DHHS, Administration for Children and Families*

*Budget Recommendation*.—Increase discretionary funding in this program to $89.75 million to support the President's $20 million initiative to increase tribal capacity and rural child welfare.

The Promoting Safe and Stable Families (PSSF) Program provides funds to tribes for coordinated child welfare services that include family preservation, family support, family reunification, and adoption support services. There is a 3 percent set-aside for tribes based on a formula, however if a tribe would qualify for less than $10,000 then it is not eligible to receive any funding under this program. This means that many tribes, typically those tribes who are most in need, cannot access PSSF funding because the overall appropriation is currently too low and affects the individual tribal allocation. This means that tribes are providing intensive family preservation and family reunification services in spite of inadequate funding and insufficient staffing. This puts incredible strain on individual workers and programs.

This strain stands in the way of tribes' ability to build capacity, expand programs, and coordinate services.

The President's fiscal year 2016 budget includes a $20 million increase to PSSF Program discretionary funds for a tribal child welfare capacity building initiative. This initiative would provide tribes with the resources necessary to support the staff time, infrastructure, and development of child welfare departments and services. NICWA recommends that this initiative be funded.

CHILDREN'S MENTAL HEALTH

The Attorney General's Advisory Committee on American Indian/Alaska Native Children Exposed to Violence provided the following recommendation:

> The Secretary of Health and Human Services should increase and support access to culturally appropriate behavioral health services in all AI/AN communities (USDOJ, 2014, p. 88).

Children's Mental Health funding must also account for the understanding that effective mental and behavioral healthcare requires an entire tribal system dedicated to treatment. In order to effectively serve AI/AN children and communities, funding must provide flexible opportunities that allow tribes to integrate mental and behavioral health interventions throughout government services. Congress must provide the funding necessary to help AI/AN youth access life-saving mental and behavioral health services. NICWA provides the following recommendations:

| Agency | Program | President's fiscal year 2016 budget | NICWA fiscal year 2016 recommendation |
|---|---|---|---|
| DHHS SAMHSA | Programs of Regional and National Significance—Children and Family Programs (includes Circles of Care) | $6.5m | $8.5m (Reserve $6.5m for Circles of Care) |
| DHHS SAMHSA | Children's Mental Health Services Program—Systems of Care | $117m | $117m |
| DHHS SAMHSA | GLS State/Tribal Youth Suicide Prevention | $40.5m | $40.5m |
| DHHS SAMHSA | GLS Campus Suicide Prevention Program | $8.9m | $9.5m |
| DHHS SAMHSA | AI/AN Suicide Prevention | $2.9m | $3m |
| DHHS SAMHSA | Tribal Behavioral Health Grant | $30m | $50m |
| DHHS SAMHSA | Project LAUNCH | $34.5m | $34.5m |

PRIORITY RECOMMENDATIONS

*Tribal Behavioral Health Program*

*DHHS, Substance Abuse Mental Health Services Administration*

*Budget Recommendation*.—Increase funding of this program to $50 million to make this funding available across Indian Country.

The Consolidated Appropriations Act of 2015 recommended that $5 million be allocated to Tribal Behavioral Health Grants in the form of the Native Connections grant program appropriating this funding for the first time. These are competitive grants designed to target tribal entities with the highest rates of suicide per capita over the last 10 years. These funds must be used for effective and promising strategies to address the problems of substance abuse and suicide, and to promote mental health and well-being among AI/AN young people.

As originally conceptualized, the fiscal year 2012 budget request sought $50 million for a new Behavioral Health-Tribal Prevention Grant. Approximately half of the funding was to be allocated as a "base level" to federally recognized tribes that applied for these funds. It was anticipated that the base amount that each tribe would be eligible for was $50,000. The remaining funding would be distributed to best serve AI/AN communities. As eventually passed by Congress in the 2015 budget, funding for what is now known as the Native Connections grant program, focuses

more specifically on youth and, due to the level of funding, are competitive grants available to approximately 20 tribes based on the per capita suicide rate and an application process. The President's fiscal year 2016 budget request includes a $25 million increase, $10 million additional dollars in the Mental Health Services appropriations and $15 million new dollars in the Substance Abuse appropriations, for a total of $30 million. This additional funding is still not enough to provide the program with adequate support to fulfill its initial conceptualization—to make it available across Indian Country. NICWA recommends this program be funded at $50 million in accordance with the initial conceptualization of the program.

*Children's Mental Health Initiative (Systems of Care)*

*DHHS, Substance Abuse Mental Health Services Administration*

*Budget Recommendation*.—Maintain funding at $117 million to continue support of the current cohorts of grantees, and allow for new grantees in fiscal year 2017.

The children's mental health initiative line item supports the development of comprehensive, community-based "systems of care" for children and youth with serious emotional disorders. This includes funding for 1 year System of Care Expansion Planning Grants, 4-year System of Care Expansion Implementation Grants, and 6-year Children's Mental Health Initiative System of Care Grants. AI/AN communities are eligible for, and recipients of, each of these grants, but must compete with non-tribal applicants to receive these funds.

Children's Mental Health Initiative System of Care Grants support a community's efforts to plan and implement strategic approaches to mental health services. These approaches are based on important principles, they must be family-driven; youth-guided; strengths-based; culturally and linguistically competent; and meet the intellectual, emotional, cultural, and social needs of children and youth. Since 1993, 180 total projects have been funded, dozens of which have been in tribal communities. Currently, 17 tribal communities are funded under the Children's Mental Health Initiative line item.

The system of care model of mental health service provision has been found to be more in line with the AI/AN worldview and traditional tribal ways of helping than any other service system. Therefore, funding should be continued at the fiscal year 2015 level of $117 million so that tribes can continue to access these funds and provide vital mental health services to children and youth.

If you have any questions about this testimony please contact NICWA Government Affairs Associate Addie Smith.

*References:*

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## PREPARED STATEMENT OF THE NATIONAL INDIAN COUNCIL ON AGING

On behalf of the National Indian Council on Aging (NICOA), the only national organization dedicated to the well-being of American Indian and Alaskan Native Elders, we thank you for the opportunity to submit testimony in support of the Department of Health and Human Services' proposed increase of $2.9 million for the Older Americans Act Title VI American Indian senior nutrition programs, as well as the Department of Labor's proposed funding for the Older Americans Act Title V Community Services Employment for Older Americans program (also known as SCSEP).

American Indians and Alaskan Natives are more likely to live in poverty in their old age. Title VI is an example of a lack of parity between States and tribal organizations. According to the 2010 Census, the American Indian/Alaskan Native population increased at a rate faster than the total population, rising from 4.1 million to 5.2 million. Yet, the funding for Title VI nutrition and supportive services programs has continually decreased since fiscal year 2011, though Title VI recipients are supposed to receive "comparable services" according to the Older Americans Act.

Under the Older Americans Act, Native American nutrition and supportive services are funded by grants awarded under Title VI to Indian tribal organizations, Alaskan Native organizations and non-profit groups representing Native Hawaiians. These grants were awarded to 264 tribal organizations and 1 Native Hawaiian organization in fiscal year 2014.

As an organization which works on a daily basis with older American Indians/Alaskan Natives, we see the increasing need for these services as the population grows. These services, like the Title III services that States receive, help delay costly nursing home care and allow American Indians/Alaskan Natives to remain at home, in the community, and/or on the reservation, even if they have limitations on their activities of daily living. According to the Administration for Community Living's Congressional Justification, the fiscal year 2016 request level will provide 620,000 rides, 2.9 million meals at home, and 2.5 million meals at congregate sites to over 74,000 American Indian/Alaskan Native elders.

We also provide our support for Title V of the Older Americans Act, the Community Services Employment for Older Americans program (also known as SCSEP). We are proud to serve as a national contractor for the program, operating in fourteen States. We are pleased that the President's budget this year does not recommend cutting the program as it has recommended in prior years. In this time of high unemployment for older adults, we hope that you continue funding the one program that is specifically targeted toward low-income older workers at the $434.4 million level from fiscal year 2014 and fiscal year 2015, if not consider an increase.

We are also pleased that the President's budget does not recommend transferring the program from the Department of Labor to the Department of Health and Human Services. We believe it operates well under the Department of Labor and does not need to be transferred as has been proposed in prior years.

As the American Indian/Alaskan Native population ages, now is the time to provide funding for their nutrition and supportive services. We hope you will consider the President's request as a modest but necessary increase for these much-needed programs.

Thank you for your past and future support.

[This statement was submitted by Randella Bluehouse, Executive Director, National Indian Council on Aging.]

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## PREPARED STATEMENT OF THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

My name is Rachel Gandell. I currently serve as Chair of the Friends of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). On behalf of the Friends, I urge the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to support at least $32 billion for the NIH, including $1.37 billion for NICHD for fiscal year 2016. Our coalition includes over 100 organizations representing scientists, physicians, healthcare providers, patients and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to support the extraordinary work of NICHD.

Since its establishment in 1963, NICHD has achieved great success in meeting the objectives of its broad biomedical and behavioral research mission, including research on child development before and after birth; maternal and child health; learning and language development; women's health and reproductive biology; population issues; and medical rehabilitation. With sufficient resources, NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health and developmental problems for women, children and families in your States. Scientific breakthroughs supported by NICHD serve to prevent and treat many of the Nation's most devastating health problems including infant mortality and low birthweight, birth defects, intellectual and developmental disabilities, and the reproductive and gynecologic health of women throughout their lifespan. Some of these research areas are described below.

*Preterm Birth*.—NICHD supports a comprehensive research program to study the causes of preterm birth, prevention strategies and treatment regimens. Preterm birth costs our Nation $26 billion annually and is a leading cause of infant mortality and intellectual and physical disabilities. Continued prioritization of extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network and the intramural research program related to prematurity are necessary to further this work. Resources should also be available to support transdisciplinary science as recommended in NICHD's Scientific Vision to study and identify the complex causes of preterm birth.

NICHD supports research on the causes of preterm birth with the goal of discovering ways to prevent it. In the U.S., the rate of preterm birth is approximately 11.4 percent, one of the highest rates in all industrialized countries. Although research has identified some factors that influence preterm birth (e.g., multiple gestation, in-

fections, diabetes, high blood pressure, closely spaced pregnancies), it cannot be fully explained by physical health. Support is needed for research on the complex interaction of psychological, behavioral, social, and environmental factors in addition to genetic and biological influences, with the ultimate goal of developing interventions to decrease this epidemic. In addition, a baby is stillborn in the U.S. every 21 minutes, and NICHD should join with other researchers to establish a research agenda that will lead to better prevention strategies.

*National Children's Study (NCS)/Strategic Pediatrics Research*.—The NCS was created as a result of the Children's Health Act of 2000 to evaluate a wide range of environmental influences on the health and development of children. After years of effort and public investment, the NCS was unfortunately deemed unfeasible and was closed. However, the child health goals of the Children's Health Act remain as important today as 14 years ago. The President's fiscal year 2016 budget includes $158 million within the NIH Office of the Director for Strategic Pediatrics Research to succeed the NCS. The Friends support this request and urge the NIH, with input and participation from NICHD, to undertake innovative pediatric research beginning in the prenatal period to determine the effects of physical and social environments on child health. We also support the President's budget request for $7 million to maintain and provide researcher access to the data and biospecimens collected during the NCS pilot phase.

*Contraceptive Research and Development*.—NICHD's Contraceptive Discovery and Development Branch supports basic, applied and clinical research on contraceptive methods. Through its contraceptive evaluation research, NICHD plays a key leadership role in addressing behavioral issues related to fertility and contraceptive use. Specific contraceptive evaluation opportunities and research priorities include evaluation of the safety and effectiveness of hormonal contraceptive options for women who are overweight or obese. NICHD's investment in contraceptive research and development is critical for producing new contraceptive modalities that are more effective, affordable, acceptable, and easier to deliver. Specific opportunities and research priorities in this area include the need for non-hormonal contraception, pericoital contraception, and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

*Reproductive Sciences*.—Through its investment in reproductive science, NICHD conducts research to improve women's health by developing innovative medical therapies and technologies and improving existing treatment options for gynecological conditions affecting overall health and fertility. NICHD's reproductive science research makes a vital contribution to women's health by focusing on serious conditions that have been overlooked and underfunded, despite the fact that they impact many women. Future work could focus on infertility and the need for treatments for disorders such as endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids which can prevent couples from achieving desired pregnancies.

*Pelvic Floor Disorders Network (PFDN)*.—Female pelvic floor disorders represent a major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting approximately 25 percent of American women. The PFDN is conducting research to improve treatment of these painful gynecological conditions. Current research is aimed at improving female urinary incontinence outcome measures and ensuring high quality patient-centered outcomes.

*Development of the Research Workforce*.—Adequate levels of research require a robust research workforce. The years of training combined with funding uncertainty are disincentives for students considering a career in biomedical research. For instance, there is a huge gap between the too-few women's reproductive health researchers being trained and the immense need for research. NICHD's Women's Reproductive Health Research (WRHR) Program and Reproductive Scientist Development Program (RSDP), both aimed at ob-gyns to further their education and experience in basic, translational, and clinical research, provide training grants to hundreds of researchers and provide new insight into a host of diseases, such as ovarian cancer. Continued investment in these and other training programs at NICHD is critical to future scientific advances.

*Population Research*.—The NICHD Population Dynamics Branch supports a research portfolio on how population change affects the health, development, and wellbeing of children and their families. The branch is known for supporting large-scale longitudinal studies, such as the National Longitudinal Study of Adolescent to Adult Health (Add Health), a survey of over 20,000 adolescents who have been followed for 15 years into adulthood, and the Fragile Families and Child Wellbeing Study, following nearly 5,000 children in large U.S. cities, most born to unmarried parents between 1998 and 2000. These datasets enable scientists to understand how genetic, biological and social factors, including family stability, parental involvement, social networks, and neighborhoods, interact to influence child health and de-

velopment. In 2014, scientists using Add Health data reported new findings on the long-term effects of birth weight and breastfeeding duration on inflammation (a contributing factor to disease and disability) in early adulthood.

*Sex Differences in Research*.—The Friends encourages NICHD to look at ways to increase data reporting to address gaps in gender and sex differences in research. Sex differences need to be acknowledged as a critical biological variable. In addition to including more women in clinical research, we believe sex differences should be included as part of the design of all basic biological studies and clinical research. If the researchers were to consider sex differences in the design of basic science studies, and incorporate data on sex as a biological variable in animal and human studies, more appropriate conclusions could be drawn from basic research, and clinical research would provide more representative data on safety and efficacy of drugs.

*Clinical Trials in Pregnant Women*.—Pregnant women have historically been excluded from most research trials due to concern that trial participation could harm the fetus. Although there has been substantial progress in the inclusion of women in federally funded research, pregnant women are still excluded, even from research that would advance our knowledge of medical conditions and treatments in pregnancy. Mindful of the important considerations of clinical trials on pregnant women, we support establishment of a Federal work group to propose how clinical research might be done appropriately in this area.

*Data on Pediatric Enrollment in NIH Trials*.—NIH policy mandates the inclusion of women, minorities, and children in clinical studies whenever appropriate. While NIH collects enrollment data on women and minorities, it does not collect enrollment data on children. We urge NIH, with leadership from NICHD, to begin tracking the numbers of children, broken down by pediatric age group, enrolled in NIH-funded studies. Better tracking is needed to ensure adequate representation of children in relevant trials.

*Mother-Infant Relationships*.—NICHD supports multidisciplinary, cutting edge research to advance our understanding of attachment in mother-infant relationships and its impact on development. Early life experiences can have profound impacts on behavioral and health outcomes later in life, but often require specific experimental controls to pinpoint the impacts of various factors. Thus, we urge NICHD to continue support of a robust intramural and extramural research portfolio identifying and describing the complex interaction of behavioral, social, environmental, and genetic factors on health outcomes leading to improved understanding of and interventions for mental illnesses such as depression, addiction, and autism.

*Best Pharmaceuticals for Children Act (BPCA)*.—Through the BPCA program, NICHD funds the study of drug products that are important to children but have been inadequately studied in pediatric populations. We urge continued funding and support for this important research as well as support for training the next generation of pediatric clinical investigators.

*Rehabilitation Science*.—The National Center for Medical Rehabilitation Research (NCMRR) currently resides within NICHD, yet there is a strong need for elevating the stature of NCMRR. We recommend moving the NCMRR to an independent Institute or Center reporting directly to the NIH Director, or to establish a new Office of Rehabilitation Research within the Office of the NIH Director. Implementation of this structural recommendation would require a statutory change. Elevation of NCMRR is a critical step in achieving enhanced coordination of rehabilitation science across all the Independent Centers at NIH that conduct and support research directly addressing or related to rehabilitation science.

*Down Syndrome*.—NICHD-funded investigators have made unprecedented progress toward identifying treatments to reverse or ameliorate the cognitive impairment associated with Down syndrome, as well as understanding how a gene on the 21st chromosome might contribute to the development of Alzheimer's disease in people with Down syndrome. In addition, the NICHD-supported Down Syndrome Registry, DS Connect, has allowed the Down syndrome community to share information and health history in a safe, confidential, online database.

*Intellectual and Developmental Disabilities Research Centers (IDDRC)*.—These Centers have greatly improved our understanding of the causes of developmental disabilities and have developed effective treatments consistent with their translational science mission. However, the Friends are concerned that the IDDRC network does not have sufficient resources to sustain the progress made in this critical area. We urge NICHD to provide additional resources to the IDDRCs for research infrastructure and expansion of cores, so that they can conduct basic and translational research to develop effective prevention, treatment and intervention strategies for children and adults with developmental disabilities.

*Human-Animal Interaction*.—NICHD plays an essential role in human-animal interaction research. Sixty-five percent of American households include a pet, and

there is growing evidence of the health benefits of pet ownership. The bond between humans and animals can impact the health and development of children, from strengthening early childhood immune systems to mitigating childhood obesity to improving mental health. Research on the benefits of animal-assisted therapy for children with autism spectrum disorder (ASD) and other neurological conditions relies on the NICHD human-animal interaction research program. We urge NICHD to continue to support a strong pipeline of peer-reviewed research in this area.

These research efforts have made significant contributions to the well-being of all Americans, but there is still much to discover. We urge you to support NICHD at funding levels that meet current needs for addressing health issues across the lifespan. Thank you for your consideration and we look forward to working with you on these critical issues.

[This statement was submitted by Rachel Gandell, Chair, Friends of National Institute of Child Health and Human Development.]

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## PREPARED STATEMENT OF THE NATIONAL INSTITUTES OF HEALTH AND THE NATIONAL EYE INSTITUTE

### EXECUTIVE SUMMARY

ARVO requests a $32 billion and $730 million investment in NIH and NEI, respectively, as well as waiving NIH from sequester cuts and Budget Control Act caps in fiscal year 2016.

—Taxpayer investment in research has an impressive return on investment (ROI) of 121 percent. This return takes many forms: as dedicated scientists founding their own startup companies after years of taxpayer-supported research; as new technologies cutting waste in the healthcare system; as entire new private industries supporting companies, jobs and economic growth.

—While the U.S. has largely paused its investments in research, China has accelerated its own. In the past 10 years, China has tripled the amount of money flowing to its researchers. This flood of resources has attracted ambitious scientists from the entire world—even causing researchers employed at NEI to leave. Our loss is their gain.

—NIH and NEI are pushing forward with agency-wide initiatives (e.g., BRAIN, Precision Medicine, Audacious Goals) aimed at specific goals with significant possible outcomes. But these new initiatives require new investment to be successful. Instead, since fiscal year 2003 NIH has lost 22 percent of its budget in inflation-adjusted dollars; NEI is down 25 percent in that same timeframe and down $25 million since fiscal year 2012.

*Past Investments in Research Yield Current Returns on Investment*

It's an often cited statistic: every $1 of NIH funding generates $2.21 in local economic growth.[1] But, what does that 121 percent ROI look like in the real world?

In one example, taxpayer ROI takes the form of dedicated scientists who have doggedly pursued a medical problem that lacks great treatment options. Gordon Laurie, PhD, Associate Professor at the University of Virginia, has been studying the cause and potential treatments for dry eye disease, a debilitating condition that costs the U.S. healthcare system $3.8 billion a year. Long-term investment in his research has recently yielded a startup company. Laurie says:

> "I recently started a small business that stemmed from my research in the lab. The company—and its potential impact on patients and the economy—would not have been possible without the support I've received from the government over the past 15 years. That kind of direct return on investment is important to show in a time when every Federal dollar is being scrutinized."

In another example, taxpayers rest their head against their ROI every time they visit an ophthalmologist (eye doctor). A powerful technology initially discovered over 20 years ago—with NIH support —has matured to become the standard of care used by ophthalmologists today. Known as Optical Coherence Tomography (OCT), it offers doctors a way to spot the appearance of vision-stealing conditions without any need for needles, blood or eye dilation. If treatment is needed, OCT minimizes wasted time and expense on ineffective medication or therapies by offering objective, quantitative images of how the patient's eyes are responding to treatment. OCT is one of the many returns on taxpayer investment in research that anyone can see—and one of the relatively few that preserves sight.

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[1] Families USA "In Your Own Backyard: How NIH Funding Helps Your State's Economy" (2008).

The commercial products made possible by taxpayer-funded scientific discoveries support companies, jobs and governments. For instance, the private OCT manufacturing industry (responsible for making the instruments used by ophthalmologists) hit $350 million in 2012. OCT has spread to cardiology and other medical disciplines as well, with those fields having a collective estimated manufacturing market value of over $60 million in 2012.

These people, products and private industries represent success in the long-standing model of American-led innovation: public-supported efforts into research leading to discoveries that grow into new products—primarily funded by private entities—that go on to benefit the same public that made it all possible.

*While the U.S. Slows Investment, Others Speed Up*

The estimated time it takes to move from an initial discovery (bench) to widespread adoption (bedside) is 15–20 years.[2] Fifteen years ago, NIH was in the middle of a 5 year span that saw its budget jump from $13.7 billion (fiscal year 1998) to $27.1 billion (fiscal year 2003). Since then, appropriations for NIH have essentially flat lined. Will the rate of innovation begin to flat line as well?

While the U.S. has hit the "pause" button on taxpayer investment in research for the past dozen years, other countries have hit "fast forward." China, for example, has tripled its support for researchers in the past 10 years. ARVO member Qingjiong Zhang, MD, PhD, Professor at Sun Yat-Sen University in Guangzhou, China, completed his training to be an ophthalmologist in the U.S. before returning home. On a recent visit to Washington, D.C., he said:

> "I think it is valuable to discuss how different the research climate is in China compared to the U.S. In the past 10 years, our [research] grants have tripled in value, and my institution has recruited 10 scientists directly from the NEI. The contrast is stark—and judging by some of the reactions of my U.S. peers—surprising."

When investment dries up in one country, smart and ambitious people move to another. With them, they take their future ideas, companies and the accompanying jobs and profits.

But that's not the worst possible outcome from a long-term pause on investment in research. Susana Chung, OD, PhD, Professor of Optometry at the University of California, Berkeley, said it best:

> "The danger of flat funding is that the next generation could be choosing other fields. Imagine losing the next generation of brilliant scientists who may discover ways to save or recover sight!"

*Audacious Goals Possible with Future Investment*

Sometimes, big advancements come from individual researchers toiling away in their labs on their own projects. Other advancements require the cooperation of huge groups of researchers, public agencies and private organizations. Recent examples like the BRAIN and Precision Medicine Initiatives are NIH-led efforts aimed at very specific goals with far-reaching effects.

The NEI is pushing forward with its own targeted goal of restoring vision by regenerating nerves in the eye and visual system. Called the Audacious Goal Initiative (AGI), NEI Director Paul Sieving, MD, PhD, described the effort:

> "The goals are bold but achievable. They are beyond what medicine currently can do. We are planning for a 10–15 year effort to reach these endpoints. Success would transform life for millions of people with eye and vision diseases. It would have major implications for medicine of the future, for vision diseases, and even beyond this, for neurological diseases."

The AGI builds upon discoveries from past investments in research—such as OCT—and combines these with new discoveries to develop therapies that could prevent or treat the degeneration of the nerves responsible for vision.

These initiatives at the NIH and NEI have set ambitious goals that require increased—not decreased—funding. Yet decreases are exactly what has happened over the past dozen years. Since fiscal year 2003, NIH has lost 22 percent of its budget in inflation-adjusted dollars; NEI is down 25 percent in that same timeframe and down $25 million since fiscal year 2012.

Again, we all know the number: a 121 percent ROI for every taxpayer dollar invested in research. ARVO encourages the Senate LHHS subcommittee to invest our limited taxpayer dollars in agencies that deliver a great return—in companies and jobs, industries and profits, therapies and healthy citizens.

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[2] Morris, Z. S. et al. doi: 10.1258/jrsm.2011.110180.

ARVO requests an investment of $32 billion in NIH, $730 million in NEI, and a waiver for NIH from sequester cuts and Budget Control Act caps in fiscal year 2016. These actions will build upon past taxpayer investments, undo the counter-productive sequester cuts of fiscal year 2013 and begin to restore the steep loss of purchasing power at NIH and NEI.

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## PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (NKF) is pleased to submit testimony in support of the Centers for Disease Control and Prevention Chronic Kidney Disease Program, the National Institute of Diabetes and Digestive and Kidney Disease, and the Health Resources and Services Administration Division of Transplantation. NKF is America's largest and oldest health organization dedicated to the awareness, prevention and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. In addition, we have provided universally recognized evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD) since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI). We respectfully request fiscal year 2016 funding of $2.2 million for the CDC Chronic Kidney Disease Program, $2.066 billion for NIDDK, and $24 million for the HRSA Division of Transplantation.

In 2012, more than 636,000 Americans had End Stage Renal Disease (ESRD), including more than 450,000 dialysis patients and the remainder kidney transplant recipients, with minority populations disproportionately affected. Complicating the cost and human toll is the fact that it is a disease multiplier, with patients very likely to be diagnosed with diabetes, cardiovascular disease, or hypertension (two-thirds of ESRD patients have diabetes or hypertension). In 2012, ESRD was present in less than 2 percent of Medicare beneficiaries but responsible for nearly 6 percent of Medicare expenditures.[1]

Last year NKF announced an initiative to help improve early detection and diagnosis of CKD by primary care practitioners. Over 26 million people have CKD, yet only 10 percent are aware they have it.[2] Intervention at the earliest stage is vital to improving outcomes, lowering healthcare costs, and improving patient experience, yet in a recent clinical study only 12 percent of primary care clinicians were properly diagnosing CKD in their patients with diabetes who are at the highest risk of kidney disease.[3] There often is a misconception that once someone is diagnosed with CKD, there must be a referral to a nephrologist. However, there are not enough nephrologists to care for the 15 percent of the U.S. population with chronic kidney disease, nor is it necessary in most instances for referral to a nephrologist in early stages. NKF's CKD Primary Care Initiative aims to transform PCP detection and care of to the growing numbers of Americans with CKD by deploying evidence based clinical guidelines into primary care settings through education programs, symposia and practical implementation tools. Our initiative will help build on CDC's program outlined below.

### CDC CHRONIC KIDNEY DISEASE PROGRAM

To address the social and economic impact of kidney disease, NKF worked with Congress to initiate a Chronic Kidney Disease Program at CDC in fiscal year 2006. Prior to this, no national public health program focusing on early detection and treatment of CKD existed. CKD is often asymptomatic—especially in the early stages—and therefore goes undetected without laboratory testing. Some people remain undiagnosed until they have reached CKD Stage 5 and must begin dialysis immediately. However, cost-effective early identification and treatment can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. NKF urges the Committee to provide $2.2 million for the CKD program for fiscal year 2016, an increase of $100,000.

The CDC CKD program is designed to identify members of populations at high risk for CKD, develop community-based approaches for improving detection and control, and educate health professionals about best practices for early detection and treatment. The program has consisted of three projects to promote kidney health by

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[1] 2014 U.S. Renal Data System Annual Report.

[2] Tuot DS, Plantinga LC, Hsu CY, et al. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. Aug 2011;6(8):1838–1844.

[3] Szczech LA, et al. Primary Care Detection of Chronic Kidney Disease in Adults with Type-2 Diabetes: The ADD–CKD Study (Awareness, Detection and Drug Therapy in Type 2 Diabetes and Chronic Kidney Disease), PLOS One November 26, 2014.

identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects include (1) demonstrating approaches for identifying individuals at high risk for CKD through state-based screening; (2) conducting an economic analysis on the economic burden of CKD and the cost-effectiveness of interventions; and (3) establishing a surveillance system for CKD by analyzing and interpreting information to assist in prevention and health promotion efforts for kidney disease. The surveillance project includes a CDC website program containing information on risk factors, early diagnosis, and strategies to improve outcomes.

As a result of consistent congressional support, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objectives. However, increasing the proportion of persons with CKD who know they are affected requires expanded public and professional education programs and detection initiatives targeted at populations who are at high risk. This momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not increased.

A recent study published by researchers leading the program shows that the burden of kidney disease is increasing and that over half of U.S. adults age 30–64 are likely to develop CKD.[4] Congressional support for an increase in funding to the CDC program will benefit kidney patients and those at risk for kidney disease, advance the objectives of Healthy People 2020 and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of the Medicare Improvement for Patients and Providers Act. Agency priorities going forward include addressing disparities among racial and socioeconomic populations and adding new and local data on CKD including additional risk factors.

While progression of CKD can lead to ESRD, CKD patients are at a greater risk of death, cardiovascular events and adverse drug events. An American Heart Association task force noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function.[5] Testing for kidney disease in at risk populations provides the opportunity for interventions to foster awareness, foster adherence to medications and control risk factors. Therefore the CDC CKD program addresses three priorities in the National Strategy for Quality Improvement in Health Care, including (1) making care safer by reducing harm caused in the delivery of care, (2) promoting the most effective prevention and treatment of the leading causes of mortality, starting with cardiovascular disease, and (3) working with communities to promote widespread use of best practices to enable healthy living.

Undetected kidney disease can lead to costly and debilitating irreversible kidney failure. However, cost-effective interventions are available if patients are identified in the early stages. With the continued support of Congress, NKF is confident a feasible detection, surveillance and treatment program can be advanced to as a first step to slow the progression of kidney disease.

NIDDK

NKF joins other members of the Friends of NIDDK to request $2.066 billion for the Institute in fiscal year 2016. Medicare spends $87 billion annually to care for patients with kidney disease, including nearly $29 billion for individuals with ESRD, yet NIH funding for kidney disease research is only about $600 million annually.

In March, NKF hosted the Second Annual Kidney Patient Summit that included participation from nearly 100 advocates from NKF and five other kidney patient organizations. Increased Federal support for kidney disease research was a top priority in meetings with the advocates' congressional delegations. This is particularly important for individuals whose kidney disease is the result of genetic factors. NIDDK Director Dr. Griffin Rodgers addressed our advocates and discussed exciting opportunities in CKD research. America's scientists are at the cusp of many potential breakthroughs in improving our understanding of CKD and providing new therapies to delay and treat various kidney diseases. With the unique status of ESRD in the Medicare program, CKD research has the potential to provide cost savings to the Federal Government like that of no other chronic disease. We urge Con-

[4] Hoeger, Thomas, et al. The Future Burden of CKD in the United States: A Simulation Model for the CDC CKD Initiative, Am J Kidney Dis. 2015;65(3):403–411.

[5] Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. Circulation 2003: 108: 2154–69.

gress to continue its strong bipartisan support for NIH and fund NIDDK at this requested level.

Many individuals at high risk of CKD rely on community health centers for their healthcare services. NKF believes this represents a valuable opportunity to provide information to patients on risk factors and increase detection of CKD in early stages. We urge Congress to direct NIDDK to build upon its efforts from 2008–2010 to "test effective strategies for improving CKD detection and care in primary care settings, focusing primarily on integrating CKD into diabetes care" in community health centers as a method to better reach Americans who are most vulnerable to kidney disease.[6]

### HRSA ORGAN TRANSPLANTATION

NKF urges the Committee to provide $26.55 million for organ donation and transplantation programs in the Health Resources and Services Administration's (HRSA) Division of Transplantation (DoT), $3,000,000 above the President's Request. This funding request is supported by many patient and professional members of the transplant community.

As of March 15, 2015, more than 123,000 Americans were on the wait list for a transplant, including nearly 102,000 waiting for a kidney. Transplantation remains the treatment of choice for most patients with kidney failure yet few will be given an opportunity to receive a new kidney. Kidney recipients often have an improved quality of life (and are more likely to stay in or return to the work force) and transplantation is tremendously cost effective—Medicare spends about $25,000 per year on a kidney recipient after the year of transplant, compared to more than $86,000 annually on a dialysis patient.

Additional activities supported by DoT include initiatives to increase the number of donor organs. For example, the National Donor Assistance Program has helped more than 4,800 individuals obtain a transplant by assisting living donors with out-of-pocket expenses such as travel and subsistence that are not reimbursed by insurance, a health benefit program, or any other State or Federal program. Last year, NKF established an organ donation task force to review the state of organ donation and identify opportunities to expand the number of transplants. The task force continues to develop its recommendations but much of its discussion is focused on opportunities to expand living donation, and financial constraints are frequently cited as a barrier to donation. Additional funding for the Donor Assistance Program will to enable more individuals to consider being a living donor.

Thank you for your consideration of our fiscal year 2016 funding requests.

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## PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The NLN promotes excellence in nursing education to build a strong and diverse nursing workforce to advance the health of our Nation and the global community. The League represents more than 1,200 nursing schools, 40,000 members, and 26 regional constituent leagues. The NLN urges the subcommittee to fund the Health Resources and Services Administration's (HRSA) Title VIII nursing workforce development programs at $244 million in fiscal year 2016. This amount is equal to the fiscal year 2010 funding level for the Title VIII programs.

### NURSING EDUCATION

Health inequities, inflated costs, and poor healthcare outcomes are intensifying because of today's shortfall of appropriately prepared registered nurses (RNs) and licensed practical nurses (LPNs). With 4.5 million active, licensed RNs/LPNs, nurses are the primary professionals delivering quality healthcare in the Nation. According to the Bureau of Labor Statistics (BLS), the RN workforce is projected to grow by 19.4 percent from 2012 to 2022, resulting in 1,052,600 job openings due to growth and replacement needs. BLS also calculates the LPN workforce will grow by 25 percent resulting in 363,100 job openings during the same timeframe. This increase is fueled by technological advancements for treatments, preventive care needs, expanding demand from new health reform enrollments, and accelerating demand from the two million Baby Boomers aging into Medicare every year. The situation is further affected by the needed replacement of some 526,800 jobs vacated by RNs and 182,900 vacated by LPNs who will leave the profession and/or retire by 2022.

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[6] Quality Improvement in Primary Care Settings, National Kidney Disease Education Program, National Institutes of Health, NIDDK, October 10, 2012 http://nkdep.nih.gov/identify-manage/quality-improvement.shtml.

The nursing shortage continues to outpace the level of Federal resources allocated by Congress to help alleviate it. Appropriations for nursing education are inconsistent with the healthcare reality facing our Nation today. For the last 50 years, the Title VIII nursing workforce development programs have provided training for entry-level and advanced practice registered (APRNs) nurses to improve the access to, and quality of, healthcare in underserved communities. The Title VIII programs are fundamental to the infrastructure delivering quality, cost-effective healthcare. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. Insufficient Federal investments in the nursing workforce are a shortsighted course of action that further jeopardizes access to, and the quality of, the Nation's healthcare delivery.

The current Federal funding falls short of the healthcare inequities facing our Nation. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in funding fill the gap generated by a 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

## THE NURSE PIPELINE AND EDUCATION CAPACITY

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and States. As the United States tackles the workforce shortage that exacerbates the stress in the healthcare system, nursing programs across the country are rejecting qualified candidates because there is not enough faculty to teach them. Sixty-four percent of all nursing programs turn away qualified applicants. Pre-licensure nursing programs ? which serve as the gateway into the nursing workforce ? reject 72 percent of qualified applicants due to limited space.

NLN research on America's nearly 60,000 nurse educators shows that a core cause of the shortage is an aging and overworked faculty who earn less than nurses entering clinical practice do. Sixty percent of all full-time nurse faculty members are 45- to 60-years old. Fifty-five percent of nurse faculty says they are likely to leave academic nursing by 2020. BLS projects a need of 35 percent more faculty members to meet the expected increase in demand. In addition, with 10,200 current faculty members expected to retire, 34,200 new nursing instructors will be needed by 2022.

## EQUALLY PRESSING IS LACK OF DIVERSITY

Health disparities are multi-dimensional and exist throughout the United States. These preventable differences in health and health outcomes adversely affect individuals who experience obstacles based on race/ethnicity; religion; socioeconomic status; age; cognitive, sensory, or physical disability; gender identity; and/or geography. The NLN's goal to attain health equity requires valuing every person equally, with enduring efforts to address avoidable inequalities and injustices.

Besides representing an untapped talent pool to remedy the nationwide nursing shortage, diversity in nursing is essential to developing a healthcare system that understands and addresses the needs of our rapidly changing population. Our Nation is enriched by cultural complexity—37 percent of our population identify as racial and ethnic minorities. Yet diversity eludes the nursing student and nurse educator populations. Minorities only constitute 26 percent of the student population and males only 16 percent of pre-licensure RN students. A survey of nurse educators conducted by the NLN and the Carnegie Foundation's Preparation for the Professions Program found that only 7 percent of nurse educators were minorities compared with 16 percent of all U.S. faculty. The lack of faculty diversity limits nursing schools' ability to deliver culturally appropriate health professions education.

Besides representing an untapped talent pool to remedy the nursing shortage, ethnic, cultural, and gender-diverse minorities in nursing are essential to developing a healthcare system that understands and addresses the needs of our rapidly diversifying population. Workforce diversity is needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to healthcare inequities.

## TITLE VIII FEDERAL FUNDING REALITY

Today's undersupply of appropriately prepared nurses and nurse faculty, as well as the projected loss of experienced nurses over the next decade, does not bode well for our Nation. The Title VIII nursing workforce development programs are a com-

prehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. HRSA's Title VIII data below provide a perspective on current Federal investments.

*Advanced Nursing Education (ANE)*

The ANE program supports infrastructure grants to schools of nursing for advanced practice programs preparing nurse-midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, nurse educators, public health nurses, or other advanced level nurses. In fiscal year 2013, ANE program grantees trained 10,504 nursing students and produced 2,475 graduates. In addition, 36 percent of students trained were underrepresented minorities and/or from disadvantaged backgrounds. The majority of ANE students were female (90 percent) and between ages 20 and 29 (31 percent).

*Nursing Workforce Diversity (NWD)*

NWD grants increase educational opportunities for individuals from disadvantaged backgrounds (including racial and ethnic minorities underrepresented in nursing) through scholarship or stipend support, pre-entry preparation, and retention activities. In fiscal year 2013, the number of nursing program students trained was 6,691, 2,419 nursing students graduated from nursing programs, and grantees of the NWD program provided scholarships to 1,416 students.

*Nurse Education, Practice, Quality, and Retention Grants (NEPQR)*

NEPQR addresses the critical nursing shortage via projects to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. The NEPQR program trained more than 1,289 BSN students in fiscal year 2013. The NEPQR program funded the Veterans' Bachelor of Science in Nursing (VBSN) program for the first time in fiscal year 2013 and made awards to nine schools. Forty-five veterans were enrolled in BSN degree programs and five graduated with a BSN degree. It is estimated that 42 percent of participating veterans were underrepresented minorities in the field of nursing, and 56 percent reported coming a financially and/or educationally disadvantaged background. Lastly, the NEPQR program funded several Nurse Managed Health Clinics (NMHC) with the primary purpose of creating infrastructure and serving as clinical training sites for students across the health professions. It is estimated that more than 900 health professions students were trained because of these activities

*Nurse Faculty Loan Program (NFLP)*

NFLP supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. Ongoing NFLP support for faculty production is critical to building the pipeline that assures the full capacity of the Nation's future nursing workforce. Targeting a portion of those funds for minority faculty preparation is fundamental to achieving that goal. In fiscal year 2013, the NFLP supported 2,401 students pursuing faculty preparation. Seventeen percent of students who received a loan reported coming from a disadvantaged background and about one out of every four students receiving the NFLP loans were underrepresented minorities.

*Comprehensive Geriatric Education Program (CGEP)*

CGEP provides support to educate individuals in providing geriatric care for the elderly. This goal is accomplished through curriculum development and dissemination, continuing education, and traineeships for individuals preparing for advanced nursing education degrees. In fiscal year 2013, CGEP grantees awarded traineeships to 77 students—the majority of whom (70 percent) were pursuing a Master's Degree in Nursing to become nurse practitioners in the fields of Adult gerontology or Acute Care in Adult Gerontology. A majority of students received clinical training in a medically underserved community (62 percent) and/or a primary care setting (74 percent).

*NURSE Corps Scholarship and Loan Repayment Program (NURSE Corps)*

NURSE Corps offers to individuals, who are enrolled or accepted for enrollment as full-time or part-time nursing students, the opportunity to apply for funds. Upon graduation, a nurse is required to work in a healthcare facility with a critical shortage of nurses for no less than 2 years. The NURSE Corps repays up to 85 percent of nursing student loans in return for at least 3 years of practice in a designated nursing shortage area. The trends in nursing projections suggest that there is a

greater need to focus on distribution and diversity in the RN and LPN workforce. In fiscal year 2014, the NURSE Corps loan repayment program made 667 loan repayment awards and 412 continuation awards. The NURSE Corps scholarship program made 242 new scholarship awards and 13 continuation awards during the same time period.

The NLN urges the subcommittee to fund the Title VIII nursing workforce development programs at the fiscal year 2010 funding level of $244 million in fiscal year 2016.

[This statement was submitted by Beverly Malone, Ph.D., RN, FAAN, Chief Executive Officer and Marsha Adams, Ph.D., RN, CNE, FAAN, ANEF, President, National League for Nursing.]

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## PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and Members of the Subcommittee, thank you for this opportunity to provide testimony regarding funding of critically important Federal programs that impact those affected by multiple sclerosis. We urge the Subcommittee to provide the following in fiscal year 2016: at least $32 billion for the National Institutes of Health (NIH); $5 million for the Lifespan Respite Care Program; robust support for Medicare and Medicaid; and $12.7 billion for the Social Security Administration (SSA).

Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease.

The National MS Society sees itself as a partner to the government in many critical areas. As we advocate for NIH research, we do so as an organization that in 2014, funded approximately $50 million in MS research through funds generated through the Society's fundraising efforts. And as we advocate for Lifespan Respite funding, we do so as an organization that works to provide some level of respite relief for caregivers. So while we're here to advocate for Federal funding, we do it as an organization that commits tens of millions of dollars each year to similar or complementary efforts as those being funded by the Federal Government.

### NATIONAL INSTITUTES OF HEALTH

As mentioned previously, the National MS Society invested $50 million to MS research in 2014 and sees the NIH as an invaluable partner to stop MS in its tracks, restore function and end MS forever. Over the years, NIH research projects have helped make significant progress in understanding MS, however declining funding has directly affected its recent ability to advance the field of research. Approximately $102 million of fiscal year 2014 NIH-appropriated funding was directed to MS-related research. Since fiscal year 2011, funding has decreased by $20 million.

Twenty years ago, there were no MS therapies or medications—now there are twelve. The NIH provided the basic research necessary so that these therapies could be developed. NIH scientists were among the first to report the value of MRI in detecting early signs of MS and have enhanced knowledge about how the immune system works and its role in the development of MS lesions. Despite this progress, there are still no treatments approved for people living with progressive MS. Only with continued investment will the innovation momentum continue, allowing us to find successful treatments for those with progressive MS and a cure for all.

The NIH also directly supports jobs in all 50 States and 17 of the 30 fastest growing occupations in the U.S. are related to medical research or healthcare. More than 83 percent of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State.

For these reasons, the Society urges Congress to provide at least $32 billion for the NIH in fiscal year 2016.

### LIFESPAN RESPITE CARE PROGRAM

Up to one quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver. According to a 2011 AARP report, 61.6 million family caregivers provided care at some point during 2009 and the value of their uncom-

pensated services was approximately $450 billion per year. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities.

Family caregiving, while essential, can be draining and stressful. A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that on average, caregivers spend 24 hours a week providing care. Sixty 4 percent of caregivers were emotionally drained, 32 percent suffered from depression and 22 percent have lost a job due to caregiving responsibilities.

The Lifespan Respite Care Program, enacted in 2006 under President Bush, provides competitive grants to States to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite programs are often the only open door to needed respite services.

For these reasons, the National MS Society asks that Congress provide $5 million for the Lifespan Respite Care Program in fiscal year 2016.

## CENTERS FOR MEDICARE & MEDICAID SERVICES

*Medicare*.—It is estimated that over 20 percent of the MS population relies on Medicare as its primary insurer. The majority of these individuals are under the age of 65 and receive the Medicare benefit as a result of their disability. Of particular importance to the MS community are: having appropriate reimbursement levels for Medicare providers; , maintaining access to diagnostics and durable medical equipment;, protecting access to needed speech, physical and occupational therapy services without arbitrary coverage limits or documentation requirements; updating local coverage determinations to keep pace with advances in care; and discouraging overly burdensome cost-sharing for prescription drugs.

*Medicaid*.—Medicaid provides comprehensive health coverage to over eight million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. The latest statistics (which are pre-recession) show that about 5–10 percent of people with MS have Medicaid coverage. The most recently available data (2007) reveals that the average annual direct and indirect (e.g. lost wages) cost for someone with MS in the U.S. is approximately $69,000. After years of paying to manage their disease, some people with MS have spent the vast majority of their earnings and savings, making their financial situation so dire that Medicaid becomes their only option for health coverage.

The National MS Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program. Any of these proposals would merely shift costs to States, forcing States to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. The Society also urges Congress to protect and promote access to home- and community-based care in line with the 1999 U.S. Supreme Court decision Olmstead.

## SOCIAL SECURITY ADMINISTRATION

Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. The National MS Society urges Congress to provide $12.7 billion for the SSA's administrative budget so that it can continue efforts to reduce hearings and disability backlogs, pay monthly benefits in a timely manner, and determine post-entitlement issues in a timely manner.

## CONCLUSION

The National MS Society thanks the Committee for the opportunity to provide written testimony and our recommendations for fiscal year 2016 appropriations. The agencies and programs we have discussed are of vital importance to people living with MS and we look forward to continuing to working with the Committee to help move us closer to a world free of MS. Please don't hesitate to contact me with any questions.

[This statement was submitted by Laura Weidner, Senior Director, Federal Government Relations.]

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PREPARED STATEMENT OF THE NATIONAL NETWORK TO END DOMESTIC VIOLENCE

Labor, Health and Human Services Appropriations Subcommittee Chairman Blunt, Ranking Member Murray, Chairman Cochran, Ranking Member Mikulski and distinguished members of the Appropriations Committee, thank you for this opportunity to submit testimony on the importance of investing in Family Violence Prevention and Services Act (FVPSA) and Violence Against Women Act (VAWA) programs. I sincerely thank the Committee for its ongoing support for these life-saving programs.

I am the President and CEO of the National Network to End Domestic Violence (NNEDV), the Nation's leading voice for domestic violence survivors and their advocates. We represent all of the 56 State and territorial domestic violence coalitions, each of which is a member of NNEDV, their nearly 2,000 member domestic violence and sexual assault programs, as well as the millions of victims they serve. Our direct connection with victims and victim service providers gives us a unique understanding of their needs and the vital importance of continued Federal investments. I am submitting this testimony to request a targeted investment of $253 million in Family Violence Prevention and Services Act (FVPSA), Violence Against Women Act (VAWA) and related programs administered by the U.S. Department of Health and Human Services fiscal year 2016 Budget (specific requests detailed below).

*Incidence, Prevalence, Severity and Consequences of Domestic and Sexual Violence*.—The crimes of domestic and sexual violence are pervasive, insidious and life-threatening. Recently, the Centers for Disease Control and Prevention (CDC) released the first-ever National Intimate Partner and Sexual Violence Survey (NISVS) which found that domestic violence, sexual violence, and stalking are widespread. Domestic violence affects more than 12 million people each year and nearly three in ten women and one in four men have experienced rape, physical, violence, or stalking in his or her lifetime. Female victims of rape, physical violence, or stalking by an intimate partner experienced severe impacts such as fear, concern for their safety, need for medical care, injury, need for housing services, and missing work or school.

The CDC has estimated that 854,000 women in Missouri and 1,094,000 women in Washington State have experienced rape, physical violence, or stalking by an intimate partner in their lifetime.[1] The terrifying conclusion of domestic violence is often murder, and every day in the United States, an average of three women are killed by a current or former intimate partner.[2] The cycle of intergenerational violence is perpetuated as children are exposed to violence. Approximately 15.5 million children are exposed to domestic violence every year.[3] One study found that men exposed to physical abuse, sexual abuse and witnessing adult domestic violence as children were almost 4 times more likely than other men to have perpetrated domestic violence as adults.

In addition to the terrible cost domestic and sexual violence have on the lives of individual victims and their families, these crimes cost taxpayers and communities. The cost of intimate partner violence exceeds $5.8 billion each year, $4.1 billion of which is for direct healthcare services.[4] Domestic violence costs U.S. employers an estimated $3 to $13 billion annually.[5]

Despite this grim reality, we know that when a coordinated response is developed and immediate, and essential services are available, victims can escape from life-threatening violence and begin to rebuild their lives. To address unmet needs and build upon its successes, FVPSA and VAWA programs should receive significant in-

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[4] National Center for Injury Prevention and Control. Costs of Intimate Partner Violence Against Women in the United States. Atlanta (GA): Centers for Disease Control and Prevention; 2003.

[5] Bureau of National Affairs Special Rep. No. 32, Violence and Stress: The Work/Family Connection 2 (1990); Joan Zorza, Women Battering: High Costs and the State of the Law, Clearinghouse Rev., Vol. 28, No. 4, 383, 385.

creases in the fiscal year 2016 Labor, Health and Human Services Appropriations bill.

*Family Violence Prevention and Services Act (FVPSA) (Administration for Children and Families)—$175 million request*.—Since its passage in 1984 as the first national legislation to address domestic violence, FVPSA has remained the only Federal funding directly for shelter programs. Now in its 30th year, FVPSA has made substantial progress toward ending domestic violence. Despite the progress and success brought by FVPSA, an unconscionable need remains for FVPSA-funded victim services.

There are more than 2,000 community-based domestic violence programs for victims and their children (approximately 1,500 of which are FVPSA-funded through State formula grants). These programs offer services such as emergency shelter, counseling, legal assistance, and preventative education to millions of adults and children annually and are at the heart of our Nation's response to domestic violence. A recent multi-State study conclusively shows that the Nation's domestic violence shelters are addressing victims' urgent and long-term needs and are helping victims protect themselves and their children.

This same study found that, if shelters did not exist, the consequences for victims would be dire, including "homelessness, serious losses including [loss of] children [or] continued abuse or death."[6] Additionally, non-residential domestic violence services are essential to addressing victims' needs. Such programs provide a wide variety of services to victims including counseling, child care, financial support, and safety planning. Without the counseling services she received from her local domestic violence program, one victim said, "I would not be alive, I'm 100 percent certain about that."[7]

*The Increased Need for Funding: to Maintain Programs and Bridge the Gap*.—Many programs across the country use their FVPSA funding to keep the lights on and their doors open. We cannot overstate how important this funding is: victims must have a place to flee to when they are escaping life-threatening violence. As increased training for law enforcement, prosecutors and court officials has greatly improved the criminal justice system's response to victims of domestic violence, there is a corresponding increase in demand for emergency shelter, hotlines and supportive services. Additionally, demand has increased as a result of the economic downturn, and victims with fewer personal resources become increasingly vulnerable. Since the economic crisis began, three out of four domestic violence shelters have reported an increase in women seeking assistance from abuse.[8] As a result, shelters overwhelmingly report that they cannot fulfill the growing need for these services.

Each year NNEDV releases a report entitled Domestic Violence Counts: A 24-hr National Census of Domestic Violence Services (Census). The report revealed that in just 1 day in 2014, while more than 67,000 victims of domestic violence received services, almost 10,000 requests for services went unmet, due to lack of funding and resources. Of those unmet requests, 56 percent were for safe shelter. In 2014, domestic violence programs laid off nearly 1,400 staff positions including counselors, advocates and children's advocates (in addition to the 1,700 laid off in 2013), and also had to reduce or completely eliminate over 1,800 services including emergency shelter, legal advocacy, and counseling. I strongly encourage you to read NNEDV's DV Counts Census (www.nnedv.org/census) to learn more about the desperate needs of victims State-by-State and nationally.

In fiscal year 2013, domestic violence programs funded by FVPSA provided shelter and non-residential services to over 1.3 million victims. Due to lack of capacity, however, an additional 186,552 requests for shelter went unmet. Since 2011, at least 19 local domestic violence programs across the country have been forced to close entirely.

For those individuals who are not able to find safety, the consequences can be extremely dire, including continued exposure to life-threatening violence or homelessness. It is absolutely unconscionable that victims cannot find safety for themselves and their children due to a lack of adequate investment in these services. In order to help meet the immediate needs of victims in danger and to continue this work to prevent and end domestic violence, FVPSA funding must be increased to its authorized level of $175 million.

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ADDITIONAL REQUESTS

National Domestic Violence Hotline (Administration for Children and Families)—$5 million; DELTA Prevention Program (Centers for Disease Control and Injury Prevention)—$6 million; Rape Prevention and Education (RPE) (Centers for Disease Control and Injury Prevention)—$50 million; Preventative Health and Health Services Block Grant, Rape Set-Aside—$7 million.

[This statement was submitted by Kim Gandy, President and CEO, National Network to End Domestic Violence.]

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PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of state respite coalitions, respite providers, family caregivers, national, State and local organizations that support respite. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 100 national, State and local groups. The NRC is requesting that the Subcommittee include $5.0 million for the Lifespan Respite Care Program in the fiscal year 2016 Labor, HHS, and Education Appropriations bill as recommended in the President's fiscal year 2016 budget. This will enable:

—State replication of best practices in Lifespan Respite to allow family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today, saving Medicaid billions;
—Improvement in the quality of respite services currently available;
—Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
—Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

*Who Needs Respite?*—A 2013 Pew Research Center survey found that four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30 percent in 2010 (Fox, S, et al, 2013). A new RAND Corporation study estimates the value of informal caregiving in the U.S. by friends and relatives of the aging at $522 billion a year. Replacing that care with unskilled paid care at minimum wage would cost $221 billion, while replacing it with skilled nursing care would cost $642 billion annually (Chari, et al., 2014). The value of caregiving increases by at least $100 billion when caregivers of younger persons are included. Caregiver support is a lifespan issue with the majority of family caregivers caring for someone under age 75 (56 percent) (National Alliance for Caregiving (NAC) and AARP, 2009).

National, State and local surveys have shown respite to be the most frequently requested service of the Nation's family caregivers (The Arc, 2011; National Family Caregivers Association, 2011). Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (NAC and AARP, 2009). Yet respite is in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The NAC 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers were "finding time for myself" (32 percent), "managing emotional and physical stress" (34 percent), and "balancing work and family responsibilities" (27 percent), nearly 90 percent of family caregivers across the lifespan are not receiving respite services at all (NAC and AARP, 2009).

A 2014 report prepared by the Rand Corporation for the Elizabeth Dole Foundation, Hidden Heroes: America's Military Caregivers, recommended that respite care should be made more widely available to military caregivers (Ramchand, et al., 2014). The Dole Foundation's Respite Impact Council recently found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

Families of the wounded warriors, military personnel who returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions, don't have full access to respite. Even with enactment of the VA Family Caregiver Support Program which serves only veterans since 9/11, the need for respite will remain high for all veterans and their family caregivers. A 2010 survey found that caregivers whose veterans have PTSD are about half as likely as other caregivers to receive respite (11 percent vs. 20 percent) (NAC, November 2010). Sixty-eight percent of veterans' caregivers reported their situation as highly stress-

ful compared to 31 percent of caregivers nationally, and three times as many say there is a high degree of physical strain (40 percent vs. 14 percent) (NAC, 2010). Veterans' caregivers specifically asked for up-to-date lists of respite providers in their communities and help to find services, the very thing Lifespan Respite is charged to provide (NAC, 2010).

An estimated 80 percent of all long-term care in the U.S. is provided at home. This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living with their aging parents or other caregivers, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

*Respite Barriers and the Effect on Family Caregivers*.—Barriers to accessing respite include fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. A critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to help States eliminate barriers through improved coordination and capacity building.

While most families want to care for family members at home, research shows that family caregivers are at risk for serious emotional, mental, and physical health problems (Family Caregiver Alliance, 2006). Parents of children with special healthcare needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing (TD) children (McBean, A, et al, 2013). When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health (American Psychological Association, nd).

Supports that would ease family caregiver stress, most importantly respite, are too often out of reach or completely unavailable. Restrictive eligibility criteria preclude many families from receiving services. Children with disabilities age out of the system when they turn 21 and lose services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88 percent), emotional stress (81 percent) and emotional upset or guilt (81 percent); 1 out of 5 families (20 percent) report that someone in the family quit their job to provide care; and more than 75 percent of family caregivers could not find respite services (The Arc, 2011). Respite may not exist at all for those with Alzheimer's, with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions.

*Respite Benefits Families and is Cost Saving*.—Respite has been shown to help reduce stress and improve the health and well-being of family caregivers that in turn helps avoid or delay out- of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A study of parents of children with autism found that respite was associated with reduced stress and improved marital quality (Harper, Amber, et al, 2013). A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent (NAC, 2012).

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for one person with Alzheimer's can save Medicaid and other government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every $1,000 States spent on respite, there was an 8 percent drop in the odds of hospitalization (Mandell, David S., et al, 2012). In the private sector, U.S. businesses lose from $17.1 to $33.6 billion per year in lost productivity of family caregivers (MetLife Mature Market Institute, 2006). Higher absenteeism among working caregivers costs the U.S. economy an estimated $25.2 billion annually (Witters, D., 2011). Respite for working family caregivers could improve job performance, saving employers billions.

*Lifespan Respite Care Program Helps*.—The Federal Lifespan Respite program, administered by the Administration for Community Living (ACL) provides competitive grants to eligible State agencies. Congress appropriated $2.5 million each year from fiscal year 2009—fiscal year 2012 and slightly less in fiscal year 2013-fiscal year 2015. Since 2009, 32 States and DC have received Lifespan Respite Grants.

States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining respite access. Lifespan Respite helps States maximize use of limited resources across age and disability groups and deliver services more efficiently. Increasing funding, even slightly, for the program in fiscal year 2016 could allow several new States to start Lifespan Respite Programs and help assist the remaining grantees to complete the work that they have started. As it is, given the limited funding for fiscal year 2015, no new States may be funded and fewer of the current grantees will be funded to carry on their important work.

*How is Lifespan Respite Program Making a Difference?*—With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

—In TN and RI, the Lifespan Respite program is building respite capacity by expanding volunteer networks of providers by recruiting University students or Senior Corps volunteers or expanding the national TimeBanks model for establishing voluntary family cooperative respite strategies.

—In Texas, the Lifespan Respite program has established a statewide Respite Coordination Center, and an online database.

—In SC, the state respite coalition and the Lifespan Respite program are partnering in new ways with the untapped faith community to provide respite, especially in rural areas.

—The North Carolina Lifespan Respite Program has challenged each of its 100 counties to improve respite service delivery locally, and has partnered with the Money Follows the Person program to develop family caregiver peer-to-peer support and respite.

—In NH, new providers have been recruited and trained through partnerships with the NH National Alliance on Mental Illness, New Hampshire Family Voices, and others to expand the pool of respite providers to work with teens and older individuals with mental health conditions or other groups where respite is in short supply.

Partnerships between State agencies are changing the landscape. The AZ Lifespan Respite program housed in Division of Aging and Adult Services partnered with the State's Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the State's Federal Transit Administration's to develop mobile respite to serve isolated rural areas of the State. States are building respite registries and "no wrong door systems" to help family caregivers access respite and funding sources. AL, NC, NV, OK, RI, SC, TN, WA and others are using Lifespan Respite grants to implement consumer-directed respite so that family caregivers have control over the respite they select. Funding must be maintained to help sustain these innovative State efforts. States are developing comprehensive sustainability plans, but without Federal support, many of the grantees will be cut off before they have had a chance to have a lasting impact.

No other Federal program mandates respite as its sole focus, helps ensure respite quality or choice, and allows funds for respite start-up, training or coordination to address accessibility and affordability issues for families. With tens of millions of families affected, caregiving is a public health issue requiring an immediate proven preventive response, such as respite. We urge you to include at least $5 million in the fiscal year 2016 Labor, HHS, and Education appropriations bill. This will allow Lifespan Respite Programs to be replicated and sustained. Families, with access to respite, will be able to keep their loved ones at home, saving Medicaid and other Federal programs, billions of dollars.

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[This statement was submitted by Jill Kagan, Chair, National Respite Coalition.]

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## PREPARED STATEMENT OF THE NATIONAL SAFETY COUNCIL

Chairman Blunt, Ranking Member Murray, and Members of the subcommittee, thank you for the opportunity to submit testimony regarding the National Safety Council appropriations priorities. My name is Deborah Hersman, and I am President and CEO of the National Safety Council. We are a more than 100 year-old Congressionally chartered nonprofit safety organization dedicated to saving lives by preventing injuries and deaths at work, in homes and communities, and on the roads through leadership, research, education, and advocacy. Our more than 13,000 member companies represent nearly 8 million employees at more than 53,000 U.S. worksites. Today I am seeking support for $592.1 million for the Occupational Safety and Health Administration (OSHA) and $334.863 million for the National Institute for Occupational Safety and Health (NIOSH), two agencies whose work is vital to protecting the health and safety of America's workers. I am also seeking support for increased funding to fight the continuing prescription opioid abuse epidemic, including $68 million for the Centers for Disease Control and Prevention (CDC) and $210.9 million for the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Substance Abuse Prevention.

*Occupational Safety and Health Administration*

The National Safety Council was founded more than 100 years ago because a group of industrialists were concerned about the high rate of fatalities and injuries in their workplaces. They believed that these losses could be prevented by placing a greater focus on the safety of workplaces and the work being performed. They were right, and ever since then we have made great progress reducing the number of deaths and injuries in the workplace—some estimates say we've saved more than 6 million lives. But we continue to lose about 4,000 workers on the job every year, so there is still a lot of work to be done.

We believe that an effective and efficient OSHA is critical to sustaining this positive trend. NSC supports balanced, stable funding for OSHA that adequately funds all the agency's key functions, including compliance assistance and support to companies striving for safety excellence, the timely promulgation of regulations to protect America's workers, enforcement actions against companies that fail to comply with OSHA standards, and whistleblower protection for workers.

The Council supports the top line funding level of $592.1 million for the agency included in the President's fiscal year 2016 budget request, and we strongly encourage the committee to fund the agency at a minimum of this funding level. While the Council is pleased that OSHA rulemaking and enforcement efforts have been restored to pre-sequester funding levels, we continue to have strong concerns about funding constraints placed on the agency's Federal compliance assistance efforts, which are presently funded at $68.4 million, more than 10 percent less than fiscal year 2012 enacted levels. The President's proposed funding level of $73 million would restore most of these funds.

*National Institute for Occupational Safety and Health*

Funding NIOSH at a minimum of the fiscal year 2015 program level of $334.863 million, and preserving the fiscal year 2015 level of $24 million for the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and $27.5 million for the Education and Research Centers (ERCs), is essential to ensuring that NIOSH can fulfill its mission of saving lives and preventing injuries.

NIOSH programs play an important role in reducing workplace injuries and fatalities. NIOSH's primary responsibility is to conduct research and make recommendations for the prevention of work-related injuries and illnesses. NIOSH works to ensure the health and safety of the American workforce through research, education and training. The Council is disheartened to see the President's budget request again target for elimination the Institute's Agriculture, Forestry and Fishing (AgFF) Sector Program and Education and Research Centers (ERCs).

NIOSH established the AgFF program in 1990 in response to evidence that agricultural workers were suffering higher rates of injury and illness than other U.S. workers. The agriculture, forestry, and fishing, industry fatality rate is more than 8 times that of the all-industry average. Yearly, almost 18,000 workers in this sector are injured seriously enough to require time away from work.[1] Daily, an average of nearly 330 workers in this sector sustain injuries serious enough to require medical consultation, and over 1 worker dies from an injury suffered at work.[2] Today, the initiative includes nine regional centers and one national center to address children's farm safety. These centers conduct vital research leading to evidence-based standards that save lives. The AgFF Program is the only substantive Federal effort to meet the obligation to ensure safe conditions for workers in this sector, and it is effective.

NIOSH supports education and research in occupational health through academic degree programs and research opportunities, primarily through 18 university-based ERCs located at leading universities around the country serving all 50 States. The mission of the ERCs is to reduce work-related injuries and illnesses in the U.S. by performing prevention research and by educating, through degree programs and continuing education, high-quality professionals who implement programs to improve occupational health and safety and minimize the dangers faced by workers across the country. The ERCs provide programs in a unique group of disciplines that benefit employers of all sizes and industries in every part of the country. Currently, the ERCs are responsible for supplying many of the country's OSH graduates who will go on to fill professional roles. With an aging occupational safety and health workforce, and a critical shortage of qualified OSH professionals, ERCs are essential to educating the next generation of professionals.

PRESCRIPTION DRUG OVERDOSES

Today, fatalities from drug overdose, mainly due either directly or indirectly to opioid pain killers, have become the leading cause of unintentional death. Two of the agencies working to address the prescription drug overdose epidemic are the Centers for Disease Control and Prevention and the Substance Abuse and Mental Health Services Administration.

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[1] U.S. Bureau of Labor Statistics, U.S. Department of Labor. (2013). Table 2. numbers of nonfatal occupational injuries and illnesses by case type and ownership, selected industries, 2012. Retrieved February 12, 2014, from http://www.bls.gov/news.release/osh.t02.htm.

[2] National Safety Council. (2014). Injury Facts®, 2014 Edition.

*CDC Injury Center*

The CDC's Injury Center addresses the need for a coordinated effort to prevent injuries in the United States, and functions as a focal point for the public health approach to preventing injuries. CDC Injury Center activities have focused on two main drivers of the prescription drug overdose problem—high-risk prescribing and high-risk patients. Much of their effort to date has focused on conducting research on the issue, with several peer-reviewed materials recently published.

Funding the Injury Center's prescription drug efforts at the $68 million funding level included in the President's fiscal year 2016 budget request would immeasurably advance the agency's ability to make a significant impact on the epidemic. CDC would use these additional funds to expand the Prescription Drug Overdose Prevention for States program to fund all 50 States and the District of Columbia to create a unified, national approach to the epidemic. In the past decade, we have witnessed this epidemic spread from the Appalachian States of Kentucky, Tennessee, Ohio and West Virginia to become a serious concern on a national scale, causing thousands of deaths and destroying countless lives. These funds would be used for activities such as enhancing prescription drug monitoring programs, implementing guidelines to improve physician prescribing behaviors, and enhancing insurance mechanisms to improve prevention.

*Substance Abuse and Mental Health Services Administration*

Lastly, I'd like to discuss funding for the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA leads public health efforts to address behavioral health issues by reducing the impact of substance abuse.[3] The Center for Substance Abuse Prevention (CSAP) is responsible for developing policies, programs, and services to prevent the onset of illegal drug use, prescription drug misuse and abuse, alcohol misuse and abuse, and underage alcohol and tobacco use.

The National Safety Council requests that Congress at a minimum fund CSAP at the $210.9 million funding level requested in the President's fiscal year 2016 budget, including $12 million for the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths program, to advance the distribution and use of naloxone.

Naloxone treats opioid and heroin overdoses by stopping the respiratory depression caused by too much of these drugs. Available by prescription, it is not a controlled substance and has no demonstrated potential for abuse. Research has shown that administering naloxone is a cost-effective and life-saving treatment, and the use of naloxone has reversed more than 10,000 overdoses.[4] Another study of naloxone use among heroin users estimated that 6 percent of overdose deaths were prevented due to the distribution of naloxone, with 1 death prevented for every 227 naloxone kits distributed.[5]

Funding this new grant program in CSAP will provide for grants to 10 States to address the overdose burden. States can use these funds to purchase naloxone, equip first-responders in high-risk communities, support education on the use of naloxone and provide the necessary materials to assemble overdose kits.[6] In a time of tight budgets at the Federal, State and municipal levels, ensuring a dedicated funding stream for these life-saving efforts is critical to driving down the rate of prescription opioid overdose.

Thank you again for the opportunity to submit testimony for the record.

[This statement was submitted by Deborah Hersman, President and CEO, National Safety Council.]

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## PREPARED STATEMENT OF THE NATIONAL SENIOR CORPS ASSOCIATION

Mr. Chairman, Members of the Committee, my name is Gary Goosman and I am Director of the Senior Programs Division at the Corporation for Ohio Appalachian Development. I testify today as President of the National Senior Corps Association, representing the interests and ideals of more than 350,000 senior volunteers throughout the country.

SENIOR CORPS is a federally authorized and funded network of national service programs that provides older Americans with the opportunity to apply their life experiences to volunteer service. Senior Corps is comprised of the Foster Grandparent

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[3] SAMHSA. About Us. Accessed from: http://www.samhsa.gov/about-us.

[4] Wheeler E. MMWR: community-based opioid overdose prevention programs providing naloxone—United States, 2010. 2012. Centers for Disease Control and Prevention.

[5] Coffin, P. & Sullivan, S. Cost-effectiveness of distributing naloxone to heroin users for lay overdose reversal. 2013. Annals of internal medicine.

[6] SAMHSA. fiscal year 2016 Congressional Budget Justification.

Program, RSVP, and the Senior Companion Program, through which Americans age 55 and older provide essential services to cost-effectively address critical community needs. I am speaking today about the concern of the NSCA and thousands of elderly Americans that provide services in hundreds of communities. Last year, the President's budget threatened to eliminate service opportunities for approximately 200,000 seniors—nearly two-thirds of those serving in the Retired Senior Volunteer Program (RSVP). This year additional damage will plague these programs if the previous sequestration and other cuts are not mitigated.

As expressed by Congressman DeFazio of Oregon, "Senior Corps and its associated programs have always received strong bipartisan support because they are a cost effective way to meet local community needs and support the health of American seniors. President Nixon signed the Senior Companion Program into law. President Reagan and First Lady Nancy Reagan were consistent champions of the Foster Grandparents Program. President Clinton logically organized Senior Companion, Foster Grandparent, and RSVP under Senior Corps. President George W. Bush continued support of all three programs. This year should be no different.

Unfortunately, the President's fiscal year 2016 budget proposal does not restore cuts the Senior Corps programs absorbed as a result of the sequester, and leaves intact the 20 percent funding cut applied to RSVP in fiscal year 2011."

The NSCA is in full agreement with Congressman DeFazio and with Ann Maura, CEO of Voices for National Service when she recently said, "At a time when record numbers of Americans are stepping forward to serve and increasing numbers of communities are looking for innovative ways to address local challenges, our country should invest in national service programs."

NSCA respectfully requests the reversal of the 20 percent cut to the RSVP program. RSVP programs provide critical support to thousands of small, non-profit organizations that are the primary safety net for low income individuals and families in rural and inner city communities. RSVP engages senior volunteers that allow these organizations to continue their existence and ensures that our safety net assists those in need. NSCA respectfully requests $111,241,000 for the Foster Grandparent Program and $47,007,000 for the Senior Companion Program (restoring funding to levels prior to sequestration). This combined expenditure of $221,248,000 will allow for continued support to existing Senior Corps programs and sponsors.

These grant funds allow existing Senior Corps programs and the nearly 337,000 volunteers to continue providing critical services, including:

*Foster Grandparent Program* provides one-on-one attention to children and youth most at risk in schools, shelters, correctional facilities, early childhood centers and after-school programs. Through a caring, nurturing, mentoring role, Foster Grandparents provide assistance and encouragement to help improve reading skills, school attendance, behavior and the well-being of children in their care. NSCA recommends a return to budget levels from 2013 that would support 27,900 Foster Grandparents contributing 24 million hours (valued at $531,360,000 based on Independent Sector's data) to help over 232,300 children and youth. Foster Grandparents currently serve through more than 320 federally funded programs nationwide and partner with over 10,000 community organizations. Returning to 2013 funding levels means over 232,000 children could be provided tutoring, mentoring and one-on-one attention. This also would provide support for nearly 7,000 children of incarcerated parents and 2,250 children of military families. Foster Grandparents are 55 years of age and older with limited incomes (200 percent of poverty), and serve weekly schedules ranging from 15–40 hours. They are provided with a modest hourly stipends, mileage and meal reimbursements, so that they may volunteer at little or no personal cost to themselves.

*RSVP* connects volunteers 55 and older with service opportunities that impact positive change, improve quality of life and meet critical needs in their communities. Volunteers help build capacity and improve sustainability in agencies and organizations where they serve. RSVP engages seniors in a wide array of community services including health, nutrition, human services, education, community and economic development, and public safety to nonprofit and community based organizations. In 2012 there were 296,000 RSVP volunteers, a decrease of over 100,000 volunteers from the 2010 level of engagement. By restoring funding to 2010 levels, thousands of additional RSVP volunteers could be added to improve upon the 62 million hours of service that was recently delivered (valued at $1,372,680,000 based on Independent Sector's data). This effort would be delivered through more than 685 sponsoring programs nationwide, and work with more than 65,000 community organizations. Volunteers would mentor more than 80,000 children including 16,000 children of prisoners and provided independent living services for 696,000 frail elderly and people with

disabilities. RSVP offers flexible volunteer opportunities with commitments from a few hours a week to 40 hours a week. Volunteers do not receive monetary incentives or stipends.

*Senior Companion Program* provides assistance and friendship to frail individuals who are homebound and, generally, living alone. By taking care of simple chores, providing transportation to medical appointments, and offering contact with the outside world, Senior Companions often provide the essential services that enable frail citizens to remain in their homes. The program meets the growing need for cost effective long-term care for the aging by helping with activities of daily living, friendly visits and providing respite for primary caregivers. By restoring funding to 2013 levels, 13,600 Senior Companions could provide 12.2 million hours of service (valued at $270,108,000 based on Independent Sector's data) through 194 federally funded programs nationwide to help 60,940 frail clients, preventing premature and costly institutionalization. Senior Companions are 55 years of age and older with limited incomes (200 percent of poverty), and serve weekly schedules ranging from 15–40 hours. They are provided with hourly stipends, mileage and meal reimbursements, so that they may volunteer at little or no personal cost to themselves.

Some prime examples of Senior Corps service are:

—Gene Assink, a Washington RSVP volunteer, has logged 34,694 miles since 1999 driving clients to medical appointments and grocery stores, saving clients and agencies over $14,000 in mileage costs. RSVP volunteer, Ted Stegemen, draws intricate plans and directs a team of volunteers to make repairs on older homes of low-income neighbors.

—An angry, temperamental 4th grade boy ended daily trips to the office after being matched with the encouragement and persistence of 91 year-old Missouri Foster Grandparent, Marie Yeakey, and has now graduated from high school.

—While doing routine housework, a Missouri woman's fall resulted in permanent paralysis of her arms and hands. Three Senior Companions provide caregiver respite for her daughter, the mother of three young children ages 7, 5 and 18 months and son-in-law, a long haul truck driver.

It has been stated that baby boomer and senior volunteers represent our Nation's single and fastest growing resource. During this unprecedented economic crisis facing our Nation, the number of baby boomer and senior volunteers should be greatly expanded and mobilized as solutions to the problems facing our local communities. We need to provide the opportunity for thousands more older adults to serve in their communities and enhance the lives of those most in need, including children with special needs, the frail and isolated elderly striving to maintain independence, and expanding the services of local non-profit agencies.

[This statement was submitted by Gary Goosman, President, National Senior Corps Association.]

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## Prepared Statement of the National Technical Institute for the Deaf and Rochester Institute of Technology

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2016 budget request for NTID, one of nine colleges of RIT, in Rochester, N.Y. Created by Congress by Public Law 89–36 in 1965, NTID provides a university technical and professional education for students who are deaf and hard of hearing, leading to successful careers in high-demand fields for a sub-population of individuals historically facing high rates of unemployment and under-employment. NTID students are part of a university (RIT) that includes more than 16,000 hearing students studying at the associate, baccalaureate, master's and doctoral levels. NTID also provides baccalaureate and graduate-level education for hearing students in professions serving deaf and hard-of-hearing individuals.

### BUDGET REQUEST

On behalf of NTID, for fiscal year 2016 I would like to request $68,451,000 for Operations. NTID has worked hard to manage its resources carefully and responsibly. As of Fall 2014, NTID's workforce had been reduced by almost 8 percent as compared to pre-sequestration levels with a corresponding 13 percent decrease in personnel compensation costs. In terms of non-Federal revenues, from fiscal year 2010 to fiscal year 2015, student tuition and fees increased by 37 percent to offset the rising costs of providing a state-of-the-art college education. Additionally, from fiscal year 2006 to fiscal year 2014, NTID raised approximately $21 million in support from individuals and organizations.

NTID's fiscal year 2016 request of $68,451,000 in Operations would allow NTID to admit all qualified students for Fall 2016 enrollment, keep the fiscal year 2016 tuition increase relatively low (3–4 percent), and continue to offer Grants in Aid to more students. With this funding, NTID can continue to hire and maintain crucial positions that support our students, such as sign-language interpreters, captionists, audiologists, etc. These positions were cut as a result of sequestration, causing large waiting lists for these services. With this fiscal year 2016 request, NTID can continue to propose new technical programs for our students, purchase the cutting-edge equipment necessary for their success, and ensure 40-year-old classroom spaces are meeting their needs.

ENROLLMENT

Truly a national program, NTID has enrolled students from all 50 States. In Fall 2014 (fiscal year 2015), NTID's enrollment was 1,387 students. For fiscal year 2016, NTID hopes to maintain an enrollment near 1,400, if resources enable us to do so. NTID's enrollment history over the last 10 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2006—FISCAL YEAR 2015

| Fiscal Year | Deaf/Hard-of-Hearing Students | | | | Hearing Students | | | Grand Total |
|---|---|---|---|---|---|---|---|---|
| | Undergrad | Grad RIT | MSSE | Sub-Total | Interpreting Program | MSSE | Sub-Total | |
| 2015 | 1,153 | 44 | 16 | 1,213 | 146 | 28 | 174 | 1,387 |
| 2014 | 1,195 | 42 | 18 | 1,255 | 147 | 30 | 177 | 1,432 |
| 2013 | 1,269 | 37 | 25 | 1,331 | 167 | 31 | 198 | 1,529 |
| 2012 | 1,281 | 42 | 31 | 1,354 | 160 | 33 | 193 | 1,547 |
| 2011 | 1,263 | 40 | 29 | 1,332 | 147 | 42 | 189 | 1,521 |
| 2010 | 1,237 | 38 | 32 | 1,307 | 138 | 29 | 167 | 1,474 |
| 2009 | 1,212 | 48 | 24 | 1,284 | 135 | 31 | 166 | 1,450 |
| 2008 | 1,103 | 51 | 31 | 1,185 | 130 | 28 | 158 | 1,343 |
| 2007 | 1,017 | 47 | 31 | 1,095 | 130 | 25 | 155 | 1,250 |
| 2006 | 1,013 | 53 | 38 | 1.104 | 116 | 36 | 152 | 1,256 |

MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing Students.
Grad RIT: Other graduate programs at RIT.

NTID ACADEMIC PROGRAMS

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also is expanding the number of its transfer associate degree programs to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees. These transfer programs provide seamless transition to baccalaureate studies in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including sign language interpreting, real-time speech-to-text captioning, and notetaking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op gives students the opportunity to experience a real-life job situation and focus their career choice. Students develop technical skills and enhance vital personal skills such as teamwork and communication, which will make them better candidates for full-time employment after graduation. Last year, 238 students participated in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

STUDENT ACCOMPLISHMENTS

NTID deaf and hard-of-hearing students persist and graduate at higher rates than the national persistence and graduation rates for all students at 2-year and 4-year colleges. For NTID deaf and hard-of-hearing graduates, over the past 5 years, an average of 92 percent have found jobs commensurate with their education level. Of our fiscal year 2013 graduates (the most recent class for which numbers are available), 94 percent were employed 1 year later, with 60 percent employed in business and industry, 31 percent in education/non-profits, and 9 percent in government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In fiscal year 2012, NTID, the Social Security Administration, and Cornell University examined earnings and Federal program participation data for more than 16,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a higher rate and earn more (therefore paying more in taxes) than students who withdraw from NTID or attend other universities. NTID graduates also participate at a lower rate in SSI and SSDI than students who withdrew from NTID.

Using SSA data, at age 50, 78 percent of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73 percent with associate degrees report earnings, compared to 58 percent of NTID deaf and hard-of-hearing students who withdrew from NTID and 69 percent of deaf and hard-of-hearing graduates from other universities. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, $58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and $41,000 for those with associate degrees, compared to $34,000 for deaf and hard-of-hearing students who withdrew from NTID and $21,000 for deaf and hard-of-hearing graduates from other universities. Higher earnings, of course, yield higher tax revenues.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participated in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participated in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

ACCESS SERVICES

NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and Assistive Listening Services.

As enrollments have steadily increased, so has the demand for access services. In fiscal year 2014, 132,055 hours of interpreting were provided—an increase of 13 percent compared to fiscal year 2010. In fiscal year 2014, 21,601 hours of real-time captioning were provided to students—an 11 percent increase over fiscal year 2010. The increase in demand is partly a result of the increase in the number of students enrolled in baccalaureate programs at RIT and the number of students with cochlear implants. In fiscal year 2015, there were 529 deaf and hard-of-hearing students enrolled in baccalaureate programs at RIT, an 11 percent increase compared to fiscal year 2010, and 394 students with cochlear implants, a 44 percent increase over fiscal year 2008.

SUMMARY

It is extremely important that NTID's fiscal year 2016 funding request be granted in order that we might continue our mission to prepare deaf and hard-of-hearing people to excel in the workplace. NTID students persist and graduate at higher rates than national rates for all students. NTID graduates have higher salaries, pay more taxes, and are less reliant on Federal SSI/SSDI payments. NTID's employment rate is 92 percent over the past 5 years. Therefore, I ask that you please consider funding our fiscal year 2016 request of $68,451,000 for Operations.

We are hopeful that the members of the Committee will agree that NTID, with its long history of successful stewardship of Federal funds and outstanding educational record of service with people who are deaf and hard of hearing, remains deserving of your support and confidence. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens. Quite simply, NTID is a Federal program that works.

[This statement was submitted by Dr. Gerard J. Buckley, President, NTID, Vice President and Dean, RIT.]

PREPARED STATEMENT OF THE NATIONAL VIRAL HEPATITIS ROUNDTABLE

The National Viral Hepatitis Roundtable, on behalf of the above listed organizations, respectfully submits this testimony to the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding the fiscal year 2016 Appropriations budget hearing. As a coalition of organizations representing HIV/AIDS, viral hepatitis, drug policy, and faith-based organizations, among others, we are gravely concerned about the public health consequences created by the restriction of Federal funds to local health agencies to provide prevention programming through syringe services programs (SSPs).

Recent headlines such as "Indiana calls in CDC to help with HIV outbreak" should resonate with Members of this subcommittee with jurisdictional oversight of prevention programs. As of March 20th, there were 55 confirmed and 13 preliminary positive cases of HIV from the sharing of drug injection equipment in Indiana along the Kentucky border. In fact, Governor Pence (R-IN) has declared a public health emergency and issued an executive order allowing for the operation of an SSP to help reduce the transmission of blood borne disease.

We therefore urge the Subcommittee to prevent policy riders prohibiting the use of Federal funds for any program for the purpose of distributing needles or syringes for the purpose of preventing the spread of blood borne pathogens from the fiscal year 2016 LHHS Appropriations Bill. Such language prohibits State public health authorities from using Federal prevention funding for syringe services programs which prevent disease transmission, do not encourage drug use or increase crime, promote public safety, and connect participants to healthcare and social services, including drug treatment.

Eliminating the ban (1) has received broad national and international support, (2) supports public and law enforcement safety, (3) provides for desperately-needed and highly-effective HIV and hepatitis C prevention among people who inject drugs (PWID), and (4) is a cost-neutral policy change supporting cost-effective interventions.

BROAD SUPPORT

Despite the persistence of the ban on Federal funds for syringe access, SSPs have enjoyed broad support from many professional and public health entities. Supportive entities in our own government include the CDC,[1] Substance Abuse and Mental Health Services Administration,[2] U.S. Surgeon General,[3] National Institutes of Health,[4] and the White House Offices of National AIDS Policy[5] and National Drug Control Policy.[6] U.S.-based organizations expressing support for syringe access include: the American Medical Association,[7] the American Public Health Association,[8] the National Academy of Sciences,[9] the American Academy of Pediatrics,[10] the American Nurses Association,[11] the American Bar Association,[12] the U.S. Conference of Mayors,[13] and the Infectious Diseases Society of America.[14] Supportive

[1] Http://www.cdc.gov/idu/facts/aed__idu__syr.pdf.
[2] Http://media.samhsa.gov/ssp/.
[3] Https://www.Federalregister.gov/articles/2011/02/23/2011-3990/determination-that-a-demonstration-needle-exchange-program-would-be-effective-in-reducing-drug-abuse.
[4] Http://consensus.nih.gov/1997/1997PreventHIVRisk104html.htm.
[5] 5Https://www.whitehouse.gov/blog/2010/07/16/expanding-access-evidence-based-services-injection-drug-users.
[6] Https://www.whitehouse.gov/blog/2012/01/05/Federal-funding-ban-needle-exchange-programs.
[7] American Medical Association 6/97 Statement on Syringe Exchange.
[8] Http://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/08/08/04/defining-and-implementing-a-public-health-response-to-drug-use-and-misuse.
[9] Http://www.nytimes.com/1995/09/24/weekinreview/sept-17-23-the-aids-epidemic-scientists-endorse-needle-exchanges.html.
[10] Http://pediatrics.aappublications.org/content/94/6/945.
[11] Http://nursingworld.org/MainMenuCategories/Policy-Advocacy/Positions-and-Resolutions/ANAPositionStatements/Position-Statements-Alphabetically/Needle-Exchange-and-HIV.html.
[12] Http://www.americanbar.org/publications/governmental__affairs__periodicals/washingtonletter/2011/april/syringeexchange.html.
[13] U.S. Conference of Mayors. Needle Exchange: Moving Beyond the Controversy. Wash., DC: U.S. Conference of Mayors; 1997.
[14] Http://www.hivma.org/uploadedFiles/HIVMA/News__Announcements/SEP__Press__Release__May__2014__Final__BEM.pdf.

global entities include: the World Health Organization,[15] the World Bank,[16] and the International Red Cross-Red Crescent Society.[17]

It is long past time to treat syringe access for what it is—a critical component of any comprehensive response to the interconnected epidemics of opioid and heroin addiction, HIV/AIDS, hepatitis C, and overdose which have gripped the Nation.

SUPPORTING PUBLIC AND LAW ENFORCEMENT SAFETY

SSPs do much more than provide sterile syringe access. A practical service SSPs are able to provide, thanks to the trust established among PWID, is used syringe collection and disposal. Fear of arrest or incarceration for possession of syringes (considered illegal drug paraphernalia by many States), can result in improper disposal or failure to disclose possession if stopped by law enforcement. When SSPs provide safe disposal, the majority of syringes distributed are returned.[18] Safe disposal reduces the risk of accidental needlestick injuries for the public, whether for children playing in parks or for first-responders at a medical emergency. SSPs' safe disposal services also reduce the risk of needlestick injuries for police officers,[19] an occupational hazard that concerns many officers and their families. Finally, there is no evidence supporting the assertion that SSPs increase either crime or drug use.

EFFECTIVE INFECTIOUS DISEASE PREVENTION

Syringe services programs have been proven over the last 20 years to be highly effective at reducing HIV and hepatitis C transmission,[20] two viruses that disproportionately impact PWID. Many also provide services such as HIV and hepatitis C testing, overdose prevention training, referrals to social services and housing, as well as linkage to medical care, mental healthcare, and drug treatment services for communities not often served by traditional healthcare providers. SSPs are a crucial support for PWID at every point along the continuums of care for both HIV and hepatitis C. The District of Columbia exemplifies this—when Congress lifted a similar ban barring the District from using its own local dollars on SSPs in 2007, the DC Department of Health expanded syringe access services and subsequently reported an 81 percent decrease in new HIV infections among PWID from 2008–2012.[21]

It is a critical time to support SSPs as a tool in addressing the hepatitis C and HIV epidemics. As Americans across the Nation are devastated by the crisis of prescription opioid addiction and overdose, the trend—particularly among youth under 30 in rural and suburban communities—begins with misuse of oral opioid painkillers, to experimenting with injecting, followed often by a transition to heroin.[22] Directly on the heels of this opioid/heroin and overdose crisis, is a new wave of the hepatitis C epidemic, with the Centers for Disease Control and Prevention (CDC) reporting a 75 percent increase in new infections from 2010–2012[23] (likely a significant underestimate due to lack of surveillance infrastructure). In response to the overwhelming burden of hepatitis C in this context, the Kentucky State Legislature passed a comprehensive bill to address these issues in March 2015, effectively legalizing SSPs as part of its package of legislation.[24]

With overlapping modes of transmission, HIV often follows in hepatitis C's tracks, and Indiana is the first to experience a large outbreak of HIV among a network of people injecting an opioid painkiller.[25] As mentioned above, Governor Pence declared the outbreak a public health emergency, with a temporary allowance for SSPs in the county where the outbreak occurred. This was an important step in the right direction, but for interventions like SSPs to be truly impactful, they must be legal, widespread, and fully resourced. We may look to Scotland for a successful countrywide example, which saw a significant decrease in hepatitis C incidence upon expan-

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[15] Http://www.who.int/hiv/topics/idu/needles/en/.

[16] Http://siteresources.worldbank.org/INTURBANHEALTH/Resources/1090754-1242053198381/handbook.pdf, p16.

[17] Http://www.ifrc.org/PageFiles/96733/Red__Cross__spreading__the__light__of__science.pdf.

[18] Http://www.amfar.org/uploadedFiles/—amfarorg/Articles/On__The__Hill/2013/IB%20SSPs%20031413.pdf, p4.

[19] Ibid.

[20] Http://www.who.int/hiv/pub/idu/pubidu/en/.

[21] Http://doh.dc.gov/sites/default/files/dc/sites/doh/page__content/attachments/Newly%20Diagnosed%20HIV%20Cases.pdf, p17.

[22] https://www.aids.gov/pdf/hcv-and-young-pwid-consultation-report.pdf.

[23] Http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm#hepC.

[24] Http://www.cincinnati.com/story/news/politics/beating-heroin/2015/03/24/ky-heroin-deal-reached-last-day/70405676/.

[25] Http://www.indystar.com/story/news/2015/02/25/two-dozen-hiv-cases-diagnosed-southeastern-indiana/23986393/.

sion of two key interventions for PWID: SSPs and opioid substitution therapy.[26] New York achieved a major reduction in HIV/AIDS from 1992, when 52 percent of AIDS cases were attributed to injection drug use, to 2004, when only 5.4 percent of HIV cases were so attributed. The Department of Health credits the Syringe Exchange and Expanded Syringe Access Program with the State's remarkable results.[27]

Finally, it is vital to acknowledge SSPs' pioneering role in providing naloxone access to those at-risk of experiencing or witnessing overdose. SSPs remain uniquely positioned not only to reach PWID with prevention and screening for HIV and hepatitis C, but also to continue to lead the field in overdose prevention, thanks in large part to the positive relationships built with traditionally hard-to-reach communities.

COST-NEUTRAL AND COST-EFFECTIVE

The ban on Federal funds for SSPs takes the form of an annual General Provisions policy rider in the LHHS Appropriations bill. Removing the ban language—or replacing it with verbiage affirming the use of Federal funds for SSPs—is entirely cost-neutral, requiring no offset. Eliminating the ban costs taxpayers nothing; it simply provides States and local jurisdictions the control to best utilize their existing Federal funds to address HIV, viral hepatitis, and overdose prevention.

Additionally, providing sterile syringes to PWID is proven to be highly cost-effective. For every dollar invested in syringe access, approximately $3–8 in HIV treatment are saved.[28] This does not take into account savings from averted hepatitis C infection, avoiding the increased healthcare costs of living with the virus without treatment, the cost of treatment, or the even higher costs of the potential long-term consequences of chronic hepatitis C—end-stage liver disease, liver cancer, and/or liver transplantation.

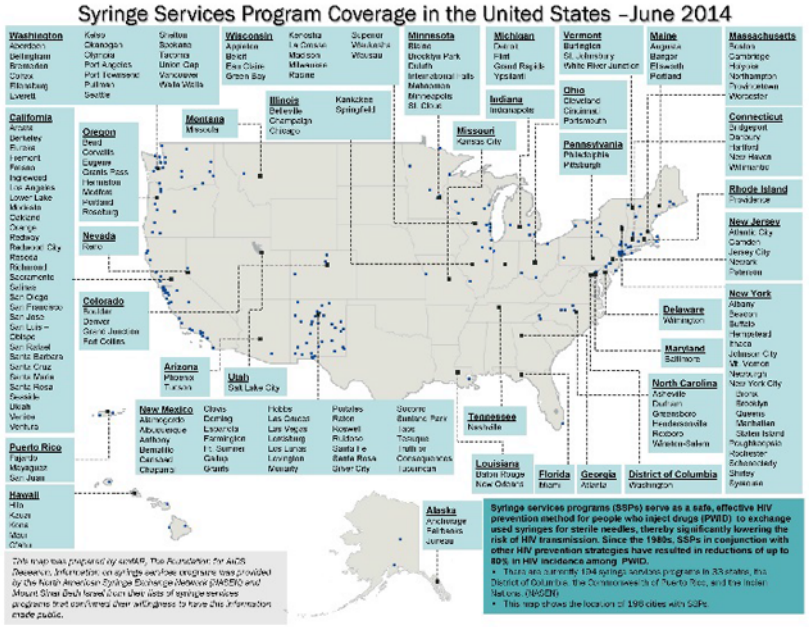
As the map to the right illustrates, despite the ban on using Federal funds for SSPs, 33 States, the District of Columbia, and Puerto Rico have made local investments to support the preventive value of syringe services programs as of June 2014—and that number is growing as evidenced by Kentucky's recent legislation legalizing SSPs mentioned previously. Federal grant funding would provide vital support to ensure the sustainability of SSPs nationwide, as States increasingly elect to include this intervention among their comprehensive prevention plans.

[The illustrated map follows:]

[26] Http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0104515&representation=PDF.

[27] Http://www.health.ny.gov/diseases/aids/general/about/prevsup.htm#harmred.

[28] Http://download-v2.springer.com/static/pdf/564/art%253A10.1007%252Fs10461-014-0789-9.pdf?token2=exp=1428003463~acl=%2Fstatic%2Fpdf%2F564%2Fart%25253A10.1007%25252Fs10461-014-0789-9.pdf*~hmac=6d08a736f3ca0409b0a5e0596561f95a3db56e462a3787a7e7912a5055fc3d14.




Again, we strongly urge the Subcommittee to prevent policy riders prohibiting the use of Federal funds for syringe access in the fiscal year 2016 LHHS Appropriations bill. We thank Chairman Blunt, Ranking Member Murray, and members of the Subcommittee for their thoughtful consideration of our request.

[This statement was submitted by AIDS Foundation Chicago; AIDS United; American Medical Student Association, Association of Nurses in AIDS Care; HIV Medicine Association; HIV Prevention Justice Alliance; Harm Reduction Coalition; National Alliance of State and Territorial AIDS Directors; National Viral Hepatitis Roundtable; Ryan White Medical Providers Coalition; United Methodist Church, General Board of Church and Society; and Urban Coalition of HIV/AIDS Services.]

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## PREPARED STATEMENT OF THE NATIONAL VIRAL HEPATITIS ROUNDTABLE

The National Viral Hepatitis Roundtable (NVHR) respectfully submits this testimony to the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies (LHHS) regarding the fiscal year 2016 Appropriations hearing. As a broad national coalition representing over 200 organizations committed to fighting, and ultimately ending, the hepatitis B and hepatitis C epidemics, we are gravely concerned about the many missed opportunities and negative public health consequences resulting from the lack of resources to adequately address these two communicable viruses in the United States.

We therefore urge the Subcommittee to increase the allocation for the Division of Viral Hepatitis (DVH) at the Centers for Disease Control and Prevention (CDC) to the full $62.8 million requested by the Administration for fiscal year 2016, an increase of $31.3 million over fiscal year 2015. Further, particularly due to the current rise in hepatitis C cases that is interconnected with the opioid and heroin addiction crisis, we also urge the Subcommittee to prevent policy riders prohibiting the use of Federal funds for any program for the purpose of distributing needles or syringes for the purpose of preventing the spread of blood borne pathogens from the fiscal year 2016 LHHS Appropriations Bill, given the critical role syringe services programs (SSPs) play in hepatitis C prevention and linkage to healthcare and drug treatment. For more detailed information regarding the ban on Federal funds for

SSPs, please see separate testimony on the issue submitted by NVHR and allied organizations to this Subcommittee.

This request is both timely and urgent, given: (1) the vital need for a robust surveillance infrastructure; (2) the overwhelming contribution of hepatitis B and C to the rising incidence of liver cancer; and (3) the current state of the hepatitis C epidemic, with unique challenges in addressing prevalence and incidence among two distinct generations, and tremendous opportunity created by new curative treatment.

SCOPE OF THE EPIDEMICS

Despite a safe, effective vaccine for hepatitis B, and new curative treatments for hepatitis C, the CDC conservatively estimates that approximately 1.4 million Americans are living with chronic hepatitis B, and 3.2 million are living with chronic hepatitis C.[1] These are likely underestimates however, as surveillance systems across the Nation are disjointed at best, with only five States and two jurisdictions (Florida, Massachusetts, Michigan, New York, Washington, Philadelphia, and San Francisco) federally funded for such activities.[2] Of primary concern is that of the nearly 5 million individuals thought to be living with hepatitis B and/or C, up to 75 percent of them do not know they are infected with a potentially life-threatening, communicable virus, as both hepatitis B and C most often present with no symptoms until the liver is already significantly damaged.[3] On average, hepatitis B and/or C will shorten one's lifespan by 15–20 years.[4]

There are significant disparities among various communities for both of these viruses as well. While comprising less than 5 percent of the U.S. population, Asian Americans and Pacific Islander communities comprise over 50 percent of all hepatitis B prevalence.[5] As hepatitis B is also endemic in many regions of the world, particularly in Asia and Africa, the foreign-born and their children are also at risk.[6] Many diverse communities are highly and disproportionately impacted by hepatitis C compared to the general population, including veterans, especially Vietnam-era service members; the "baby boomer" birth cohort (born 1945–1965); communities of color, including tribal communities; the incarcerated/returning citizens; and people who inject drugs.

STRENGTHENING SURVEILLANCE

Surveillance—the "continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice"[7]—is the core public health service driving effective interventions, particularly for infectious disease. The current system of surveillance for hepatitis B and hepatitis C is woefully underfunded, and as such the available data provides merely a snapshot of the epidemics, albeit an alarming one. Without significantly bolstering States' ability to leverage existing systems of surveillance, these epidemics will remain ahead of our efforts to eliminate them—a goal achievable in the coming decades with dedicated resources. CDC's Division of Viral Hepatitis has identified strengthening surveillance as one of its primary strategic goals given an increase in appropriations.[8]

HEPATITIS B, HEPATITIS C, AND LIVER CANCER

Liver cancer is one of several potential long-term consequences of chronic hepatitis B and C infection, and is one of the most aggressive and deadliest cancers with a devastatingly low 15 percent 5-year survival rate for all stages combined.[9] Despite a downward trend in incidence of various cancers, unfortunately we see the reverse with liver cancer where rates are rising. In fact, hepatitis C infection alone leads

[1] Http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm.
[2] Http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations__budget__form__pdf/FY2016__CDC__CJ__FINAL.pdf, p. 85–91.
[3] Http://www.cdc.gov/fmo/topic/budget%20Information/FY-2016-Fact-Sheets/FY2016__Pres__Budget__Final__VHHMP.pdf.
[4] Http://www.cid.oxfordjournals.org/content/58/8/1047.full.pdf+html.
[5] Http://www.cdc.gov/hepatitis/Populations/api.htm.
[6] Ibid.
[7] Http://www.who.int/topics/public__health__surveillance/en/.
[8] Http://www.cdc.gov/fmo/topic/Budget%20Information/appropriations__budget__form__pdf/FY2016__CDC__CJ__FINAL.pdf, p. 85-91.
[9] Http://www.cancer.org/cancer/livercancer/detailedguide/liver-cancer-survival-rates.

all causes of liver cancer burden.[10] Not only can the debilitating consequences of hepatitis B and hepatitis C be avoided with effective intervention—including vaccination for hepatitis B and curative treatment for hepatitis C—addressing these epidemics can serve the secondary purpose of preventing a substantial proportion of primary liver cancer cases.

HEPATITIS C—UNIQUE CHALLENGES AND OPPORTUNITIES

The hepatitis C epidemic presents in two fairly distinct waves. First is the majority of prevalence, existing among the baby boomer cohort which comprises about 75 percent of those currently living with hepatitis C. While this population by and large is not continuing to transmit the virus, the majority do not know they are infected and have likely been living with hepatitis C for decades. As this community ages, the long term impacts of the disease are going to become more apparent as patients increasingly present with cirrhosis (scarring) of the liver, end-stage liver disease, liver cancer, and the need for liver transplantation. A recent study suggests that nearly half of individuals in this birth cohort already have severe liver scarring and are in need of immediate treatment.[11] As baby boomers rapidly age into Medicare, it is vital to identify those living with hepatitis C and link them to appropriate care and treatment.

A second and recently emerging wave of the epidemic drives current transmission. As Americans across the Nation have been devastated by the current crisis of prescription opioid addiction—particularly youth under 30 in rural and suburban communities—the trend begins with misuse of oral opioid painkillers, to experimenting with injecting, followed often by a transition to heroin.[12] Directly on the heels of this crisis is a new, sustained spike in hepatitis C, with the Centers for Disease Control and Prevention (CDC) reporting a 75 percent increase in new infections from 2010–2012 [13] (likely a significant underestimate due to lack of surveillance infrastructure). As illustrated in the map above, while new infections in just three States —Tennessee, West Virginia, and Kentucky—comprise 20 percent of overall incidence, a distressing 35 of 41 States reporting data to CDC saw increases in hepatitis C infection rates.[14]

[The illustrated map follows:]

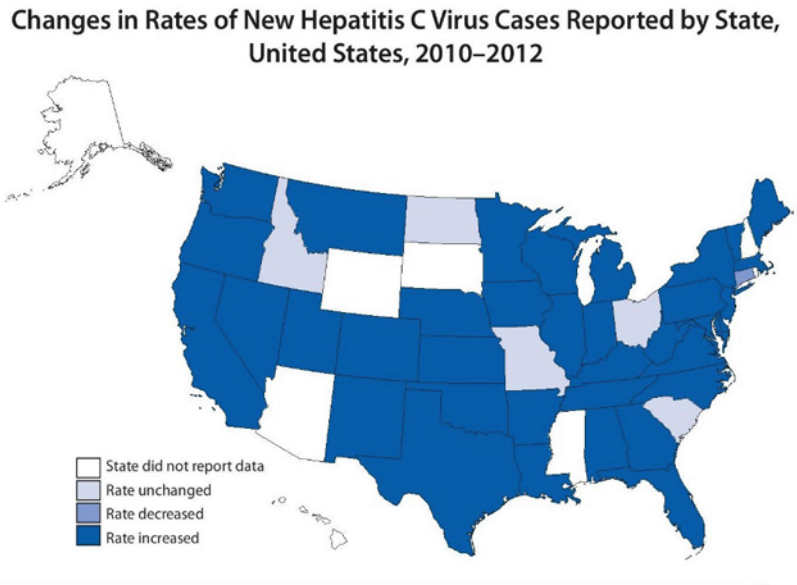
[10] Http://www.cdc.gov/fmo/topic/budget%20Information/FY-2016-Fact-Sheets/FY2016__Pres__Budget__Final__VHHMP.pdf.

[11] Http://www.hivandhepatitis.com/hepatitis-c/hepatitis-c-topics/hcv-disease-progression/5086-croi-2015-liver-disease-progression-is-common-among-baby-boomers-with-hepatitis-c.

[12] Https://www.aids.gov/pdf/hcv-and-young-pwid-consultation-report.pdf.

[13] Http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm#hepC.

[14] Http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm.




Decades of research have proven syringe services programs to be an effective prevention intervention for hepatitis C, serving also to connect people who inject drugs to medical, mental health, and social services, overdose prevention, as well as drug treatment.[15] It is critical that States have full control over their existing Federal prevention grant funding to address the unique circumstances of local epidemics; as such, lifting the ban on the use of Federal funds for SSPs is an urgent and cost-neutral policy fix.[16]

Despite the many challenges currently facing us in catching up to this epidemic, this is also a time of tremendous opportunity for those living with hepatitis C. In just the past several years, new direct-acting antivirals have entered the market that offer cure rates of over 90 percent, as well as much shorter regimens and few to no side effects compared to previous treatments. With this medical innovation has come hope for millions, and an effective intervention can be offered to those who test positive. Although these new options have revolutionized hepatitis C treatment, there are a number of natural barriers to treating everyone who needs it; most significantly, up to 75 percent of those living with hepatitis C do not know it as most will not experience symptoms, and there is a significant lack of provider capacity. Building the capacity of providers and scaling efforts to identify those with hepatitis C are among the strategic priorities DVH intends to address given a modest increase in resources.

Again, we strongly urge the Subcommittee to increase the allocation for CDC's DVH to $62.8 million for fiscal year 2016, an increase of $31.3 million over fiscal year 2015, as well as to prevent policy riders prohibiting the use of Federal funds for syringe access in the fiscal year 2016 LHHS Appropriations bill. We thank Chairman Blunt, Ranking Member Murray, and members of the Subcommittee for their thoughtful consideration of our request.

[This statement was submitted by Christine Rodriguez, Public Policy Manager, National Viral Hepatitis Roundtable.]

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[15] Http://www.amfar.org/uploadedFiles/__amfarorg/Articles/On__The__Hill/2013/IB%20SSPs%20031413.pdf.

[16] Please see separate testimony on this issue submitted by NVHR and allied organizations to this Subcommittee.

PREPARED STATEMENT OF THE NEPHCURE KIDNEY INTERNATIONAL

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2016

—Provide $32 billion for the National Institutes of Health (NIH)
—Provide a corresponding increase to the NIH Institutes and Centers
—Support the Expansion of the FSGS/NS research portfolio at NIDDK, the Office of Rare Diseases Research (ORDR) and the National Institute on Minority Health and Health Disparities (NIMHD) by funding more research proposals for primary Glomerular Disease

Thank you for the opportunity to present the views of NephCure Kidney International regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS that is caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS. Researchers continue to study the pathogenesis of these variants.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent $26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of $3 billion. It is estimated that there are currently approximately 20,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal healthcare costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

ENCOURAGE FSGS/NS RESEARCH AT NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research could lead to fewer patients undergoing ESRD and tremendous savings in healthcare costs in the United States. NephCure works closely with NIH and has partnered with NIH on two large studies that will advance the pace of clinical research and support precision medicine. These studies are the Nephrotic Syndrome Study Network and the Cure Glomerulonephropathy Network.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for NephCure Kidney International, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). Now in its second 5-year funding cycle, NEPTUNE has recruited over 450 NS research participants, and has supported pilot and ancillary studies utilizing the NEPTUNE data resources. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

NIDDK recently initiated the Cure Glomerulonephropathy Network (Cure GN), a multicenter 5-year cohort study of glomerular disease patients. Participants will be followed longitudinally to better understand the causes of disease, response to therapy, and disease progression, with the ultimate objective to cure glomerulonephropathy. NephCure recommends that the subcommittee encourage NIDDK to continue to support CureGN as well as other primary glomerular disease program announcements.

It is estimated that annually there are 20 new cases of ESRD per million African Americans due to FSGS, and 5 new cases per million Caucasians. This disparity is largely due to variants of the APOL1 gene. Unfortunately, the incidence of FSGS is rising and there are no known strategies to prevent or treat kidney disease in individuals with the APOL1 genotype. NIMHD began supporting research on the APOL1 gene in fiscal year 2013. Due to the disproportionate burden of FSGS on minority populations, it remains appropriate for NIMHD to continue to advance this research. NephCure asks the subcommittee to encourage NIMHD to continue to study FSGS/NS, including the APOL1 gene.

Thank you for the opportunity to present the views of the FSGS/NS community. Please contact NephCure Kidney International if additional information is required.

[This statement was submitted by Irving Smokler, Ph.D., President and Founder, Nephcure Kidney International.]

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## PREPARED STATEMENT OF THE NEUROFIBROMATOSIS NETWORK

Thank you for the opportunity to submit testimony to the Subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population. We respectfully request that you include the following report language on NF research at the National Institutes of Health within your fiscal year 2016 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF]—The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair, learning disabilities, autism and attention deficit disorders. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 basic and clinical research.

On behalf of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large part to this Subcommittee's strong support, scientists have made enormous progress since the discovery of the NF1 gene in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, pain, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and is more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which initially involves tumors causing deafness and balance problems, and Schwannomatosis, the hallmark of which is severe pain. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deaf-

ness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

*Learning Disabilities/Behavioral and Brain Function*

Learning disabilities affect one-half of people with NF1. They range from mild to severe, and can impact the quality of life for those with NF1. In recent years, research has revealed common threads between NF1 learning disabilities, autism and other related disabilities. New drug interventions for learning disabilities are being developed and will be beneficial to the general population. Research being done in this area includes a clinical trial of the statin drug Lovastatin, as well as other categories of drugs.

*Bone Repair*

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. Research currently being done to understand bone biology and repair will pave the way for new strategies to enhancing bone health and facilitating repair.

*Pain Management*

Severe pain is a central feature of Schwannomatosis, and significantly impacts quality of life. Understanding what causes pain, and how it could be treated, has been a fast-moving area of NF research over the past few years. Pain management is a challenging area of research and new approaches are highly sought after.

*Nerve Regeneration*

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals. Light-based therapy is being tested to dissect nerves in surgery of tumor removal. If successful it could have applications for treating nerve damage and scarring after injury, thereby aiding repair and functional restoration.

*Wound Healing, Inflammation and Blood Vessel Growth*

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells, important players in NF1 tumor growth, are critical mediators of inflammation, and they must be quelled and regulated in order to facilitate healing. Researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling, resulting in slower tumor growth. As researchers learn more about blocking mast cell signals in NF, this research can be translated to the management of mast cells in wound healing.

*New Cancer Treatments*

NF can cause a variety of tumors to grow, which includes tumors in the brain, spinal cord and nerves. NF affects the RAS pathway which is implicated in 70 percent of all human cancers. Some of these tumor types are benign and some are malignant, hard to treat and often fatal. One of these tumor types is malignant peripheral nerve sheath tumor (MPNST), a very aggressive, hard to treat and often fatal cancer. MPNSTs are fast growing, and because the cells change as the tumor grows, they often become resistant to individual drugs. Clinical trials are underway to identify a drug treatment that can be widely used in MPNSTs and other hard-to-treat tumors.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that numerous institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from $3 million in fiscal year 1990 to $21 million in fiscal year 2014. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the Subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

PREPARED STATEMENT OF NEW LEADERS

Thank you for the opportunity to provide testimony regarding the fiscal year 2016 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill. This process represents a tremendous opportunity to create positive, lasting change in our education system and I hope that New Leaders can provide useful insights to help guide your decisions on these important issues.

New Leaders is a national non-profit dedicated to enabling high academic achievement for all children by developing transformational school leaders and advancing the policies and practices that allow great school leaders to succeed. Since our founding in 2000, we have helped to train and equip more than 1,600 school leaders with the knowledge and skills to positively impact the lives of more than 350,000 children, many of whom are students of color and come from low-income backgrounds.

New Leaders is committed to making every school a place where great teachers love to teach and all students love to learn. We can reach this goal by paying more attention to how our schools—not just individual classrooms, but all classrooms within a school—are organized and led. The current appropriations process is an opportunity for Congress to show it is serious about improving student outcomes—by making meaningful investments in the programs that will enable and empower great principals to create schools where teachers can thrive and students can excel.

Our more than 15 years of experience have helped us to identify the following priorities, which are critical for the development of effective principals and other school leaders, as well as the improvement of outcomes for students, particularly economically disadvantaged and other at-risk students. We hope that you will consider these priorities during your upcoming negotiations.

—*The School Leadership Program* (SLP), which provides grants to high-poverty school districts to assist in the recruitment, preparation, and retention of effective principals, is the only program currently in the Federal budget dedicated to school leadership. SLP gives high-poverty districts the resources to develop dynamic leaders who have a measurable, positive impact on student achievement; leaders like Principal Alison Harris and Assistant Principal Erica Jordan-Thomas at Ranson Middle School in Charlotte, North Carolina. After training and support from New Leaders, Principal Harris and Assistant Principal Jordan-Thomas helped Ranson become the second highest performing Title I school in the district in terms of student growth. It is critical that we continue to provide school districts with the resources to develop effective school leaders and pursue professional development practices that have shown evidence of effectiveness. We recommend that the fiscal year 2016 appropriation continue funding for a dedicated school leadership program. We would support funding the current SLP at $38.8 million, a substantial increase over the fiscal year 2015 level. We would also be supportive of the President's proposal to replace and build on SLP through the Teacher and Principal Pathways as long as the dedicated funding stream for principal effectiveness includes support for both aspiring principals as well as and current principals and their instructional leadership teams. We would also support $138.8 million in funding for the Teacher and Principal Pathways program proposed in the Presidents fiscal year 2016 budget request, including $38.8 million dedicated specifically to principals.

—*The Investing in Innovation Fund* (i3) supports the development, validation, and scaling up of innovative strategies and interventions for addressing persistent education challenges. The Department has established priorities for i3 relating to (1) developing and implementing models for principal preparation that deepen proven leadership skills, and (2) increasing equitable access to effective teachers and principals for student from low-income families and other high-needs students. Thus, i3 can play a key role in identifying and expanding school leadership development programs that truly have a positive effect on student achievement and school performance, especially in predominantly low-income districts. Take Green Street Academy in Baltimore, Maryland: New Leader Principal Crystal Harden-Lindsey is hyper focused on the success of her teachers in this innovative secondary school. Since assuming the principalship in 2012, Principal Harden-Lindsay has supported the development of five Emerging Leaders, teacher leaders who learn to lead teams of teachers to meet school improvement goals, and two Aspiring Principal Residents, educators on the path to becoming transformational school leaders. This "leadership lab" approach is enabling Principal Harden-Lindsey and her team to turn around one of the lowest-performing schools in the area and has been supported, in part, by New Leaders' i3-funded leadership programming. New Leaders recommends

funding i3 at a level of $300 million, the amount requested by the Administration.

—*The Teacher Incentive Fund* (TIF) provides for the development and implementation of sustainable, performance-based compensation systems for teachers, principals, and other personnel in high need schools in order to increase educator effectiveness and student achievement. This program has been instrumental in helping schools and districts move from a pay system based primarily on seniority to one that focuses on student outcomes. TIF helps send the message that the ultimate goal is to enable meaningful learning for all kids—regardless of their background, zip code, native language, or developmental needs. Take Memphis City Schools in Memphis, Tennessee: recognizing the need for strategic compensation to recruit, support, and retain great teaching talent, the district sought out data. Based on local survey information from New Leaders' EPIC Knowledge Management system (created in part with TIF funding)—including that 81 percent of school leaders and 77 percent of teachers said that higher salaries are "very important" or "absolutely essential" in retaining effective teachers and 96 percent of teachers said that supportive leadership was critical to their decision to continue teaching—the district developed a compensation structure with higher salaries tied to performance rather than years of experience or education. The district also recognized the critical role of the principal in creating and maintaining a supportive context where teachers want to work. New Leaders recommends at least $350 million in funding for TIF in fiscal year 2016—the amount requested by the Administration—and a continued focus on broader human capital systems in schools. These human capital systems include a deeper focus on school leadership, in part recognized by renaming it the Teacher and Leader Incentive Fund.

—*Supporting Effective Educator Development* (SEED) makes grants to national nonprofit organizations for projects that recruit, select, and prepare, or provide professional development activities for, teachers or principals. The importance of recruiting, training, and retaining effective school leaders cannot be overstated; principals can account for as much as 25 percent of a school's effect on a certain student's achievement,[1] and 97 percent of teachers say that the principal is responsible for determining if a school can attract and retain great teachers.[2] It is imperative that we make the necessary investments in evidence-based programs that help develop and retain these leaders. New Leaders recommends that SEED be funded with $117.5 million in set-aside funds in fiscal year 2016, as recommended in the Administration's budget request. We also recommend that these funds continue to be used for non-profits that support either teachers or leaders or both.

—*School Improvement Grant* (SIG) provides funding to State education agencies (SEAs), which the SEAs use to make competitive subgrants to districts that demonstrate the greatest need and the strongest commitment to use the funds to support students in their lowest-performing schools. The SIG program is designed specifically to support the lowest performing schools—those that are most in need of strong leadership. In fact, research has shown that improvement simply does not occur without strong school leadership.[3] Take Fenger High School in Chicago, Illinois: in 2011, Fenger received a 3-year school improvement grant totaling more than $5.5 million. New Leader Principal Elizabeth Dozier used the turnaround model framework and Federal funds to completely re-staff the school and bring in supplemental academic, social, and emotional support services for her students. The results of Principal Dozier's school improvement strategies were profound: the percentage of students meeting or exceeding State standards more than doubled in just 3 years. New Leaders recommends $555.8 million in fiscal year 2016 funding for SIG, the same as recommended in the Administration's budget request; in particular, New Leaders supports the Turnaround School Leaders Program that funds efforts to select, prepare, support, and retain school leaders in SIG schools.

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[1] Leithwood, K., Louis, K. S., Anderson, S., & Wahlstrom, K. (2004). How Leadership Influences Student Learning. New York, NY: Wallace Foundation.

[2] Scholastic Inc. (2012). Primary Sources: America's Teachers on the Teaching Profession. New York, NY: Scholastic and the Bill and Melinda Gates Foundation.

[3] Bryk, A. S., Sebring, P. B., Allensworth, E., Luppescu, S., & Easton, J. Q. (2010). Organizing schools for improvement: Lessons from Chicago. Chicago, IL: University of Chicago Press. Aladjem, D. K., Birman, B. F., Orland, M., Harr-Robins, J., Heredia, A., Parrish, T. B., & Ruffini, S. J. (2010). Achieving dramatic school improvement: An exploratory study. Washington, DC: U.S. Department of Education. Louis, K. S., Leithwood, K., Wahlstrom, K. L., & Anderson, S. E. (2010). Investigating the links to improved student learning: Final report of research findings Learning from Leadership Project. Minneapolis, MN: University of Minnesota.

Thank you for the opportunity to provide the views of New Leaders on the fiscal year 2016 appropriations. If you would like to discuss our recommendations, please do not hesitate to contact our Chief Policy Office, Jackie Gran.

[This statement was submitted by Jean Desravines, CEO, New Leaders.]

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## PREPARED STATEMENT OF THE NURSING COMMUNITY

The Nursing Community is a coalition comprised of 61 national professional nursing associations that builds consensus and advocates on a wide spectrum of healthcare issues surrounding education, research, and practice. These organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents over one million Registered Nurses (RNs), Advanced Practice Registered Nurses (APRNs-including certified nurse-midwives (CNMs), nurse practitioners (NPs), clinical nurse specialists (CNSs), and certified registered nurse anesthetists (CRNAs)), nurse executives, nursing students, faculty, and researchers.

For fiscal year 2016, our organizations respectfully request $244 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]) and $150 million for the National Institute of Nursing Research (NINR), one of the centers and institutes within the National Institutes of Health (NIH).

### NURSES ARE ESSENTIAL TO ENSURING ACCESS TO HIGH-QUALITY CARE

As integral members of the healthcare team, nurses collaborate with other professions and disciplines to improve the quality of America's healthcare system. RNs comprise the largest group of health professionals with approximately over three million licensed providers in the country. The reach of their care is vast: they offer essential patient care in a variety of settings, including hospitals, long-term care facilities, community centers, State and local health departments, schools, workplaces, and patient homes.

Factors including an aging nursing workforce, an aging Baby Boomer population, and growth in newly-insured individuals are driving the demand for nursing services. Additionally, as our Nation's healthcare system transforms and more services are provided outside of hospital walls, nurses must be educated for these challenges and opportunities. Therefore, the recruitment and retention of RNs and APRNs to underserved areas are a national priority. Moreover, increasing the number of nursing professionals with advanced education to serve in this capacity is of critical importance.

The U.S. Bureau of Labor Statistics (BLS) projects that employment of CRNAs, CNMs, and NPs is expected to grow 31 percent between 2012 and 2022.[1] A constant focus must be placed on education to ensure a stable workforce, particularly in geographic regions that will continue to experience health provider shortages in the coming years. A significant investment must be made in the education of new nurses to provide the Nation with the services it demands.

### TITLE VIII NURSING WORKFORCE DEVELOPMENT PROGRAMS: ENSURING A PIPELINE OF HIGHLY-EDUCATED NURSES TO SERVE ACROSS THE NATION

For over 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped to build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met.

Title VIII programs target specific aspects of America's nursing workforce and patient populations that require Federal support in order to ensure efficient and effective delivery of healthcare services. For example, in academic year 2013–2014, the Nurse Education, Practice, Quality, and Retention (NEPQR) program supported 9,448 students. Among them, 45 were recipients of the innovative NEPQR Veterans' Bachelor of Science in Nursing program, which assists America's servicemen and women in pursuit of a nursing career. In addition, 900 health professions students received clinical training at NEPQR-supported Nurse-Managed Health Clinics, of

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[1] U.S. Bureau of Labor Statistics. (2014). Occupational Outlook Handbook. Registered Nurses. Retrieved from: http://www.bls.gov/ooh/healthcare/registered-nurses.htm.

which 94 percent were located in medically underserved areas; 54 percent served as primary care settings for the community, and 40 percent of which served veteran populations and their families.[2]

As noted, the BLS projects a high need for APRNs due to increasing patient care demands. The Advanced Nursing Education (ANE) grants program supported 10,504 students in academic year 2013–2014. ANE grants help prepare NPs, CNSs, CNMs, CRNAs, nurse educators, administrators, public health nurses, and other nurses requiring a graduate degree. The settings in which these students were educated reflect the national effort to immerse providers into delivery settings where they are most needed. During this same year, ANE grantees partnered with 5,100 clinical training sites, and 46 percent were located in underserved areas and 40 percent were in primary care settings. Students are afforded the opportunity to serve the unique needs of these communities, thus provided care for regions of our Nation that struggle to recruit and retain highly-educated clinicians. Federal dollars allocated to Title VIII programs are a lifeline to the nursing profession that yields a high return on investment for communities across the country.

—*The Nursing Community respectfully requests $244 million for the Nursing Workforce Development programs in fiscal year 2016.*

NATIONAL INSTITUTE OF NURSING RESEARCH: FOUNDATION FOR EVIDENCE-BASED CARE

The care that RNs and APRNs provide must be rooted in evidence. As one of the 27 Institutes and Centers at the NIH, NINR funds research that lays the groundwork for evidence-based nursing practice. NINR examines ways to improve care models to deliver safe, high-quality, and cost-effective health services to the Nation. Our country must look toward the prevention aspect of healthcare as the vehicle for saving our system from further financial burden, and the work of NINR embraces this endeavor through research related to care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR addresses these challenges through its Strategic Plan, which includes the following key themes:

—Symptom science to improve personalized health strategies for individuals living with chronic illness and pain;
—Wellness to promote health and prevent illness across health conditions, settings, the lifespan, and in minority and underserved populations;
—Patient self-management to improve qualify of life while reducing the burden for caregivers and the healthcare system; and
—End-of-life and palliative care science to improve symptom management, coordination, and informed decisionmaking for patients, families, and healthcare professionals.[3]

In addition, NINR recognizes the need for improving global health and promotes research to reduce communicable diseases such as HIV, and improve public health and wellness such as maternal-newborn care. Moreover, NINR allots a generous portion of its budget towards training new nursing scientists, thus helping to sustain the longevity and success of nursing research. Training programs at NINR develop future nurse researchers, many of whom also serve as faculty in our Nation's nursing schools.

—*The Nursing Community respectfully requests $150 million for the NINR in fiscal year 2016.*

The Ad Hoc Group for Medical Research requests at least $32 billion for NIH in 2016, and the request level of $150 million for NINR denotes the same percentage increase for NIH applied to NINR.

MEMBERS OF THE NURSING COMMUNITY SUBMITTING THIS TESTIMONY

Academy of Medical-Surgical Nurses
American Academy of Nursing
American Assembly for Men in Nursing
American Association of Colleges of Nursing
American Association of Critical-Care Nurses
American Association of Heart Failure Nurses
American Association of Nurse Anesthetists

[2] U.S. Department of Health and Human Services. (2015). Health Resources and Services Administration Fiscal Year 2016 Justification of Estimates for Appropriations Committees. Retrieved from: http://hrsa.gov/about/budget/budgetjustification2016.pdf.

[3] National Institutes of Health. National Institute of Nursing Research. Implementing NINR's Strategic Plan: Key Themes. Retrieved from: http://www.ninr.nih.gov/aboutninr/keythemes#.VRVhGWZ__SSU.

American Association of Nurse Assessment Coordination
American Association of Nurse Practitioners
American Association of Occupational Health Nurses
American College of Nurse-Midwives
American Nephrology Nurses' Association
American Nurses Association
American Organization of Nurse Executives
American Pediatric Surgical Nurses Association
American Psychiatric Nurses Association
American Society of PeriAnesthesia Nurses
Association for Radiologic and Imaging Nursing
Association of Community Health Nursing Educators
Association of Nurses in AIDS Care
Association of periOperative Registered Nurses
Association of Public Health Nurses
Association of Women's Health, Obstetric and Neonatal Nurses
Commissioned Officers Association of the U.S. Public Health Service
Dermatology Nurses' Association
Developmental Disabilities Nurses Association
Gerontological Advanced Practice Nurses Association
Hospice and Palliative Nurses Association
Infusion Nurses Society
International Association of Forensic Nurses
International Society of Psychiatric-Mental Health Nurses
National American Arab Nurses Association
National Association of Clinical Nurse Specialists
National Association of Neonatal Nurse Practitioners
National Association of Neonatal Nurses
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Black Nurses Association
National Council of State Boards of Nursing
National Forum of State Nursing Workforce Centers
National Gerontological Nursing Association
National Nursing Centers Consortium
National Organization of Nurse Practitioner Faculties
Nurses Organization of Veterans Affairs
Oncology Nursing Society
Organization for Associate Degree Nursing

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PREPARED STATEMENT OF REVEREND DR. GARY OLIN

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization

and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE OPEN HAND ATLANTA

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Open Hand Atlanta is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. Open Hand's mission is to help people prevent or better manage chronic disease through Comprehensive Nutrition Care™, which combines home-delivered meals and nutrition education as a means to reinforce the connection between informed food choices and improved quality of life. In our service area, we provide 1,345,263 medically tailored, home delivered meals annually. Open Hand has been the primary nutrition provider in Metro Atlanta for PLWHA for over 27 years. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

### *Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on pre-

vention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Matthew Pieper, Executive Director, Open Hand Atlanta.]

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[8] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

PREPARED STATEMENT OF CHETAN PATEL

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

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Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

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PREPARED STATEMENT OF JAGRUTI PATEL

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serv-

ing people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

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## PREPARED STATEMENT OF PATH

PATH is appreciative of the opportunity afforded by Chairman Blunt, Ranking Member Murray, and members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, to submit written testimony regarding fiscal year 2016 funding for global health and immunization initiatives at the U.S. Department of Health and Human Services (HHS). We appreciate the strong leadership this Committee has shown in supporting global health and immunization programs and we ask that your support continue. I am submitting this testimony on behalf of PATH, an international nonprofit organization that drives transformative innovation to save lives and improve health in developing countries, especially among women and children. For nearly 40 years, PATH has been a pioneer in translating bold ideas into breakthrough health solutions. We accelerate innovation across five platforms—vaccines, drugs, diagnostics, devices, and systems and service innovations. We actively collaborate with public- and private-sector partners—including the U.S. Government and HHS—to develop new and adapt existing innovations across the health spectrum, and to work to ensure those solutions reach the people who need them the most, in the lowest resource settings. Through our work in more than 70 countries, we see firsthand the impact of U.S. Government investments in global health and immunization. We respectfully request that this Subcommittee ensure robust funding for HHS global health programs in fiscal year 2016 to allow the U.S. Government to achieve goals outlined in the U.S. National Vaccine Plan and the new 6-year President's Malaria Initiative Strategy.

*The Vital Role of HHS in Global Health*

The ongoing Ebola crisis and the measles outbreaks in California and New York in early 2015, have demonstrated that the health of U.S. citizens is inherently connected to the health of people living around the globe. Global pandemics and increasing overseas travel in recent decades intensify Americans' vulnerability to infectious diseases that have historically impacted communities outside our borders.

Recognizing this, HHS has been active in global health programs for decades. In recent years, HHS developed the Global Health Strategy (2011) and serves as the lead U.S. agency for the Global Health Security Agenda (launched in 2014) to better protect Americans' health and security while improving health around the world.

*Accelerating Progress Toward Global Immunization Goals*

A key strategy for achieving HHS' global health goals is immunization. Vaccines are one of the most impactful and cost-effective public health interventions available today. They have played a large role in cutting the number of deaths of children under age five in half since 1990. Worldwide, polio cases have dropped by more than 99 percent since 1988, measles deaths have declined by 75 percent from 2000 through 2013, and 2 to 3 million deaths are averted each year through immunization. HHS has contributed significantly to this achievement. For example, thanks in part to HHS' role in global polio immunization efforts, including as a leading agency in the Global Polio Eradication Initiative, 11.5 million children were reached with polio vaccine in 2014. Southeast Asia, including India, was certified polio-free in March 2014, making 80 percent of the world's population polio-free. Only three countries—Afghanistan, Pakistan, and Nigeria—remain "endemic," meaning they have never interrupted transmission of the virus, but promisingly, Nigeria has not reported a case of wild polio since July 2014.

Robust funding will enable HHS to further extend the reach of lifesaving vaccines to where they are needed most, which will save even more lives and contribute to healthier, more productive communities.

Global immunization is one of five core objectives of the U.S. National Vaccine Plan (2010–2015), emphasizing its role in providing an "umbrella of protection" for the United States. This year is a pivotal moment as HHS agencies work to update this plan and outline priorities for the next 5 years. In parallel to this plan, the CDC is in the process of developing a revised global immunization strategy. Full funding is essential to ensure they can effectively execute these strategies and support the dual objectives of protecting the health of Americans while improving children's lives overseas.

2015 marks the halfway point of the Decade of Vaccines, an initiative which established a global framework endorsed by the United States and 193 other nations with the aim of delivering universal access to immunization. While some progress has been made toward the goals outlined in the framework, and individual achievements in countries have demonstrated what is possible with focused efforts, we are off track to meet many of the milestones outlined in the plan, and the delay means more lives lost. The U.S. Government is positioned to lead the way in accelerating progress toward the framework's goals, if it maximizes its contributions across various agencies. We are pleased to see HHS making strides toward strengthening the collective impact of its agencies engaged on global immunization, including the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Food and Drug Administration (FDA), among others, as well as across other departments of the U.S. Government. We urge the committee to continue to fully fund these efforts and encourage stronger coordination.

*Supporting Vaccine Introduction and Scale*

CDC and other partner agencies play a key role in ensuring that appropriate vaccines are introduced and widely available where they are needed most. When new and improved vaccines become available, countries must weigh several factors when deciding whether or not, and how, to introduce the vaccine. CDC provides valuable epidemiological, laboratory, and policy expertise to help build the capacity of countries to make informed decisions and plan for incorporating new vaccines into their immunization program.

*Strengthening Global Immunization Systems*

Effectively delivering immunizations requires coordination at every level of the immunization system. CDC partners with domestic health ministries and the World Health Organization to ensure that health systems are robust and able to operate effective immunization programs, including human resources, processes, tools, and equipment.

Investments in immunization infrastructure have proven invaluable in promoting health more broadly and rapidly responding to outbreaks. For example, Nigeria was able to rapidly adapt its polio infrastructure, built with significant CDC input and support, to respond to an importation of Ebola in October 2014 in Lagos. Senior polio leadership quickly established an Emergency Operations Center in Lagos to respond to the outbreak, stopping the virus without incident. Meanwhile, immunization rounds in northern Nigeria continued as planned without a decrease in quality.

This effort demonstrated the quality and resilience of the program in Nigeria, and the adaptability of polio assets for use in other public health issues.

*Fighting to Eliminate Malaria*

In addition to its critical work in immunization, HHS has a long history in the fight to eliminate malaria. CDC, in particular, played a critical role in eliminating malaria from the United States. As a joint implementer of the President's Malaria Initiative (PMI) alongside the U.S. Agency for International Development (USAID), the CDC continues to play a leading role in global elimination efforts. And these efforts have made a significant impact. Between 2001 and 2013, an estimated 4.2 million lives were saved as a result of scaled up malaria interventions. While incredible progress has been made, progress is fragile, and investments need to be sustained. Recently PMI set forth a new 6-year strategy which includes an ambitious agenda to reduce malaria mortality by one-third from 2015 levels in PMI-supported countries, thereby achieving a greater than 80 percent reduction from PMI's original 2000 baseline. Robust funding is required to execute on this goal.

With evidence of growing insecticide and drug resistance, CDC's role in malaria surveillance and ensuring we have the tools necessary to fight this ever changing disease is critical. CDC provides the routine surveillance that is critical in keeping up with the changing dynamics of the disease, provides scientific leadership and training to the next generation of malaria technical experts, and works to develop and evaluate new tools to aid in the fight. Examples of CDC's contributions include evaluations of the impact of improved nets, insecticides, and strategic use of antimalarial drugs, as well as field trials of promising malaria vaccine candidates.

However as CDC's mandate has grown, their budget for malaria has been flat funded. Flat or reduced budgets make it increasingly harder to attract top talent and conduct the research necessary for ultimately meeting goals towards malaria elimination. Increased funding would better equip the agency to track the spread of drug and insecticide resistance, develop and deploy new tools, and ensure the more timely surveillance that is necessary for ultimate malaria elimination.

*Protecting U.S. Leadership in Global Health R&D*

While access to existing, proven health interventions—whether vaccines, bednets, or drugs—must be extended, it is also critical to support research and development (R&D) into future technologies that can prevent existing and emerging global health threats. Investments made by the U.S. Government, including through the NIH and CDC over the past three decades, have enabled many partners, including PATH, to advance innovations that have improved health and saved lives around the world. These innovations include new and improved vaccines, such as an effective, low-cost vaccine against meningitis A, which used to cause devastating outbreaks each year in Africa's Meningitis Belt. Zero cases of meningitis A have occurred among the more than 215 million Africans vaccinated since 2010. We also leveraged U.S. Government support to pioneer safe injection technologies that have helped to prevent millions of blood-borne infections. Thanks to a discovery made by scientists at NIH, PATH was able to develop a simple, rapid test for exposure to river blindness, a disease that affects 23 million people. This test was launched commercially last year and is an important tool in the fight to eliminate river blindness in Africa.

The promise of new global health technologies can only be realized when products are developed, tested, and scaled up for use globally. Strengthened collaboration and coordination between HHS operating divisions and other U.S. agencies funding vaccine development and delivery—namely, USAID and the Department of Defense—will be critically important to better align vaccine R&D investments and vaccination program priorities across the U.S. Government to maximize the impact of U.S. taxpayer dollars.

*An Investment in Health, at Home, and Around the World*

With strong funding for HHS, the department will be able to improve access to existing, proven health interventions in the communities where they are needed most, while at the same time investing in solutions to tomorrow's challenges, thus enabling the United States to continue its role as a leader in global health. By fully funding the global health and immunization-related accounts, the U.S. can protect the health of Americans while ensuring that people everywhere have the opportunity to lead healthy lives and reach their full potential.

[This statement was submitted by Heather Ignatius, Senior Policy and Advocacy Officer, PATH.]

PREPARED STATEMENT OF SUE PETERS

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PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION

On behalf of the 196 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year 2015 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least $280 million in fiscal year 2016 for the health professions education programs authorized under Title VII of the Public Health

Service Act and administered through the Health Resources and Services Administration (HRSA). We also request $12 million of that funding support PA programs operating across the country. This is the only designated source of Federal funding for PA education and is crucial to the U.S. PA education system's ability to meet the demand for education and to continue to produce highly skilled physician assistants ready to enter the healthcare workforce in an average of 26 months. The way that PAs are educated in America—the caliber of our institutions and the expertise of our educators—is the gold-standard throughout the world and that distinction must be maintained in this period of unprecedented patient need and rapid growth within the PA profession.

*Need for Increased Federal Funding*

The unmet need for primary care services in the United States is well documented, and only expected to grow as Baby Boomers age and require more healthcare services and as formerly uninsured patients gain access. Healthcare systems are rapidly evolving. Yet the one constant remains the need for qualified healthcare providers in numbers sufficient to meet demand. Primary care has been clearly identified as the critical entry point into the healthcare system where that access must be guaranteed. The PA profession was created specifically to address a shortage of primary care physicians almost 50 years ago; and today's PAs stand ready to help address the challenges our Nation faces in primary care and other specialties. The effectiveness of physician assistants is well-documented by studies showing better patient access, especially for Medicaid patients, high patient satisfaction, more frequent patient education, and healthcare outcomes similar to physicians. Importantly, PAs could play an even larger role in high-quality, cost-effective care if offered appropriate financial support and through innovations in the PA education system.

Like physicians, the PA profession also faces a shortage of graduates that will hinder its ability to help fully address the primary care issue in the United States. Without new solutions, at the current output of approximately 8000 graduates from PA programs per year, these shortages will persist, particularly in the rural and underserved communities where care is needed the most. Title VII is the only funding source that provides direct support for PA programs and plays a crucial role in developing and supporting the education system's ability to produce the next generation of these advanced practice clinicians.

*Background on the Profession*

Since the 1960s, PAs have consistently demonstrated they are effective partners in healthcare, readily adaptable to the needs of an ever-changing delivery system. Physician assistants are licensed health professionals with advanced education in general medicine that practice medicine as members of the healthcare team. They provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings, including prescriptive authority in all 50 States, the District of Columbia, and Guam. PAs practice medicine to the extent allowed by law and within the physician's scope of practice and their combination of medical training, advanced education, and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas where they are often the only full-time medical provider. The profession is well established, yet nimble enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges. The PA practice model is, by design, a team-based approach to patient-centered care where the PA works in tandem with a physician and other health professionals. This PA practice approach to quality care is uniquely aligned with the patient-centered, collaborative, interprofessional and outcomes-based care models transforming the U.S. healthcare system.

*PA Education: The Pipeline for Physician Assistants*

There are currently 190 accredited PA education programs in the United States. Together these programs graduate over 8,000 PA students each year. PAs are educated as generalists in medicine and that training gives them the flexibility to practice in more than 60 medical and surgical specialties. More than one third of PA program graduates are working in a primary care specialty.

The average PA education program is 26 months in length and includes 1 didactic year in the classroom, and another year devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical training, second only to physicians in time spent in clinical study.

As of today, approximately 55 new PA programs are in the pipeline at various stages of development and moving toward accredited status. The growth rate in the applicant pool is even more pronounced. Since its inception, the Centralized Applica-

tion Service (CASPA) used by most programs grew from 4,669 applicants to over 20,000. As of March 2015, there were 22,997 applicants to PA education programs, which represents over a 40 percent increase in CASPA applicants over the past 5 years alone.

The PA profession is expected to continue to grow as a result of the projected shortages of physicians and other healthcare professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. Accordingly, The Bureau of Labor Statistics projects a 39 percent increase in the number of PA jobs between 2008 and 2018. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well positioned to help fill projected shortages in the numbers of healthcare professionals—if appropriate resources are available to support the education system behind them.

AREAS OF ACUTE NEED

*Faculty Shortages*

Faculty development is one of the profession's critical needs and educators are an often overlooked element to developing an adequate primary care workforce. Nearly half of PA program faculty are 50 years or older and the PA teaching profession faces large numbers of retirements in the next 10–15 years. An interest in education must be developed early in the educational process to ensure a continuous stream of educators, and to do so, we must alleviate the significant loan burdens that prevent many physician assistants from entering academia. In order to attract the most highly qualified faculty, PA education programs must have the resources to help clinicians transition into education, including curriculum development, teaching methods, and laboratory instruction. Most educators come from clinical practice and these non-clinical professional skills are essential to a successful transition from clinical practice to a classroom setting. Without Federal support, we will face an impending shortage of educators who are prepared for and committed to the critical teaching role that will ensure the next generation of skilled practitioners.

*Clinical Site Shortages*

Outside of the classroom, PA education faces additional challenges in meeting demand. A lack of clinical sites for PA education is hampering PA programs' ability to produce PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals (preceptors) willing to teach students as they are cycling through their clinical rotations, and a lack of sites with the physical space to teach. Cutbacks in Federal and State funding of Area Health Education Centers (AHECs) has also contributed to reduced access to clinical training for PA students, particularly in rural and underserved communities.

This phenomenon is experienced throughout the health professions, and is particularly acute in primary care. It has created unintentional competition for clinical sites and preceptors within and among PAs, physicians and advance practice nurses. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for PAs and other health professionals to train together and directly interact with patients as a team. PAEA believes that interprofessional clinical training and practice are necessary for optimum patient care and will be a defining model of healthcare in the U.S. in the 21st century. We can only make that a reality if we begin to build a sufficient network of health professionals who are willing to teach the next generation of primary care professionals—that approach will benefit PAs as well as the future physicians, nurses and other clinicians that comprise the full primary care team.

*Enhancing Diversity*

Workforce diversity, and practice in underserved areas are key priorities identified by HRSA and are consistent with those of PAEA. It is increasingly important for patient care quality that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in healthcare. PA programs have been committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, including veterans who have served our country and desire to transition to civilian health professions. Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care, and PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field. If we can provide resources to schools that are particularly poised to improve their diversity recruitment efforts

and replicate or create best practices including transition programs for our veterans, we can begin to address this systemic need.

In order to leverage the efforts of PA programs through Title VII funding to increase workforce diversity in the PA profession, PAEA also supports funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps (NHSC). Historically, access to higher education has been constrained for individuals from disadvantaged backgrounds. These programs help to provide a clear path for students who might not otherwise consider a physician assistant career.

*Title VII Funding*

Title VII funding fills a critical need for curriculum development, faculty development, clinical site expansion and diversification of the primary care workforce—areas that if appropriately supported can help ensure the PA profession realizes its full promise in the U.S. healthcare system. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enable innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients with the most urgent need for access to care.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the Appropriations process specifically for PA programs working to address the health provider shortage. This funding has enhanced capabilities to train a growing PA workforce, creatively expand care to the underserved, and develop a more diverse PA workforce:

—One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.

—An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a four-week comprehensive educational program in HIV disease diagnosis and management.

—A New York program is using its PA training grant to operate a mobile health vehicle to provide health education and initial health screenings to local underserved communities. The experience has motivated students to enter primary care; the direct exposure achieved by utilizing a mobile heath vehicle provides the communities with medical and preventive education and health screenings while also addressing the students' awareness of cultural competency and health literacy.

—A Virginia program uses its PA training grant to support transitioning veterans, while increasing the placement of graduates in primary care and medically underserved communities. The grant allows the PA program to provide scholarship to incoming physician assistant students who are veterans, and who dedicate the beginning of their careers to a primary care setting

*Recommendations on Fiscal Year 2016 Funding*

The Physician Assistant Education Association, along with the support from our colleagues in the health professions community, requests the Appropriations Committee's support in funding for Title VII health professions programs at a minimum of $280 million for fiscal year 2016.This level of funding is crucial to support the Nation's ability to produce and maintain highly skilled primary care practitioners, particularly those from diverse backgrounds and the military who will practice in medically underserved areas and serve vulnerable populations. We also ask for the continuation of the 15 percent allocation for PA education programs in the Primary Care cluster. The Accreditation Review Commission on Education for the Physician Assistant (ARC–PA) estimates that an additional 55 programs will be added by 2018. Therefore, we request an increase in funding to $12 million which will allow sufficient funding for the expanding number of PA programs expected to begin enrolling students during the next four to 5 years.

We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the Nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's fiscal year 2016 funding recommendation.

[This statement was submitted by Anthony Miller, M.Ed., PA-C Chief Policy and Research Officer, Physician Assistant Education Association.]

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PREPARED STATEMENT OF BARBARA PIPER

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

## PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND ASSOCIATION OF POPULATION CENTERS

### INTRODUCTION

Thank you, Chairman Blunt, Ranking Member Murray, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH), National Center for Health Statistics (NCHS), and Bureau of Labor Statistics (BLS). These agencies are important to the members of the Population Association of America (PAA) and Association of Population Centers (APC) because they provide direct and indirect support to population scientists and the field of population, or demographic, research overall. In fiscal year 2016, we urge the Subcommittee to adopt the following funding recommendations: at least $32 billion for the NIH, consistent with the level recommended by the Ad Hoc Group for Medical Research; $172 million, consistent with the Administration's request, for the National Center for Health Statistics; and BLS, $632 million, consistent with the Administration's request.

The PAA and APC are two affiliated organizations that together represent over 3,000 social and behavioral scientists and approximately 40 population research centers nationwide that conduct research on the implications of population change. Our members, which include demographers, economists, sociologists, and statisticians, conduct scientific research, analyze changing demographic and socio-economic trends, develop policy recommendations, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including adolescent health and development, aging, health disparities, immigration and migration, marriage and divorce, education, social networks, housing, retirement, and labor. Population scientists compete for discretionary grant funding from the NIH and rely on data produced by the Nation's statistical agencies, including NCHS and BLS, to conduct research and training activities.

### NATIONAL INSTITUTES OF HEALTH

Demography is the study of populations and how or why they change. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD).

### NATIONAL INSTITUTE ON AGING

NIA-supported research confirms that by 2030, there will be 72 million Americans aged 65 and older. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well-being characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic research on these topics.

In addition to supporting an impressive research portfolio that includes the prestigious Centers on the Demography and Economics of Aging, the NIA BSR Division also supports several large, accessible surveys. These surveys include the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying trends in late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the long-term care utilization of people with chronic disabilities. Another NIA survey, the Health and Retirement Study (HRS), provides unique information about economic transitions in work, income, and wealth, allowing scientists to study how the domains of family, economic resources, and health interact. Since 1992, the HRS has collected data—including, most recently, biomarkers—from a representative sample of more than 27,000 Americans over the age of 50 every 2 years. These data are accessible to researchers worldwide and have informed numerous scientific findings. For example, in 2013, researchers using the HRS published a study in the New England Journal of Medicine, concluding that the cost of providing dementia care is comparable to, if not greater than, those for heart disease and cancer.

With additional support in fiscal year 2016, the Institute can sustain and expand its investment in population aging research. For example, the Institute is developing an initiative to explore why other industrialized countries surpass the United States both in health at older ages and in longevity—especially in light of new NIA-supported research findings that more than half of premature deaths are due to social and behavioral issues. The Institute is also interested in supporting research on the

role that educational achievement may play in the onset of dementia. Additional funding would also help the Institute improve its payline, which, as of January 2015, was only at the 7th percentile for applications under $500,000 and at the 4th percentile for applications over $500,000.

As members of the Friends of NIA, we urge the Committee to provide the NIH with an additional $500 million in fiscal year 2016 to support aging research activities not only at the NIA, but across the agency.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN DEVELOPMENT

Since 1968, NICHD has supported research on population processes and change. This research is housed in the Institute's Population Dynamics Branch, which supports research and research training in demography, reproductive health, and population health and funds major national studies that track the health and well-being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents, and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health.

In 2014, scientists, using data from these large-scale datasets published numerous findings. For example, researchers using both genetic and survey data from the Fragile Families study found that poverty and unstable family environments shorten chromosome-protecting telomeres in young African American boys as compared to children from nurturing environments. This finding provides new insights into the insidious role chronic stress plays in child health. Also, last year, using data from the Add Health study, scientists reported new findings on the long-term effects of birth weight and breastfeeding duration on inflammation (a contributing factor to disease and disability) in early adulthood.

One of the most important population research programs that the NICHD supports is the Population Dynamics Centers Research Infrastructure Program. This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists, while at the same time providing incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating research infrastructure within and across research institutions. It also supports research at private and public research institutions nationwide, the focal points for the demographic research field for innovative research and training and the development and dissemination of widely used large-scale databases. The Association of Population Centers produces an annual guide describing the activities and accomplishments of these centers, which is posted at: http://www.popcenters.org/sites/popcenters.org/files/APC__2014__Booklet.pdf.

As members of the Friends of NICHD, PAA and APC request that the Institute receive a funding level of at least $1.37 billion in fiscal year 2016—an increase that is proportional to the overall NIH increase recommended by the Ad Hoc Group for Medical Research funding. With additional support, NICHD can build upon successful research while prioritizing and investing in new research based on their revised Scientific Vision plan, including launching the Human Placenta Project.

NATIONAL CENTER FOR HEALTH STATISTICS

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System (NVSS), which contracts with the States to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey, National Health Interview Survey (NHIS), and National Survey of Family Growth. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

The Subcommittee's support of NCHS in recent years has enabled it to make significant progress toward modernizing the NVSS, moving many States from paper-based to electronic filing of birth and death statistics and expediting the release of these data to the user community. Yet, much work is needed to modernize fully the NVSS and to support necessary expansions to the agency's core surveys so that these data can effectively assess Americans' health.

As members of the Friends of NCHS, PAA and APC request that NCHS receive $160 million in budget authority in fiscal year 2016. This funding level would enable the agency to maintain its critical data collection activities and support the States in their continued implementation of electronic death registration systems (EDRS) to enhance the timeliness and quality of death data used both in public health and in fraud prevention.

We also endorse the Administration's proposed increase of $12 million in Prevention Fund funding for NCHS in fiscal year 2016. This funding would allow NCHS to continue expansions to questions and sample sizes in the National Health Interview Survey and expansions in sample sizes in the National Ambulatory Medical Care Survey (NAMCS). These expansions have yielded better data to assess Americans' access to, and use of, healthcare services. NCHS previously received Prevention Fund dollars to support the expansion of these surveys, but received no such funding in fiscal year 2014 and fiscal year 2015. Without the Prevention Fund allocation in fiscal year 2016, these NHIS and NAMCS survey enhancements will discontinue, jeopardizing the utility of these important datasets.

BUREAU OF LABOR STATISTICS

The Bureau of Labor Statistics (BLS) produces essential economic information for public and private decisionmaking. Its data are used extensively by population scientists who study and evaluate labor and related economic policies and programs. The agency also supports the National Longitudinal Studies program and the American Time Use Survey, which are invaluable datasets that the population sciences use to understand how complex factors—such as changes in work status, income, and education—interact to affect health and achievement outcomes in children and adults.

Since fiscal year 2010, the BLS budget has decreased by 10 percent in inflation-adjusted dollars, and its current purchasing power is less than it was in 2001. The agency has increasingly become unable to fulfill its basic responsibilities, despite having made a series of cost-saving program changes since 2011—eliminating in 2013 its Mass Layoffs Statistics, Measuring Green Jobs, and International Labor Comparisons programs, and curtailing (in 2014) some collection under its Quarterly Census of Employment and Wages. Last year the export pricing program was able to continue thanks only to a one-time contribution from the Department of Commerce—and without adequate resources this measure also faces elimination. Given the importance and unique nature of BLS data, we urge the Subcommittee to support a level of $633 million. Funding at this level would restore funding for all core BLS programs—including the Current Employment Survey—and also permit the agency to expand and enhance its Job Openings and Labor Turnover Survey for better, faster, and more disaggregated regional information on employment dynamics. Finally, restored funding would allow the agency to make needed and long overdue investments in its technical staff, which is essential to ensuring the quality of the data collection and analysis.

CONCLUSION

Thank you for considering the importance of these agencies under your jurisdiction that benefit the population sciences. We urge you to give them the highest funding priority as the fiscal year 2016 appropriations process proceeds.

[This statement was submitted by Mary Jo Hoeksema, Director, Government and Public Affairs, Population Association of America and Association of Population Centers.]

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PREPARED STATEMENT OF POSITIVE WOMEN'S NETWORK—USA

Dear Senate LHHS Subcommittee: I am writing to express my concern about the proposed elimination of Ryan White Part D and consolidation of the programs in to Ryan White Part C in the fiscal year 2016 budget proposal. Respectfully, I am asking you to maintain Ryan White Part D as a designated category in the Ryan White funding—not consolidating it with Part C, as has been proposed. I am a women who has been living with HIV for 27 years and a member of the Positive Women's Network—USA—Colorado chapter.

As a unique part of the legislature, Ryan White Part D's culturally sensitive, family-centered primary medical care and support services aim to increase access and help women, infants, children, and youth with HIV achieve optimal HIV medical outcomes. These critical services, which comprise under 6 percent of Ryan White funding, include coordinated care, sexual and reproductive health, specialized case

management, mental health services, child care, transportation, outreach, peer-based programming, and more. As women and youth account for an alarming amount of HIV diagnoses, Part D's targeted funding for both groups is vital.

As the Affordable Care Act brings new changes to American healthcare, retention in care during this transition period is essential. Many women served by Ryan White Part D have one or more minor children in their care. Over ¾ of Part D clients are racial minorities. Consolidating Part C and D in this manner (via budget appropriations) poses the risk of leaving vulnerable families and youth without the very services that have helped to reduce perinatal HIV transmission of HIV/AIDS by over 90 percent and retain HIV + women in care at a rate nearly double the national average.

Moreover, the Ryan White legislation specifically designates Part C funding, focused on early intervention services and capacity development, separately from Part D. Although in recent years many Ryan White grantees have been dually funded by both parts, the focus of these programs are entirely different. The potential loss of Part D's established network of vetted, culturally competent providers—many of whom are community based sub-grantees with years of experience serving this population—could have disastrous consequences for individuals, families, and communities. The risk of people falling out of care as a result of these changes is real, which could lead not only to negative health outcomes, but also to increased risk of more transmissions due to lack of viral suppression.

Ryan White Part D has a proven track record and has been instrumental into getting and keeping marginalized individuals living with HIV in care. I respectfully request that you (1) vote to reject the proposal to consolidate Ryan White Part C and Part D and (2) retain Ryan White Part D as a distinct targeted category with adequate funding to serve these vulnerable populations. Our families that are living with HIV deserve nothing less. Thank you for your consideration.

[This statement was submitted by Laurie Priddy, Positive Women's Network—USA.]

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PREPARED STATEMENT OF JANE POWELL

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding, and they cause critical reductions in care for those who can least withstand them.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R.§ 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business"calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm on a widespread scale.

Whatever care setting is considered, when imposed upon all disabled people unilaterally the outliers are discriminated against and can suffer harm. But while the harm resulting from previous discriminations was primarily a matter of self-esteem, the harm suffered as a result of current discriminations against the most severely disabled are physical, often severe, and far more detrimental. Often those who are harmed or die as a result of forced deinstitutionalization are 10–15 percent or more of the census of the institutions that discharged them to dangerous placements not equipped to care for them, with little oversight or accountability.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF PREVENT BLINDNESS

### FUNDING REQUEST OVERVIEW

Prevent Blindness appreciates the opportunity to submit written testimony for the record regarding fiscal year 2016 funding for vision and eye health related programs. As the Nation's leading non-profit, voluntary health organization dedicated to preventing blindness and preserving sight, Prevent Blindness maintains a longstanding commitment to working with policymakers at all levels of government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness respectfully requests that the Subcommittee provide the following allocations in fiscal year 2016 to help promote eye health and prevent eye disease and vision loss:

—Provide at least $1,000,000 to strengthen the Vision Health Initiative (visual screening education) at the Centers for Disease Control and Prevention (CDC).
—Provide at least $3,319,000 to continue the Glaucoma Project at the CDC.
—Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health.
—Provide at least $639 million to sustain programs under the Maternal and Child Health (MCH) Block Grant.
—Provide at least $730 million to the National Eye Institute (NEI).

### INTRODUCTION AND OVERVIEW

Vision-related conditions affect people across the lifespan. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to 10 percent of preschool age children, and is a leading cause of impaired health in childhood. Recent research estimated that the economic burden of vision

loss and eye disorders is $145 billion each year, nearly $50 billion of which is Federal spending. Alarmingly, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."[1]

To curtail the increasing incidence of vision loss in America, and its accompanying economic burden, Prevent Blindness advocates sustained and meaningful Federal funding for programs that promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. In a time of significant fiscal constraints, we recognize the challenges facing the Subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye conditions, and their treatment, through research, to develop the public health systems and infrastructure to disseminate and implement good science and prevention strategies, and to protect children's vision, millions of Americans face the loss of independence, loss of health, and the loss of their livelihoods, all because of the loss of their vision. Furthermore, an upcoming Institute of Medicine study is expected to make new recommendations to improve the vision and eye health of the population in the coming years; recommendations that would be much more difficult to advance following a decreased investment in these important programs.

VISION AND EYE HEALTH AT THE CDC: HELPING TO SAVE SIGHT AND SAVE MONEY

The CDC serves a critical role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to promote eye health and prevent vision loss; improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden; reduce vision and eye health related disparities; and integrate vision health with other public health strategies. Despite severely constrained financial resources the CDC' s Vision Health Initiative (VHI) staff has worked hard in the last year to increase awareness of vision health by partnering with other CDC programs, including the Office of Smoking and Health and the Division of Cancer Prevention and Control. Still, increased funding is absolutely necessary to take the work of the VHI to the next level.

Prevent Blindness requests at least $1,000,000 in fiscal year 2015 to strengthen vision and eye health efforts of the CDC. This funding level would allow the VHI to increase vision impairment and eye disease surveillance efforts, apply previous CDC vision and eye health research findings to develop effective prevention and early detection interventions, and begin to incorporate vision and eye health promotion activities into State and national public health chronic disease initiatives, with an initial focus on early detection of diabetic retinopathy

*Improving Access to Eye Care for those at High Risk for Glaucoma*

An estimated 2.2 million people are affected by glaucoma. A disease of the aging eye, risk for glaucoma increases with age, especially among black, Hispanic/Latinos, and Asians. Once vision is lost to glaucoma, it cannot be restored, but with early diagnosis and appropriate treatment, it is possible to slow disease progression and save the remaining sight. Detection and management of glaucoma are challenged by difficulties in reaching high-risk populations and by the lack of simple, cost-effective screening plans.

Prevent Blindness requests level funding of $3,294,000 in fiscal year 2016 to continue the work of the Glaucoma Project to improve glaucoma screening, referral, and treatment, as well as overall surveillance of glaucoma and other eye conditions. The program is intended to reach those populations experiencing the greatest disparity in access to glaucoma care through an integrated collaboration among private and public organizations.

INVESTING IN THE VISION OF OUR NATION'S MOST VALUABLE RESOURCE—CHILDREN

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. The visual system in children younger than 8 years old is in a critical developmental stage. Unidentified and untreated vision problems can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally in this critical time of a child's life. Cur-

[1] "Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America," Prevent Blindness America and the National Eye Institute, 2008.

rently, only one in three children receive eye care services before the age of six. Requirements for preventive eye care/vision screenings prior to or during the school years vary broadly from State to State. Many States have no standards and those with standards present with little consistency regarding type, frequency, and referral or follow-up requirement protocol. Inclusion of vision screenings with a comprehensive approach to follow up treatment and an integrated approach to data collection as a part of the required health component for grant recipients will help to change disparities in vision and eye health for our Nation's children.

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children.

The Center is guided by an Advisory Committee comprised of the Nation's leaders in children's vision and public health to implement national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. With this support the Center, will continue to: (1) provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye healthcare for children; (2) advance State-based performance improvement systems, screening guidelines, and mechanisms for uniform data collection and reporting; and (3) provide technical assistance to States in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

In January 2015, volunteer experts convened by the Center published three articles in the Journal of Optometry and Vision Science that provide an evidence-based approach to vision screening in children ages 3 through 5, as well as system-based public health strategies to ensure improved surveillance and program accountability as it relates to children's vision in the United States. This guidance encourages a badly needed, more uniform approach to children's vision health systems.

Prevent Blindness requests at least $639 million in fiscal year 2016 to sustain programs under the MCH Block Grant. The MCH Block Grant enables States to expand critical healthcare services to millions of pregnant women, infants and children, including those with special healthcare needs. In addition to direct services, the MCH Block Grant supports vital programs, preventive and systems building services needed to promote optimal health—including the National Center for Children's Vision and Eye Health.

## ADVANCE AND EXPAND VISION RESEARCH OPPORTUNITIES

Prevent Blindness calls upon the Subcommittee to provide $730 million to enable the NEI to pursue its primary "audacious goal" of restoring vision by bolstering its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country. By providing additional funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

## CONCLUSION

On behalf of Prevent Blindness, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding fiscal year 2016 funding for the CDC's vision and eye health efforts, the MCHB's National Center for Children's Vision and Eye Health, and the NEI. Please know that Prevent Blindness stands ready to work with the Subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to Subcommittee members and your staff. We very much appreciate the Subcommittee's attention to—and consideration of—our requests.

[This statement was submitted by Hugh Parry, President & CEO, Prevent Blindness.]

PREPARED STATEMENT OF PROJECT ANGEL FOOD

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Project Angel Food is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 500,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpa-

tient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

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*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

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—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you,

[This statement was submitted by Laurie Lang, Executive Director, Project Angel Food.]

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## PREPARED STATEMENT OF PROJECT ANGEL HEART

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Project Angel Heart is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide 315,000 medically tailored, home delivered meals annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

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*Conclusion*

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Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Erin Pulling, President & CEO, Project Angel Heart.]

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PREPARED STATEMENT OF PROJECT OPEN HAND

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Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

Thank you.

[This statement was submitted by Simon Pitchford, Ph.D. and Mark Ryle, LCSW, Co-CEO's, Project Open Hand.]

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## PREPARED STATEMENT OF THE PROSTATITIS FOUNDATION

Prostatitis or Chronic Pelvic Pain Syndrome (CPPS) has been a scourge to mankind for many years. At one International Convention of the American Urological Association the physician speaking said Chronic Prostatitis was as painful to the doctor as the patient. That is because the doctor knew he could do little to alleviate the symptoms of the patient and the patient would return over and over again with more complaints.

Prostatitis is not a new disease. It is seldom discussed publicly because of an assumed stigma. The cure has been elusive as far back as Napoleon according to some medical historians. In his battles and conquests he had to stand in a chariot rather than ride a horse it was noted. Napoleon has been quoted as having said something to the effect that doctors and generals will have much to account for on the final day of judgement. Both John Kennedy in Reader's Digest and Saddam Hussein by Reuter's were reported to have suffered from Prostatitis. Will Durant spoke about his travails with prostatitis in his autobiography.

Because of persistent efforts of the NIH light is being focused on the problem but a cure has been elusive. Many or most of the common treatments have not stood up to clinical trials. It is critical that the information gathered in the past and the research groups now in place are adequately funded to utilize the work already done and preserve any information produced thus far.

Keep in mind that because of anxiety, disability and sexual dysfunction prostatitis has an effect on the whole family. These research funds need to be increased as the costs of prostatitis are substantial and knowing the cause and prevention would provide huge savings.

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## PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the pulmonary hypertension community as you work to craft the fiscal year 2016 L-HHS Appropriations Bill.

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[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

ABOUT PULMONARY HYPERTENSION

Pulmonary hypertension (PH) is a disabling and often fatal condition simply described as high blood pressure in the lungs. It affects people of all ages, races and ethnic backgrounds. Although anyone can get PH, there are risk factors that make some people more susceptible.

Treatment and prognosis vary depending on the type of PH. In one type, pulmonary arterial hypertension (PAH), the arteries in the lungs become too narrow to handle the amount of blood that must be pumped through the lungs. This causes several things to happen: a backup of blood in the veins returning blood to the heart; an increase in the pressure that the right side of the heart has to pump against to push blood through the lungs; and a strain on the right side of the heart due to the increased work that it has to do. If this increased pressure is not treated, the right side of the heart can become overworked, become very weak and may possibly fail. Because blood has difficulty getting through the lungs to pick up oxygen, blood oxygen level may be lower than normal. This can put a strain not only on the heart, but also decrease the amount of oxygen getting to the brain.

There is currently no cure for PAH. Twelve treatment options are available to help patients manage their disease and feel better day to day but even with treatment, life expectancy with PAH is limited.

ABOUT THE ASSOCIATION

From simple beginnings—four women who met around a kitchen table in Florida in 1990—the Pulmonary Hypertension Association has evolved into a community of well over 10,000 pulmonary hypertension patients, caregivers, family members and medical professionals.

As we have grown, we have stayed true to our roots and the vision and ingenuity of our founders: We continue to work every day to end the isolation that PH patients face, and find a cure for pulmonary hypertension.

*Research*

PHA provides grants to promising researchers in the field of pulmonary hypertension. The program fosters new leaders in the field by supporting their interest in PH research and providing them with opportunities to work with mentors and learn new skills. Researchers supported by PHA are looking for new methods for early detection, new treatments to prevent the onset of PH and ultimately a cure for this terrible illness. To date, PHA has leveraged more than $15 million in PH research funding through partnerships with the NIH and others.

*Early Diagnosis Campaign*

It takes too long for pulmonary hypertension to be diagnosed. The median survival rate without treatment is approximately 2.8 years, making the need to obtain a rapid and accurate diagnosis urgent. Unfortunately, the median duration from symptom onset to a confirmed diagnosis by right heart catheterization is 1.1 years. We are reaching patients too late in the process. Almost three-fourths of patients have advanced PH by the time they are diagnosed, leading more costly treatments and poorer outcomes. For the most advanced cases of PH, a lung or heart-lung transplant may be the only treatment option. The goal of PHA's Early Diagnosis Campaign is to discover the disease sooner in the early stages. This will allow the start of a treatment regimen that can slow the progression of PH and secure a better life for the patient.

*Center Accreditation*

The Pulmonary Hypertension Association's Scientific Leadership Council, 28 global leaders in the field of pulmonary hypertension, have spearheaded the PHA-Accredited PH Care Centers (PHCC) initiative. The goal of this initiative is to establish a program for accreditation of centers with special expertise in pulmonary hypertension (PH), particularly pulmonary arterial hypertension (PAH), to raise the overall quality of care and outcomes in patients with this life-threatening disease.

ONE PATIENT'S STORY

In 2011, at the age of 29, GS12 Human Terrain Analyst Jessica (Puglisi) Armstrong began experiencing shortness of breath and dizziness. She was in Afghanistan at the time. Jessica was first diagnosed with dehydration. Then, as is the case with many PH patients, she was told she had asthma and was given an inhaler. Two months later, she fainted for no apparent reason. An echocardiogram revealed blood clots in her lungs and Jessica was medically evacuated to Germany and then

to the U.S. Six months after her fist symptoms, she was finally given a complete work up and diagnosed with pulmonary hypertension.

Jessica, she had a unique form of PH due to blood clots that can be mitigated with a pulmonary thromboendarterectomy (PTE)—a complex surgery that involves opening the chest cavity and stopping circulation for up to twenty minutes. She describes the surgery, which she underwent at the University of California San Diego, as "more painful than I could ever imagine." She notes that UCSD's PTE program did not begin until 1990 and even now, despite being recognized as the global leaders on this procedure, has only completed about 3,000 surgeries. The procedure that saved Jessica's life was developed in her lifetime.

Jessica was terminated from Army employment and spent $60,000 out of pocket on medical expenses which she has not been able to recoup. She was forced to begin a civilian job just two weeks after her PTE in order to retain health insurance. Despite this, Jessica is, in many ways, one of the lucky ones. I am glad to report that she is now doing well and serving an integral role at PHA as the coordinator of our Early Diagnosis Campaign.

Over the past decade, treatment options, and the survival rate, for pulmonary hypertension patients have improved significantly. However, courageous patients of every age lose their battle with PH each day. There is still a long way to go on the road to a cure and biomedical research holds the promise of a better tomorrow.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that the pulmonary hypertension research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. The Association has anecdotal accounts of the harms of sequestration and the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

—The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) less than in fiscal year 2003.

—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Association asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

*Health Resources and Services Administration*

Due to the serious and life-threatening nature of PH, it is common for patients to face drastic health interventions, including heart-lung transplantation. Federal organ transplantation activities are coordinated through HRSA. To ensure HRSA can expand its important mission and continue to make improvements in donor lists and donor-matching please provide HRSA with a meaningful funding increase in fiscal year 2016.

*Centers for Disease Control and Prevention*

As a result of Federal investment in medical research, there are now twelve FDA-approved treatments for PH. The effectiveness of these therapies, however, is dependent on how early a patient can receive an accurate diagnosis and begin treatment. Unfortunately, two-thirds of patients are not diagnosed until PH has reached a late stage. In addition to mitigating the impact of many treatments, late diagnosis puts PH patients in a position to face interventions like heart-lung transplantation and even death. CDC and NCCDPHP have the resources to complement PHA's own Sometimes its PH Early Diagnosis Campaign. Improving public awareness and rec-

ognition of PH will not only save lives, it can save the Federal healthcare system money. Please provide CDC with meaningful funding increases so the agency can expand its focus into increasingly important and cost-effective areas.

NATIONAL INSTITUTES OF HEALTH

NIH hosts a sizable PH research portfolio. Further, NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The twelve FDA-approved treatments, more than nearly every other rare disease, are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve diagnosis and treatment.

*NCATS*

The Office of Rare Diseases Research (ORDR), located within NCATS, supports and coordinates rare disease research and provides information on rare diseases to patients, their families, healthcare providers, researchers and the public. In collaboration with other NIH institutes, ORDR funds rare diseases research primarily through the Rare Diseases Clinical Research Network (RDCRN), which supports clinical studies, investigator training, pilot projects, and access to information on rare diseases.

*NHLBI*

The NHLBI-funded Centers for Advanced Diagnostics and Experimental Therapeutics in Lung Diseases Stage II program, which began in fiscal year 2014, provides a mechanism to accelerate the development of therapies for lung diseases, including pulmonary fibrosis and pulmonary arterial hypertension.

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PREPARED STATEMENT OF MARY A. PULTZ

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for

four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF JONITA RAINS

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PREPARED STATEMENT OF CRIS RAUB

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PREPARED STATEMENT OF BARB REALE

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PREPARED STATEMENT OF THE RESEARCH WORKING GROUP

Chairman Blunt, Ranking Member Murray and members of the Committee, thank you for the opportunity to provide testimony on the Subcommittee on fiscal year 2016 Appropriations for the National Institutes of Health.

Investments in health research via NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world. NIH funded AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions and vaccines which have saved and improved the lives of millions. These hold great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade. Despite such advances, there remain over one million HIV-infected people in the U.S., the highest number in the epidemic's 31-year history. Additionally almost 50,000 Americans become newly infected every year.

However, investment by the NIH has transformed the HIV epidemic from a terrible, untreatable disease to a chronic condition that can be managed through once a day drug regimens. NIH funding of AIDS research provides an example of innovation at work where investment in basic and translational research, working in partnership with industry and community, can move quickly to develop solutions. NIH investments in AIDS research also add value by seeding ideas later taken up in industry partnerships and creating innovation incubators for important medical advances which have significant health impact. Major advances over the last few years in HIV treatment and prevention demonstrate that adequately resourced NIH programs can transform our lives. Federal support for AIDS research has also led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis and a wide range of autoimmune disorders.

Innovation requires a stable and adequate source of funding for science. The current unstable funding environment, with the resources available to the NIH are estimated to be significantly less in constant dollars than they were in 2003, is making us less innovative. As a recent paper by senior scientists noted "hypercompetition for the resources and positions that are required to conduct science suppresses the creativity, cooperation, risk-taking, and original thinking required to make fundamental discoveries." (Alberts B, Kirschner MW, Tilghman S, Varmus H (2014) Rescuing U.S. biomedical research from its systemic flaws, Proc Natl Acad Sci USA).

Robust funding for NIH overall enables research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every State across the country, the NIH supports research at hospitals, universities, private enterprises and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts 350,000 scientists to work at research institutions across the country. According to NIH, each of its research grants creates or sustains six to eight jobs and NIH supported research grants and technology transfers have resulted in the creation of thousands of new independent private sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

Since 2003, funding for the NIH has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research. The real value of the increases prior to 2003 has been precipitously reduced because of the relatively higher inflation rate for the cost of research and development activities undertaken by NIH. According to the Biomedical Research and Development Price Index—which calculates how much the NIH budget must change each year to maintain purchasing power—between fiscal year 2003 and fiscal year 2015, the NIH budget in constant dollars according to the BRDI will have declined by almost 30 percent. So in real terms, the NIH has already sustained budget decreases of close to a third over the past 12 years due to inflation alone. Failure to repair this decline will have the clear and devastating effects of undermining our Nation's leadership in health research and our scientists' ability to take advantage of the expanding opportunities to advance healthcare. The race to find better treatments and a cure for cancer, Alzheimer's, heart disease, AIDS and other diseases, and for controlling global epidemics like AIDS, tuberculosis and malaria, all depend on a robust long term investment strategy for health research at NIH. There can be no innovation without reliable and adequate research funding.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment towards combating HIV as well as other chronic and life threatening ill-

nesses by increasing funding for NIH in fiscal year 2016. A meaningful commitment towards maintaining the U.S. pre-eminence in research and fostering innovation cannot be met without prioritizing the research investment at NIH that will lead to tomorrow's lifesaving vaccines, treatments and cures. Thank you for the opportunity to provide these written comments.

Tomorrow's scientific and medical breakthroughs depend on your vision, leadership, and commitment towards robust NIH funding this year. To this end, the Research Working Group (RWG) urges this Committee to support a funding target of $36 billion in fiscal year 2016 to maintain the U.S.'s position as the world leader in medical research and innovation.

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PREPARED STATEMENT OF RESULTS FOR AMERICA

Chairman Blunt and Ranking Member Murray: Results for America (RFA) is pleased to present our recommendations for fiscal year 2016 to the U.S. Senate Appropriations Subcommittee on the Departments of Labor, Health and Human Services, Education and Related Agencies.

RFA and our Invest in What Works coalition partners are committed to improving outcomes for young people, their families, and communities by helping shift public resources toward practices, policies, and programs that use evidence and data to improve quality and get better results. The attached letter and table outlines our requests for fiscal year 2016.

Over the last several years, governments at all levels have taken important steps toward investing taxpayer dollars in what works. This approach has a strong history of bipartisan support. President George W. Bush's Administration put a priority on improving the performance of Federal programs and encouraged more rigorous evaluations to assess their effectiveness. The Obama Administration has built on this effort by supporting an increasing number of evidence and evaluation-based policies and programs. Mayors and governors from both parties all across the country are also increasingly using data and evidence to steer public dollars to more effectively address needs in their communities and States. We urge you to continue making the "invest in what works" approach the new norm when allocating public dollars.

On behalf of Results for America and the Invest in What Works coalition, I want to thank you for your past support and look forward to working with you in the future to build a strong evidence-based, results-driven policy agenda that improves outcomes for our Nation's citizens.

On March 9, 2015, the following 58 organizations sent a letter to Chairmen Rogers and Cochran, Vice Chairwoman Mikulski, and Ranking Democratic Member Lowey highlighting our proposed evidence-based bill and report language for fiscal year 2016. To provide you with a complete picture of our agenda, we have also included our proposed bill and report language for other Federal departments, agencies, and mandatory programs outside of your Committee's jurisdiction.

INVEST IN WHAT WORKS

Dear Chairmen Cochran and Rogers, Vice Chairman Mikulski, and Ranking Democratic Member Lowey: We are writing to urge you to include the attached "Invest in What Works" provisions in the Appropriations Committees' fiscal year 2016 bills and reports for the U.S. Departments of Labor, Health and Human Services, Education, and, Related Agencies; U.S. Departments of Commerce, Justice, Science, and Related Agencies; U.S. Departments of Transportation, Housing and Urban Development, and Related Agencies; and U.S. Department of State, Foreign Operations, and Related Agencies. To provide you with a complete picture of our evidence and evaluation agenda, we have also included for your information requests for mandatory funding.

America is facing enormous social and economic shifts, budget constraints at all levels of government, significant demographic changes, and an increasingly globally competitive workforce. While the recently enacted fiscal year 2015 Consolidated and Further Continuing Appropriations Act includes an unprecedented commitment to evidence and evaluation, we must continue to focus on improving the ways in which Federal taxpayer dollars are spent. While the Administration's fiscal year 2016 budget request proposes an even greater investment in what works including but not limited to proposals in this letter, we must continue to ensure that scarce Federal resources are invested in the most effective and efficient programs in fiscal year 2016 and beyond.

We thank you for the positive steps you have taken toward building a strong evidence-based, results-driven policy agenda and we encourage you to reaffirm that commitment to improving outcomes for all Americans by incorporating the attached

"Invest in What Works" recommendations in the fiscal year 2016 appropriations bills and Committee reports.

Thank you for your consideration of our requests.

Sincerely,

AdvancED
Alliance College-Ready Public Schools
America's Promise
Ascend at the Aspen Institute
Aspire Public Schools
BELL
Breakthrough Schools
Capital Impact Partners
Cascade Philanthropy Advisors
Center for Employment Opportunities
Center for Research and Reform in Education, Johns Hopkins University
Citizen Schools
City Year
Communities in Schools
Community Training and Assistance Center (CTAC)
CSH
Democrats for Education Reform
Education Northwest
Education Reform Now Advocacy
Forum for Youth Investment
Gestalt Community Schools
Green & Healthy Homes Initiative
Green Dot Public Schools
GreenLight Fund
IDEA Public Schools
KIPP
Knowledge Alliance
LIFT
LISC
Methodist Healthcare Ministries of South Texas
Mile High United Way
Morino Institute
National Forum to Accelerate Middle Grades Reform
New Profit, Inc.
New Teacher Center
Nurse Family Partnership
REDF
Results for America
Salt Lake County (UT)
Silicon Valley Community Foundation
SRI International
StriveTogether
Success for All Foundation
Teach For America
Teach Plus
The SEED Foundation
Third Sector Capital Partners
Turnaround for Children
U.S. Soccer Foundation
United Way of Greenville County (SC)
United Way for Southeastern Michigan
Uplift Education
Urban Alliance
Venture Philanthropy Partners
WestEd
Year Up
YES Prep Public Schools
Youth Village

INVEST IN WHAT WORKS
FISCAL YEAR 2016 APPROPRIATIONS REQUESTS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

| Recommendations for Fiscal Year 2016<br>U.S. Department of Labor | Fiscal Year<br>2016 |
|---|---|
| **Workforce Innovation and Opportunity Act**—Pay for Performance provisions to deliver workforce development service to WIOA participants and provide innovative approaches to using data and evidence to improve workforce development | |
| **DOL Agency-Wide Evaluation Set-Aside**—1% of discretionary funding to be used by the Chief Evaluation Office for program evaluations | 1% |
| U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES | |
| **Maternal, Infant, and Early Childhood Home Visiting Program**—encourages HRSA and ACF to continue their collaboration and partnership to improve health and development outcomes | |
| **Mental Health Service Block Grant Program**—at least 5% set-aside for evidence-based programs to address the needs of individuals with serious mental illness | At least 5% |
| **Head Start Designation Renewal System**—set aside within the total provided for Head Start | $25,000,000 |
| **Children's Research and Technical Assistance**—to evaluate innovative approaches to reducing welfare dependency | $15,000,000 |

INVEST IN WHAT WORKS—Continued
FISCAL YEAR 2016 APPROPRIATIONS REQUESTS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

| Recommendations for Fiscal Year 2016<br>U.S. Department of Labor | Fiscal Year<br>2016 |
|---|---|
| **National Directory of New Hires**—to permit select Federal statistical and evaluation units to access the National Directory of New Hires dataset for statistical purposes | |
| U.S. DEPARTMENT OF EDUCATION | |
| **Titles I and II**—new language directing States to set-aside 1% of funds, prior to distribution to local school districts (LSD), and award grants on a competitive basis to LSD's that submit application plans to improve student achievement/graduate rates. Grants should be targeted to the 25% of LSD's with the highest poverty level through tiered evidence as defined by EDGAR | |
| **Supporting Effective Educator Development Grants (SEED)**—set aside 5% of the Improving Teacher Quality State Grants for SEED | 5% |
| **Investing In Innovation (i3)**—to fund competitive grants to replicate education programs that have a high level of effectiveness and test promising new ideas | $300,000,000 |
| **Replication and Expansion of High Quality Charter Schools**—set aside for competitive grants to charter management organizations | Not less than $100,000,000 |
| **Leveraging What Works**—for a new leveraging what works pilot to make competitive grants for LEAS to use a portion of their funds to implement evidence-based interventions | $100,000,000 |
| **Special Education**—Results Driven Accountability Grants—for States to identify and implement promising evidence-based reforms to improve service delivery to children | Up to $10,000,000 |
| **Special Education—Pay for Success**—to reserve a portion of the Grants to Infants and Families funds to increase screening, identification, early intervention for children with disabilities | Up to $15,000,000 |
| **First in the World**—with $20,000,000 set aside for minority-serving institutions to improve student completion rates; and prioritize applications that target innovative strategies at low-income students to help ensure access to practices to improve outcomes and make college more affordable | $200,000,000 |
| **Evaluation Set-Aside**—bill language directing the Secretary to reserve up to 1% of all discretionary programs, except for Pell Grants, and would also permit the pooling of funds across all education agencies for evaluations | 1% |
| CORPORATION FOR NATIONAL AND COMMUNITY SERVICE | |
| **Social Innovation Fund**—includes 20% for Pay for Success projects and language directing the CNCS to provide renewal grants to current SIF grantees demonstrating outcomes but not had time to reach goals; language would also permit SIF grantees to apply for additional SIF funds for projects not currently funded by SIF | $80,000,000 |
| **Performance Partnership Pilot**—designed to prevent youth from disconnecting from school to work, providing education and training, employment and other social services (All DOL, Ed and HHS and related agencies may participate in these partnership pilots) | Up to 10 pilots |
| MANDATORY PROGRAMS | |
| **Maternal, Infant, and Early Childhood Home Visiting Program**—permits States to provide voluntary, evidence-based home visiting to pregnant women and parents with young children | $500,000,000 |
| **Social Services Block Grant Program (SSBG)**—permits the HHS Secretary to set aside a portion of SSBG for research and evaluation | Up to 1% |

INVEST IN WHAT WORKS—Continued
FISCAL YEAR 2016 APPROPRIATIONS REQUESTS
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

| Recommendations for Fiscal Year 2016<br>U.S. Department of Labor | Fiscal Year<br>2016 |
|---|---|
| **Upward Mobility Pilot**—permits States, localities to blend funding across the Social Services Block Grant, Community Services Block Grant, HUDS's Home Investment Partnerships and the Community Development Block grant to reduce poverty and permit funds to be used implement evidence-based strategies to improve employment, children's outcomes and economic mobility | $1,500,000,000 over a 5 year period |
| U.S. DEPARTMENT OF JUSTICE | |
| **Second Chance Employment—Offender Re-entry—Pay for Success**—for performance-based awards and projects implementing permanent supportive housing models | Up to $30,000,000 |
| **Performance Partnership Pilots**—to permit Justice programs to participate in other Federal agency performance partnership pilots | |
| U.S. DEPARTMENT OF COMMERCE | |
| **Ryan-Murray Evidence-based Policy Commission**—for a Records Clearinghouse and Commission on Evidence-Based Policymaking to expedite the acquisition of Federal administrative data sources to improve data documentation | $10,000,000 |
| U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT | |
| **Multifamily Performance-Based Energy Conservation Demonstration**—to test a model that facilitates financing of energy and water conservation improvements in multifamily housing to reduce utility costs | |
| U.S. DEPARTMENT OF STATE | |
| **Development Innovation Ventures**—to invest in programs that could change millions of lives | $22,400,000 |

[This statement was submitted by Michele Jolin, CEO and Co-Founder, Results for America.]

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PREPARED STATEMENT OF JYNELLE M. REX

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or ben-

efit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF REVEREND DR. JERRY L. ROGERS

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Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

The developmental centers (DCs) serve clients who do not function well at home or in a group home setting and who may have even been placed into the DCs for care by the judicial system because they do not function well in the community, yet who do not need to be in a prison or jail. These DCs offer the least restrictive yet "controlled/safest" setting that allows many of the residents to function as best as they can given their developmental levels and behavior issues. The DCs allow them to contribute as much as they can, to society, in the day programs and workshops, and the DD population as well as learn as much as they can about social interactions and appropriate behaviors, in an atmosphere that does not demean, degrade, victimize, or discriminate against them, and they feel accomplished in the process.

If the DCs are closed, the residents of these facilities will then be placed back into the community in which they cannot function while also having the workshops they attend being taken away from them. Needless to say, this is going to be very stressful and possibly behavioral triggering for many of these unfortunate individuals. When these behaviors occur the only options that will be left for the group homes, because of available staffing, will be for them to call the police and have the individual placed into a mental health lock up for 72 hours, if not jail, and then eventually the individual being placed into a locked down unit of a nursing home because the group home can not handle them because of training and staffing issues. This is where the DCs play such a vital role in the Ohio Mental Health system. If they are closed there will be no supports and loss of most all of their freedoms that they have now—no safety net for our most vulnerable and fragile citizens. The probate judges will lose an important tool to help these individuals secure help and who are not suited or in need of incarceration in the penal system where they will yet be victimized again.

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PREPARED STATEMENT OF MRS. N. ROGERS

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## PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Blunt, members of the Subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative (GPEI) is an unprecedented model of cooperation among national governments, civil society and UN agencies working together to reach the most vulnerable children through the safe, cost-effective public health intervention of polio immunization. We appeal to this Subcommittee for continued leadership to ensure we seize the opportunity to conquer polio once and for all. Rotary International strongly supports the President's 2016 request of $168.8 million for the polio eradication activities of the CDC to enable full implementation of the polio eradication strategies and innovations outlined in the Polio Eradication and Endgame Strategic Plan (2013–2018).

### PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Significant strides were made in 2014 toward stopping transmission of polio. Thanks to this committee's leadership in appropriating funds for the polio eradication activities of the CDC:

—Eradication efforts have led to more than a 99 percent decrease in cases since the launch of the GPEI in 1988 and saved 10 million people from paralysis.
—Only 3 countries (Nigeria, Pakistan and Afghanistan) are polio-endemic—the lowest number in history. India and the entire Southeast Asia region were certified free from polio in 2014.
—Nigeria has applied lessons and infrastructure from polio eradication to effectively stop an Ebola outbreak. Nigeria's success in conquering Ebola is an example of the legacy of polio eradication in action—and of the immediate return on our collective investment. Nigeria only confirmed six cases of polio in 2014.
—There have been no cases of endemic polio on the African continent since August of 2014.
—Polio outbreaks in the Middle East, Horn of Africa, and Central Africa, which accounted for roughly 60 percent of all cases in 2013, have been brought under control. All polio free countries remain at risk for outbreaks until the wild poliovirus has been eradicated in the remaining places where it persists.
—The Global Polio Eradication Initiative is cautiously optimistic that type 3 polio may have been eradicated. There have been no cases of type 3 polio for more than 2 years.
—Pakistan is now considered to be the only country in the world with uncontrolled transmission of wild polio and as of 2 April, accounts for 20 of the 21 polio cases that have been confirmed in 2015 (the other case is in neighboring Afghanistan).
—Lack of access to children in insecure areas continues to hamper progress. In Pakistan alone, more than 60 health workers and security personnel assigned to protect them have been killed in targeted attacks since November of 2012.
—Funding remains essential to addressing challenges in the remaining polio affected countries and protecting the gains made in at risk countries.

The Polio Eradication and Endgame Strategic Plan (2013–2018) launched in 2013 lays out the strategies for the certification of the eradication of wild poliovirus by 2018. This new plan builds on the lessons learned from the successful eradication of polio to date and the substantial advances in technology in 2012. The timely availability of funds remains essential to the achievement of a polio free world. The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Rotary International appreciates the United States' generous support and recognizes increased funding provided by Congress in fiscal year 2015 to ensure the GPEI can fully implement the plan. Rotarians are committed to continuing their own fundraising for the program until the world is certified polio free. Rotarians will also continue to advocate support from the public and other governments, both polio free and polio affected, to support the successful execution of the Strategic Plan. The ongoing support of donor countries, like the United States, is essential to assure the necessary human and financial resources are made available to polio-endemic and at risk countries to certify the world polio free by the end of 2018.

### THE ROLE OF ROTARY INTERNATIONAL

Rotary International, a global association of more than 34,000 Rotary clubs in more than 170 countries with a membership of over 1.2 million business and professional leaders (more than 345,000 of which are in the U.S.), has been committed to battling polio since 1985. Rotary International has contributed more than U.S.$1.2 billion toward a polio free world—representing the largest contribution by an international service organization to a public health initiative ever. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in thanking you for your support of the GPEI.

### THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's increased support of CDC's polio eradication activities to support full implementation of the Strategic Plan. The United States is the leader among donor nations in the drive to eradicate this crippling disease. CDC has used the increased Congressional support provided in fiscal year 2015 to:

—*Globally*.—In its role as a technical lead in the GPEI, CDC supports hundreds of field staff to complete polio eradication, including, notably, almost 200 STOP Polio assignees and large "National STOP" programs in Nigeria and Pakistan. CDC also supports other contractors to work in Africa and Asia and has de-

tailed staff in several priority countries to work under WHO and from within CDC field offices. This large network is coordinated from CDC's headquarters in Atlanta.

—*Build capacity in Nigeria*.—The National Stop Transmission of Polio (N-STOP) program, adapted from the original STOP Program, has provided Nigeria with an accessible, flexible, and culturally competent workforce at the front lines of public health. N-STOP includes participatory training for public health workers composed of ten modules covering poliomyelitis, vaccine management and monitoring, program management, and problem-solving practices. The Government of Nigeria and CDC partnered in the program's implementation, which has resulted in the placement of public health staff within the government structure in more than 170 communities throughout the north to strengthen local immunization teams. It has also supported training of 10,000 health workers across the 13 States to strengthen immunization systems and improve the quality of polio immunization. To date, N-STOP has engaged more than 60,000 nomadic settlements to expand vaccine provision to more than one million hard-to-reach children. The program updates local immunization plans and increases fixed post and outreach for routine immunization.

—*Build capacity in Pakistan*.—Increased investment in Pakistan will focus on training and placing local personnel to strengthen the program in areas where access is possible. Fiscal year 2015 has brought the focus to Pakistan, where the successful model of Nigeria is being adapted. Emergency Operations Centers have been established at the national and provincial level; and the National STOP program, adapted to Pakistan, is being implemented. CDC's efforts will also focus on an increase in cross border collaborations between Afghanistan and Pakistan to intensify Polio eradication activities.

—*Laboratory Surveillance*.—Investment with CDC's Polio Global Reference Lab will allow the recruitment of additional staff, training for country and regional labs, essential IPV research, and expansion of environmental surveillance capabilities in the field. CDC provides technical and programmatic assistance to the global polio laboratory network through the Polio Laboratory in CDC's Division of Viral Diseases. CDC's labs provide critical diagnostic services and genomic sequencing of polioviruses to help guide disease control efforts. CDC will continue to serve as the global reference laboratory, while expanding environmental surveillance in countries to serve as a "safety measure" to detect any polioviruses circulating in areas without cases. Kit distribution and proficiency testing for ITD and sequencing

—*Ebola response*.—The polio infrastructure, built with significant CDC input and support, adapted quickly to respond to an importation of Ebola in October 2014 in Lagos. Senior polio leadership quickly established an Emergency Operations Center in Lagos and quickly responded to the outbreak, stopping the virus without incident. Meanwhile, immunization rounds in northern Nigeria continued as planned without a decrease in quality. This showed the quality and resilience of the program in Nigeria, and the adaptability of polio assets for use in other public health issues.

—*Vaccine Purchase*.—CDC funds are being used to purchase oral polio vaccine to immunize children against polio.

—*Vaccine Operations & Social Mobilization*.—CDC, through its cooperative agreement with WHO, provides funding for immunization activities in high risk and polio infected countries. CDC funding is essential to supporting the supplemental immunization activities that both stop existing outbreaks and prevent new outbreaks. CDC collaborates closely with UNICEF and provides critical support on analysis and use of campaign results to identify and address reasons why children are missed and address vaccine hesitancy concerns.

—*Immunization Systems Strengthening*.—Investment in this area will allow CDC to provide scientific assistance across a range of topics related to the introduction of IPV to focus countries, other GAVI-eligible countries, and to non-eligible countries.

FISCAL YEAR 2016 BUDGET REQUEST

For fiscal year 2016, we respectfully request this subcommittee to provide $168.8 million for the CDC's polio eradication activities, the level that was requested in the President's budget. Continued funding will allow CDC to provide direct support and build capacity to continue intense supplementary immunization activities in the remaining polio-affected countries, continue leadership on data management to drive evidence-based decisionmaking, and continue to implement strategies to increase effective management and accountability. These funds will also help maintain essen-

tial certification standard surveillance. This funding will also ensure that CDC continues its essential contribution toward work to interrupt polio transmission in the places where it persists. Finally, continued funding will enable CDC to continue to capitalize on polio eradication efforts to strengthen immunization systems by developing country-level capacity to protect the gains made in polio free countries and countries which remain at risk for outbreaks.

BENEFITS OF POLIO ERADICATION

Since 1988, over 10 million people who would otherwise have been paralyzed are walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

A study published in the November 2010 issue of the journal Vaccine estimates that the GPEI could provide net benefits of at least $40–50 billion over the next 20 years. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed annually in the next 10 years if the world fails to capitalize on the more than $11 billion already invested in eradication. Success will ensure that the significant investment made by the U.S., Rotary International, and many other countries and entities, is protected in perpetuity.

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PREPARED STATEMENT OF SANDRA RUFFING

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

My name is Dr. Alice C. Thornton, and I serve as Medical Director of the Bluegrass Care Clinic (BCC) at the University of Kentucky Medical Center in Lexington, Kentucky. I write to submit testimony on behalf of the Ryan White Medical Providers Coalition (RWMPC), which I Co-Chair. RWMPC is a national coalition of medical providers and administrators who work in clinics supported by the Ryan White HIV/AIDS Program funded by the HIV/AIDS Bureau (HAB) at the Health Services and Resources Administration (HRSA). I thank the Subcommittee for its support of Ryan White Part C Programs in fiscal year 2015. And while I am grateful for this support, and understand that times are hard, I request $225.1 million, or a $24 million increase for Ryan White Part C programs in fiscal year 2016. While I know that this is a lot of funding, it is in fact well below the estimated need—in 2014, my clinic alone enrolled 168 new patients into care—a 14 percent increase in 1 year. These funds help Ryan White clinics identify, engage and effectively treat persons living with HIV/AIDS in a way that saves both lives and money.

My Ryan White-funded clinic, the BCC, that has served as the source for HIV primary care in the 63 counties of central and eastern Kentucky for the past 24 years. Over half of the counties served are federally recognized as economically distressed, and BCC cares for 74 percent of the people living with HIV in the region. Since the BCC received its first Part C grant in 2001, the number of patients has increased by almost 300 percent. To help fund these enormous patient and cost increases, the University incurs an annual deficit of approximately $1.2 million.

In addition to critical funding that the Ryan White Part C provides through direct Federal grants for comprehensive medical care clinics like BCC, most Part C clinics, including BCC, also receive support from other parts of the Ryan White Program that help provide access to medication; additional medical care, such as dental services; and key support services, such as case management and transportation, which all are essential components of the highly effective Ryan White HIV care model that results in excellent outcomes for our patients.

### *Ryan White Part C Programs Support Comprehensive, Expert and Effective HIV Care*

Part C of the Ryan White Program funds comprehensive, expert and effective HIV care and treatment—services that are directly responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decade. The Ryan White Program has supported the development of expert HIV care and treatment programs that have become patient-centered medical homes for individuals living with this serious, chronic condition. In 2011, a ground-breaking clinical trial—named the scientific breakthrough of the year by Science magazine—found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96%—proving that HIV treatment is also HIV prevention.

The comprehensive, HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.[1] In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, retention in care rates

[1] See Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities at http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html.

ranged from 87 to 97 percent. In estimates from the Centers for Disease Control and Prevention (CDC)—only 37 percent of all people with HIV are in regular care nationally.[2] Once in care, patients served at Ryan White clinics do well—with 75 to 90 percent having undetectable levels of the virus in their blood. In 2014, 86 percent of BCC patients had an undetectable viral load, and many of our patients continue to work and remain active community members.

*Investing in Ryan White Part C Programs Saves Both Lives and Money*

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from the Part C Clinic at the University of Alabama at Birmingham found that patients treated at the later stages of HIV disease required 2.6 times more healthcare dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines. On average it costs $3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs. The comprehensive services provided often include lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. This is a real bargain when compared to the cost of one night as an inpatient (hospital)—$1000 to $3000 just for the bed per night.

*Current Challenges—Future Promise*

This effective and comprehensive HIV care model, however, is not completely supported by Medicaid or most private insurance. While most Ryan White Program clients have some form of insurance coverage, without the Ryan White Program, they would risk falling out of care. Barriers include poor reimbursement rates; benefits designed for healthier populations that fail to cover critical services, such as care coordination; and inadequate coverage for other important services, such as extended medical visits, mental health and substance use treatment. Full implementation of the Affordable Care Act's Medicaid expansion plus continuation of the Ryan White Program will dramatically improve health access and outcomes for many more people living with HIV disease.

*Fully Funding and Maintaining Ryan White Part C Programs Is Essential*

Because of both the inadequacy of insurance coverage for people with complex conditions like HIV and the fact that some individuals will remain uncovered, even with Affordable Care Act implementation, fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide. And while RMWPC welcomes the $4 million increase for Part C programs proposed in the President's fiscal year 2016 budget, it is concerned about the proposal to consolidate Ryan White Part D funding into Part C. RWMPC's specific concerns include:

—Parts C and D programs both provide comprehensive, effective care and treatment for women, infants, children and youth living with HIV/AIDS. However, Part D programs have cultivated special expertise for engaging and retaining women (including pregnant women) and young people in care. With adolescents accounting for 26 percent of new HIV infections in the U.S., it is still critical to target resources to support the effective, comprehensive services that Part D programs provide to these vulnerable populations.

In some communities, Part D-funded programs are the main providers of HIV care and treatment. It is critical to ensure that implementation of any budget proposal does not leave any community without adequate access to effective and comprehensive HIV care and treatment. Also, for Ryan White medical clinics that currently receive only Part D funding, it could prove difficult to successfully compete for Part C funding if there already is a Part C program serving that community; and loss of that Part D program could reduce the community's overall access to HIV and treatment.

—It is unclear how the proposed consolidation would be implemented. More detail outlining what the consolidation process would entail and how it would practically impact grantees and access to HIV care and treatment in communities is needed. Since most Ryan White medical clinics receive funding from multiple parts of the Ryan White Program, reduction of funding to one part of the Program can have damaging and unintended consequences to the overall services provided by Ryan White medical clinics, especially now, as providers work to expand access to effective HIV care and treatment. The two programs are different in their focus and services, making consolidation challenging.

[2] See CDC's HIV in the United States: The Stages of Care http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf.

At this critical time in the HIV/AIDS epidemic, when research has confirmed that early access to HIV care and treatment not only saves lives but prevents new infections by reducing the risk of transmission to near zero for patients who are virally suppressed and keeps patients engaged and working, it is essential to maintain overall funding levels for the Ryan White Program. While the ACA provides important new healthcare coverage options for many patients, most health insurers fail to support the comprehensive care and treatment necessary for many patients to manage HIV infection. Exorbitant cost sharing, benefit gaps and limited state uptake of the Medicaid expansion necessitate a vital and ongoing role for the Ryan White Program. Increasing access to and successful engagement in effective, comprehensive HIV care and treatment is the only way to lead the Nation to an AIDS-free generation and reduce the devastating costs of—including lives lost to—HIV infection.

*Remove the Ban on Federal Funding for Syringe Exchange Programs: Advance Public Health and Address Drug Use in Kentucky and Nationwide*

RWMPC strongly urges Congress to lift the ban on Federal funding for syringe exchange programs (SEPs). RWMPC is committed to evidence-based public health interventions that both increase access to healthcare and decrease transmission of HIV, viral hepatitis, and other blood?borne pathogens. Injection drug use is a major route of transmission for these infectious agents. Because transmission occurs through the sharing or re?use of infected paraphernalia, access to uninfected injection equipment is a key part of infection prevention programs.

Kentucky has one of the highest rates of acute hepatitis C in the country. We have seen a dramatic increase in hepatitis C infections with a majority of infections occurring in young persons who live in non-urban areas with a history of injection drug use, and previously used opioid agonists such as oxycodone.[3] In our infectious diseases practice, hepatitis C and infections such as endocarditis, have compromised the lives of too many Kentuckians, and we have been frustrated by our inability to employ the full range of effective tools available to prevent infections and help patients address their addiction.

However, last week, with its passage of a comprehensive bill (SB 192) to address the growing heroin epidemic in our State, Kentucky legislators acted decisively in support of policies that are critical to improving public health in Kentucky and the lives of its residents affected by addiction, including many of our patients at the University of Kentucky Medical Center. The new law emphasizes medical interventions that expand access to medicine to reverse heroin overdoses and increase access to addiction counseling and treatment. It also includes a syringe exchange program provision—a well-proven tool for preventing the spread of viral hepatitis, HIV and other infections. The provision will allow local jurisdictions to establish programs that provide clean syringes in exchange for used ones.

The importance of syringe exchange has been illustrated most recently by new data from the Centers for Disease Control and Prevention highlighting links between HIV infection and injecting drug use, while also showing how this affects all of us. The data, published in the agency's Morbidity and Mortality Weekly Report was gathered from 20 U.S. cities in 2012 and showed that of more than 10,000 injecting drug users tested for HIV, 11 percent are living with the virus that leads to AIDS. Of those who answered interview questions, 30 percent reported injecting themselves with a syringe that was shared with other people. The risk this data illustrates is not restricted to people who inject drugs; the great majority of those interviewed also reported having sex without using condoms.[4]

While the new Kentucky law is comprehensive and ambitious, it will be up to policymakers at the local and Federal levels to ensure it benefits my patients and those at risk for hepatitis C, HIV and other infections. Funding to support the continuum of services from syringe exchange to substance use treatment will be critical to stop this epidemic, and Congress should permit Federal funds to support all of these services, including syringe exchange programs.

*Conclusion*

Thank you so much for your consideration of these requests. If you have any questions, please contact the RWMPC Convener, Jenny Collier.

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[3] Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis—United States, 2012. Online at: http://www.cdc.gov/hepatitis/Statistics/2012Surveillance/Commentary.htm.

[4] Centers for Disease Control and Prevention. HIV Infection and HIV-Associated Behaviors Among Persons Who Inject Drugs—20 Cities, United States, 2012. March 20, 2015:64(10);270–275. Online at: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6410a3.htm?s__cid=mm6410a3__e.

[This statement was submitted by Alice Thornton, MD, Medical Director, Bluegrass Care Clinic and Co-Chair, Ryan White Medical Providers Coalition.]

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PREPARED STATEMENT OF CINDY R. SANDS

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs,NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

TheseHHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related tool kit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care.Thelegally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

## PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the scleroderma community's priorities while working to craft the fiscal year 2016 L-HHS Appropriations Bill.

### ABOUT SCLERODERMA

Scleroderma, or systemic sclerosis, is a chronic connective tissue disease generally classified as one of the autoimmune rheumatic diseases.

The word "scleroderma" comes from two Greek words: "sclero" meaning hard, and "derma" meaning skin. Hardening of the skin is one of the most visible manifestations of the disease. The disease has been called "progressive systemic sclerosis," but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease varies from patient-to-patient.

It is estimated that about 300,000 Americans have scleroderma. About one third of those people have the systemic form of scleroderma. Since scleroderma presents with symptoms similar to other autoimmune diseases, diagnosis is difficult. There may be many misdiagnosed or undiagnosed cases.

Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. Overall, female patients outnumber male patients at a ratio of 4-to-1. Factors other than gender, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset, and the pattern or severity of internal organ involvement. The reasons for this are still unknown. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic or autoimmune diseases. While, scleroderma can develop in every age group from infants to the elderly, its onset is most frequent between the ages of 25 to 55.

Currently, there is no cure for scleroderma. Treatments are based on a patient's particular symptoms. For instance, heartburn can be controlled by medications called proton pump inhibitors or medicine to improve the motion of the bowel. Some treatments are directed at decreasing the activity of the immune system. Due to the fact that there is so much variation from one person to another, there is great variation in the treatments prescribed.

Any chronic disease can be serious. The symptoms of scleroderma vary greatly for each person, and the effects of scleroderma can range from mild to life threatening. The seriousness will depend on which organ systems of the body are affected, and the extent to which they are affected. A mild case can become more serious if not properly treated. Prompt and proper diagnosis and treatment by qualified physicians may minimize the symptoms of scleroderma and lessen the chance for irreversible damage.

### ABOUT THE FOUNDATION

The non-profit Scleroderma Foundation is the national organization for people with scleroderma and their families and friends. It was formed January 1, 1998, by a merger between the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation. The national office is headquartered in Danvers, Massachusetts. The Foundation has a three-fold mission of support, education, and research.

*Support*

The Scleroderma Foundation offers the following tools and resources in support of people living with scleroderma and their families:

—A nationwide network of 24 chapters and more than 150 support groups
—A toll-free helpline providing information and referrals to callers
—Educational materials, including a quarterly magazine called "Scleroderma Voice″
—Offer a variety of brochures, booklets and newsletters, along with our informative website

Additionally, the Foundation hosts an annual National Patient Education Conference. The conference offers various educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends. Workshops, panel discussions and other educational sessions are led by the leading scleroderma researchers and healthcare professionals.

*Education*

As part of our education mission, we not only perform all the functions mentioned above, we also work with our Medical Advisory Board of internationally known

scleroderma experts to provide patient education programs as well as education for physician/healthcare professionals.

*Research*

The Scleroderma Foundation budgets at least $1 million a year for research funding, its single largest budgeted expense. The Scleroderma Foundation takes its fiduciary responsibility to donors very seriously, especially with regard to our research grant program.

In the case of research funds, the Foundation's Peer Research Review Committee, composed of medical experts on scleroderma from around the world, helps determine which proposals will be funded by reading, analyzing and ranking all proposals received. It follows a peer review system based on that of the National Institutes of Health.

ONE FAMILY'S STORY

Cheyenne Cogswell is an 8-year old third-grader living in the poverty-stricken town of Falmouth, Kentucky. Cheyenne was diagnosed at age six with a severe case of systemic scleroderma. The disease has caused kidney failure and significant damage to her digestive system, making it difficult for the body to receive the proper nutrition needed for a growing child. She has undergone several life-saving operations and numerous hospitalizations. Her skin and other internal organs, such as the heart and lungs, are also affected. Cheyenne's treatment first consisted of hospitalization and intense chemotherapy. She continues with daily chemotherapy injections, now given by her mother, to help suppress her immune system and slow the progression of the disease. Cheyenne is being raised by a single mother who has faced extreme consequences from the financial burden created by scleroderma, losing her job in the economic downturn, as well as the family's home. Doctors doubted if Cheyenne would survive beyond her seventh birthday, but she continues to beat the odds. Chronic diseases like scleroderma are unpredictable in their course, and the family—together with their close circle of friends—continues to fight and hope for the best. Their road is uncertain and illustrates why funding for NIH and its research programs are vital to so many people whose lives are impacted by chronic illness such as scleroderma.

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that the scleroderma research portfolio can continue to grow, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

—The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) less than in fiscal year 2003.

—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Early recognition and an accurate diagnosis of scleroderma can improve health outcomes and save lives. CDC in general and the NCCDPHP specifically have pro-

grams to improve public awareness of scleroderma and other rare, life-threatening conditions. Unfortunately, budgetary challenges at CDC have pushed the agency to focus resources on combating a narrow set of "winnable battles." Please increase funding for CDC and NCCDPHP so that the agency can invest in additional, critical education and awareness activities that have the potential to improve health and save lives.

NATIONAL INSTITUTES OF HEALTH

NIH has worked with the Foundation to lead the effort to enhance our scientific understanding of the mechanisms of scleroderma with the shared-goal of improving diagnosis and treatment, and ultimately finding a cure. Since scleroderma is a systemic fibrotic disease it is inexorably linked to other manifestations of fibrosis such as cirrhosis and pulmonary fibrosis that occurs during a heart attack. Scleroderma is a prototypical manifestation of fibrosis as it impacts multiple organ systems. In this way, it is important to promote cross-cutting research across such Institutes as NIAMS, NHLBI AND NIDDK.

Emerging NIH initiatives like the Cures Acceleration Network and the Accelerating Medicines Partnership are creating meaningful opportunities to advance scleroderma research. Please provide NIH with a significant funding increase to the scleroderma research portfolio can continue to expand and facilitate key breakthroughs.

—NHLBI, which is leading Scleroderma Lung Study II, is comparing the effectiveness of two drugs in treating pulmonary fibrosis in scleroderma.

—NIAMS, is leading efforts to discover whether three gene expression signatures in skin can serve as accurate biomarkers predicting scleroderma, and investigations into progression and response to treatment to clarify the complex interactions of T cells and interleukin-31 (IL-31) in producing inflammation and fibrosis, or scarring in scleroderma.

ADDITIONAL MEDICAL RESEARCH ACTIVITIES

In recent years, scleroderma has been listed as a condition eligible for study through the Department of Defense (DOD) Peer-Reviewed Medical Research Program (PRMRP). Since fiscal year 2005, the opportunity for scleroderma researchers to compete for funding through this mechanism led to over $10 million in scleroderma research funding as well as the initiation of meaningful research projects. Research on the underlying mechanisms of scleroderma is showing relevance to all fibrosis, which occurs at higher rates among individuals who served in the military and our veterans. Further, military service-associated environmental triggers, particularly silica, solvent, and radiation exposure, are believed to be potential triggers for scleroderma in individuals that are genetically predisposed to it.

We appreciate that the Defense Appropriations Subcommittee and the Senate play important roles in crafting the annual eligible conditions list. The scleroderma community urges you to weigh in with your colleagues on the Appropriations Committee to actively work to see that scleroderma is continues to be listed as a condition eligible for study through the PRMRP within the Committee Report accompanying the fiscal year 2016 Defense Appropriations Bill.

Thank you again for your time and your consideration of the scleroderma community's requests.

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PREPARED STATEMENT OF CAROLE L. SHERMAN

I am the mother and co-guardian of an adult son, aged 46, who from birth has lived with the effects of severe brain injuries. John is a large, mobile and nonverbal man with pica behaviors (eating inedibles) who functions on the mental level of a young toddler, a 2-year old, to be more exact. Our son has slight or little awareness of danger and for many years his safe home has been a State-operated congregate care program. The future viability of John's home is in jeopardy due to the undermining work of federally funded entities and programs in the U.S. Department of Health and Human Services.

I represent as public affairs chairman Families and Friends of Care Facility Residents (FF/CFR), Arkansas' statewide parent-guardian association. FF/CFR is an all-volunteer organization; we employ no lobbyist; we receive no public funds.

The following are examples of how government dollars are spent in the wrong way by the Department of Health and Human Services:

(1) National Council on Disability (NCD), an independent Federal agency engaged in disability policy recommendations.

On Tuesday, October 23, 2012, the National Council on Disability (NCD) released its policy project—"Deinstitutionalization: Unfinished Business." The press release read: "NCD Launches Toolkit to Speed Closure of State-Run Institutions." Prior to releasing its deinstitutionalization policy recommendations and documents, there were no public hearings or Notice to those most affected. There was no public input process for those most affected. NCD inappropriately collaborates with others in promoting its national de-institutionalization agenda out of the public eye.

*REQUEST*.—Please discontinue funding for National Council on Disability.

(2) Programs funded under Public Law 106 402, Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The DD Act funds three discretionary programs which operate in every State: (1) State Councils on Developmental Disabilities, (2) Protection & Advocacy Systems for Developmental Disabilities (P&As) and (3) University Centers for Excellence in Developmental Disabilities. The DD Act also funds a fourth program, Projects of National Significance. The four DD Act programs are administered by DHHS/Adm. on Community Living/ Adm. on Intellectual-Developmental Disabilities.

The DD Act programs' administering agency, Administration on Community Living (ACL), permits DD Act programs to engage in activities which undermine and eliminate long-term care facilities for persons who cannot care for themselves. The agency is not responsive to families' objections.

Our families seek relief from DD Act programs, which have insufficient oversight and which use public funds for deinstitutionalization activities. The Arkansas DD Act protection and advocacy system (P&A) has brought three Federal lawsuits against the State naming residents of State-operated human development centers (HDCs) as Plaintiffs without notice to their legal guardians; it contacted media, organized a rally and called for closure of Booneville HDC (2010 and 2015). In January, 2015, the Arkansas P&A contacted media and issued a report containing inaccurate information about BHDC; the report called for shifting Medicaid funds from our human development centers to other programs. Representatives of the Arkansas P&A have testified before Arkansas legislative panels against capital improvement funds for our State-operated human development centers.

ACL funds Projects of National Significance (PNS) grants, two of which continue year after year without sufficient oversight and without opportunities for families to comment or object to the grantees' deinstitutionalization activities. PNS grants have been awarded to organizations which work to eliminate long-term care facilities for persons who cannot care for themselves.

DD Act programs (State Councils, P&As and UCEDDs) provide financial support (public funds) for the work of their national organizations which operate in and around Washington, D.C. without impartial and reasonable oversight. At times—as in late 2012 when the groups worked to defeat H.R. 2032—the DD Act national organizations engage in lobbying and/or they lead others in lobbying members of Congress to achieve goals of undermining and eliminating congregate care programs for persons who cannot care for themselves.

*REQUEST*.—Please preclude use of Federal funds for:

DD Act programs' deinstitutionalization activities, including activities of their national organizations; and

Projects of National Significance' activities which undermine and eliminate long-term care facilities for persons who cannot care for themselves.

(3) DHHS Financial incentive grants—Money Follows the Person (MFP), Balance Incentive Payment Plan (BIP), Community First Choice Option (CFCO).

DHHS/CMS financial incentive grants reward States when they shift Medicaid long-term care funding from institutional care programs to community programs which generally have less oversight and accountability and the practice is misguided and dangerous. Families of individuals who require close care had little or no opportunity to review, comment and object that CMS incentive grants favor one needed program over another critically needed program. The extension of Federal funding for Money Follows the Person (MFP) grants and Community First Choice Option (CFCO) are optional programs offered to the States in the voluminous Affordable Care Act, inserted without adequate review, without discussion, and without adequate notice to families most affected. Extension of MFP, BIP, and CFCO were created by DHHS out of the public eye with inadequate opportunity for the public to review, comment or object.

*REQUEST*.—Please address the unfair, unsafe CMS de-institutionalization incentive grants.

SUMMARY

All affected parties should be allowed at the DHHS table when health and safety policies for our Nation's vulnerable populations are formulated. That has not been the case. Please resist funding DHHS programs and policies which promote harmful deinstitutionalization of persons with severest forms of developmental disabilities. My son and his peers cannot appear before committees, engage in protests or advocate for their health and safety.

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PREPARED STATEMENT OF PATRICIA SIMPSON

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

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> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

## PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY

Chairman Roy Blunt, Ranking Member Patty Murray, and distinguished members of the Subcommittee, as you begin to craft the fiscal year 2016 Labor-HHS-Education appropriations bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide $32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), $1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), full support for the National Center on Sleep Disorders Research (NCSDR), and implementation of the 2011 NIH Sleep Disorders Research Plan. These actions will ensure increased awareness of the importance of sleep and circadian rhythms and further the advancements being made by sleep researchers to better understand the relationship between sleep and health.

### SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,100 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50–70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20 percent of motor vehicle injuries. The widespread effect of sleep disorders on every age group poses a public health risk, extending from the ability to learn to maintain a healthy lifestyle. Furthermore, it is important to recognize that sleep disorders and circadian disturbances are often an indicator of, or a precursor to other major diseases and disorders including; obesity, diabetes, hypertension, cardiovascular disease, stroke, depression, bipolar disorder, and substance abuse. Another increasingly detrimental condition affecting 15 percent of the population is sleep-disordered breathing, including obstructive sleep apnea. Sleep apnea results in excessive daytime somnolence, poor performance, increased frequency of road traffic accidents, and arterial hypertension. Studies show that 85 percent of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51 percent). If left untreated, obstructive sleep apnea has significant negative impacts on health, including early mortality.

### NATIONAL INSTITUTES OF HEALTH

Due to the fact that sleep is a multi-disciplinary issue, many institutes and centers at NIH, utilize a portion of their funding to support sleep and circadian research. The majority of sleep research is coordinated by NHLBI, particularly the National Center on Sleep Disorders Research. An appropriation of $32 billion for NIH, and $3 billion for NHLBI, is needed to facilitate the continued growth and advancement in the sleep and circadian research portfolio.

The reason NCSDR is housed at NHLBI is due to the important link between sleep disorders and cardiovascular health. NCSDR supports research, health education, and research training related to sleep-disordered breathing and the fundamental function of sleep and circadian rhythms. Furthermore, NCSDR coordinates sleep research across NIH and with other Federal agencies and outside organizations.

NCSDR's coordinating role between institutes is made possible through adequate funding. These research activities also have far reaching effects, beginning with training grants targeted towards undergraduate students and career development opportunities attracting top talent in doctoral programs. Sequestration has the potential to disrupt the research training pipeline by reducing the amount of K, T, and F series awards for new investigators. It could also disrupt the career development pipeline designed to train future investigators who are pursuing research in sleep disorders and circadian rhythms. It is important to fund NIH at $32 billion and NHLBI at $3 billion in fiscal year 2016 so that we can continue these advancements in sleep and circadian research.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. Most notably, CDC engages in the National Healthy Sleep Awareness Project which conducts research on prevalence and incidence of sleep disorders, and raises awareness on the importance of healthy sleep through the production of State fact sheets, updating the CDC website, and disseminating information on sleep related topics. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at $7.8 billion including an allocation of $1 million solely for sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program, so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

NIH SLEEP DISORDERS RESEARCH PLAN

NCSDR published the NIH Sleep Disorders Research Plan in November of 2011 highlighting the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep and circadian rhythm disorders. A Joint Task Force between the two leading organizations representing the sleep medicine and research community, Sleep Research Society (SRS) and American Academy of Sleep Medicine (AASM), has identified research opportunities that will have the highest impact on health within the plan.

The Plan recommends implementation of the following sleep research goals which will help us understand the function of sleep and inform individuals on healthier lifestyle choices:

—Advance the understanding of sleep and circadian functions and of basic sleep and circadian mechanisms, in both the brain and the body, across the lifespan.

—Identify genetic, pathophysiological, environmental, cultural, lifestyle factors, and sex and gender differences contributing to the risk of sleep and circadian disorders and disturbances, and their role in the development and pathogenesis of co-morbid diseases and disability.

—Improve prevention, diagnosis, and treatment of sleep and circadian disorders, chronic sleep deficiency, and circadian disruption, and evaluate the resulting impact on human health.

—Enhance the translation and dissemination of sleep and circadian research findings and concepts to improve healthcare, inform public policy, and increase community awareness to enhance human health.

—Enable sleep and circadian research training to inform science in cross-cutting domains, accelerate the pace of discovery, and the translation of enhanced therapies from bench to bedside to community.

Research activities and stakeholders addressed by the plan benefit from the encompassing range of NIH research, training, and outreach programs. Over the past 2 years, steps have been taken to implement portions of this research plan, but additional work needs to be done. SRS encourages you to recommend that this research plan continue to be implemented during fiscal year 2016.

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

[This statement was submitted by Allan Pack, MBCHB, Ph.D., President, Sleep Research Society.]

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PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of funding for the National Institutes of Health, in particular, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We urge your support of at least $32 billion for NIH, including $1.37 billion for NICHD in fiscal year 2016.

Established in 1977, SMFM is dedicated to improving maternal and child outcomes and raising the standards of prevention, diagnosis, and treatment of maternal and fetal disease. Maternal-fetal medicine specialists, known as MFM specialists, perinatologists, or high-risk pregnancy physicians, are highly trained obstetricians/gynecologists with advanced expertise in obstetric, medical, and surgical complications of pregnancy and their effects on the mother and fetus. The complex problems faced by some mothers may lead to death as well as short-term or life-long problems

for both mothers and their babies. Such complications be understood, treated, prevented and eventually solved through research.

NICHD's mission is to ensure that every child is born healthy and that women suffer no harmful effects from reproductive processes. NICHD-supported basic, clinical, translational, and multidisciplinary research studies address a myriad of issues in pregnancy including:

*Preterm Birth*.—Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy, and can cause long-term complications. About 20 percent of premature babies die within the first year of life, and although the survival rate is improving, many preterm babies have life-long disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. $26 billion annually.

*Hypertensive Diseases in Pregnancy*.—High blood pressure (hypertension) during pregnancy is the second leading cause of maternal death in the United States, accounting for 15 percent of all deaths. For the mother, it is associated with increased need for delivery because of pregnancy complications, stroke, pulmonary or heart failure, and death. The likelihood and severity of these complications increases as the severity of the hypertension increases, and if preeclampsia develops. Preeclampsia is characterized by high blood pressure and the presence of protein in the urine. Its cause remains one of the greatest mysteries in obstetrics and is a major cause of maternal, fetal, and neonatal mortality worldwide.

*Pregestational and Gestational Diabetes*.—The hormonal changes of pregnancy can seriously worsen preexisting diabetes and often bring about a diabetic state (gestational diabetes) in predisposed women. Whether diabetes mellitus existed before conception or gestational diabetes develops during pregnancy, maternal glucose intolerance can have significant medical consequences for both mother and baby. Poorly controlled diabetes is associated with miscarriage, congenital malformations, abnormal fetal growth, stillbirth, obstructed labor, increased cesarean delivery, and neonatal complications. Up to 200,000 pregnancies are affected by gestational diabetes each year.

Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. However, there are multiple ways in which the NIH can shore up its work in the area of pregnancy and maternal health. In fact, most of the research being conducted in the U.S. on pregnancy is occurring at the NIH. There is very little private support for such efforts, and therefore it is essential for the NIH to continue this important work. Key areas of research that SMFM supports are:

*Funding the Goals of the National Children's Study*.—Although SMFM was disappointed that the National Children's Study (NCS) itself was canceled, we fully support continued efforts at the NIH to achieve the statutory mandates set forth in Section 1004 of the Children's Health Act of 2000. We were pleased to see the Committee appropriate $165 million for these efforts in fiscal year 2015, and we urge you to continue this work with dedicated funding in fiscal year 2016. Current funding for projects like the Human Placenta Project will allow us for the first time to understand the role of the placenta on fetal development as well as the health of the mother. The goals and mission of the NCS should continue to be advanced aggressively in future years. As a result of the work conducted by NCS and other NIH research, we now understand that the effects of physical and social environments on health begin earlier and reach farther than we had ever imagined. We must work now with even greater commitment and urgency to better understand the precursors of child and adult disease in order to develop new treatment and prevention strategies that will improve the health of the entire population.

*Prioritizing Pregnancy and Breastfeeding Research*.—With additional support NICHD could explore the effect of medications in pregnancy and breastfeeding. We know that a majority of women take one or more medications during pregnancy, but we know very little about the safety or efficacy of these drugs on the woman or her child. As MFMs, we often prescribe disease managing medications to pregnant women and do the best we can with the information available. But we need more information. Women and their babies could be healthier with additional research in this area.

*Building on the Infrastructure in Place via NICHD's Research Networks*.—One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These net-

works deal with different aspects of pregnancythe problem of preterm birth and its consequence.

—The Stillbirth Collaborative Research Network (SCRN) was created to study the extent and causes of stillbirth in the United States, and is conducting a geographic population-based determination of the incidence of stillbirth and is determining the causes of stillbirth using a standardized protocol that includes clinical histories, autopsies and pathologic examinations of the fetus and placenta as well as other postmortem tests to illuminate genetic, maternal and environmental influences. The information from this Network will benefit families who have experienced a stillbirth, women who are pregnant or who are considering pregnancy, and obstetric care providers. In addition, the knowledge gained from this Network will support future research aimed at improving preventive and therapeutic interventions and at understanding the mechanisms that lead to fetal death.

—Another important network is the Maternal-Fetal Medicine Units Network (MFMU), established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy. The MFMU Network has identified new effective therapies and will put an end to practices that are not useful. It is the only national research infrastructure capable of performing the much needed large trials that provide the evidence on which sound medical practice is based. The MFMU Network is also the ideal vehicle to collaborate with other NIH networks, as well as international networks in order to improve global health. Since its inception, the Network has made several exciting scientific advancements and has been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures that directly benefit those affected:

  —Following a series of studies in the 1970s and 1980s, an MFMU Network clinical trial showed that progesterone treatment resulted in a substantial reduction in the rate of preterm delivery among women who had a previous preterm birth, reduced the risk of newborn complications, and was effective in both African American and Non-African American women.

  —The MFMU Network conducted the largest, most comprehensive trial to date to test whether magnesium sulfate given to a woman in labor with a premature fetus (24 to 31 weeks out of 40) would result in a reduction in cerebral palsy. In August 2008, NIH announced that magnesium sulfate, when administered to women at risk of imminently delivering preterm, reduces the risk of cerebral palsy in surviving preterm infants by 45 percent.

  —The MFMU Network provided the first conclusive evidence that treating pregnant women who have even the mildest form of gestational diabetes can reduce the risk of common birth complications among infants, as well as blood pressure disorders among mothers. These findings will change clinical practice and lead to better outcomes for both mothers and babies.

—Vigorous support of the MFMU Network is needed so that therapies and preventive strategies that have significant impact on the health of mothers and their babies will not be delayed. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics.

—The NuMoM2b network was developed to use current genomic and proteomic techniques in combination with traditional markers for the prediction of adverse pregnancy outcomes, including preterm birth, preeclampsia, fetal growth restriction, and stillbirth in first pregnancies, since adverse pregnancy outcomes are at increased risk for complications in future pregnancies and over 40 percent of pregnancies in the United States are first pregnancies. The NuMoM2b study of 10,000 women provides the infrastructure for additional multicenter study of sleep disordered breathing in pregnancy. Epidemiologic studies have shown that a woman's health status during pregnancy is associated with her long-term health after pregnancy, suggesting that findings in pregnancy may be a better indicator for determining a woman's future health status than traditional risk factors. The NuMoM2b study could serve as the basis for long-term studies to determine the relationships between adverse pregnancy outcomes and long-term maternal health.

Finally, opportunities for future study include collaborative work by NICHD, NHLBI and NIDDK to more closely study these epidemiologic findings in an effort to identify predictive markers during pregnancy for subsequent heart disease and diabetes; develop tests to evaluate health after pregnancy; and test interventions both during and after pregnancy that may mitigate risk. Research is the cornerstone for improving our understanding of the physiology and pathophysiology of preg-

nancy, the interrelationship between the mother and fetus, the impact of medical conditions on pregnancy and the impact of medical diseases and pregnancy outcomes on the long term health of both mother and child. With your support, researchers can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences. Please support at least $32 billion for the NIH in fiscal year 2016, and continue the important work that is being done there. Without predictable, sustainable funding, many of these breakthroughs, as well as future breakthroughs, would not be possible. Already the contribution of such research on the health and wellbeing of mothers and children is making a difference, but we must build on that for future strides.

[This statement was submitted by Dr. Laura Riley, President, Society for Maternal-Fetal Medicine.]

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PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the Subcommittee, my name is Steven E. Hyman, and I am privileged to offer this testimony in support of increased funding for NIH for fiscal year 2016. I offer this testimony in my capacity as president of the Society for Neuroscience (SfN). I am also director of the Stanley Center for Psychiatric Research at the Broad Institute of MIT and Harvard as well as Harvard University Distinguished Service Professor of Stem Cell and Regenerative Biology. The Stanley Center is focused on using human genetic analysis to discover the neurobiological bases of neuropsychiatric disorders with a view to discovering new treatments.

The mission of SfN is to advance understanding of the brain and nervous system. Drawing on knowledge from the life sciences, physical sciences, and engineering, brain research is among the most promising and productive areas of science today. Given the tremendous human and economic toll of brain disorders worldwide—including autism, depression, schizophrenia, multiple sclerosis, Parkinson's disease, and Alzheimer's disease—it is among those areas of research in which continued progress is most powerfully needed. SfN leads efforts to disseminate and discuss emerging neuroscience discoveries, hosting one of the world's largest annual scientific meetings and publishing two leading scientific journals. SfN works to cultivate the next generation of scientists and physicians by providing professional development and training activities. SfN is also committed to actively educating the public about the brain both in health and in illness, and to engaging policymakers regarding the tremendous progress and potential of brain research. On behalf of the nearly 40,000 members of SfN, I thank you for your past support of the NIH and of neuroscience research. Thank you also for your support and investment in the NIH portion of the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. As one crucial part of the Federal investment in neuroscience, NIH-funded BRAIN programs will accelerate future discoveries across many areas of neuroscience and throughout the life sciences more broadly.

The Society stands with others in the research community in requesting $33 billion for NIH for fiscal year 2016. This level of support would help mitigate some of the damage done to the scientific enterprise of the United States by sequestration, which has taken an enormous toll on the research enterprise. Following the first year of sequestration cuts in fiscal year 2013, approximately 640 fewer competitive research project grants were issued and 750 fewer new patients admitted to the NIH Clinical Center. The last 4 years, including 2014, have seen the lower success rates for Research Project Grants than in the previous thirteen. In recent years, funding has failed to keep pace with inflation and, more importantly, with the remarkable scientific opportunities that hold the potential for life-altering breakthroughs. It is time to put research on a trajectory of sustained growth that recognizes its promise, its importance as a springboard for economic development, and the centrality of NIH-funded science to new and more effective approaches to the advancement of health and well-being for all Americans.

*Cross-Disciplinary Neuroscience*

The basic research funded by NIH at universities and hospitals across the Nation leads to discoveries that will inspire scientific and medical progress for generations. Such research also serves as a springboard for industry, which cannot take on the long-term investment or risks inherent in basic science. Past NIH-supported projects have helped neuroscientists make tremendous strides that have led to advances in the diagnosis and treatment of neurological and psychiatric disorders.

The following examples are just a few of the many success stories made possible by brain research funded by a strong historic investment in NIH and other research agencies.

*New Light on Autism, Schizophrenia, and Alzheimer's disease*

Among the risk factors for many common, devastating brain disorders, genetic contributors loom large. Identification of risk genes is critically important, because they can provide clues both to biomarkers and ideas for new therapies.

For more than a decade, it has been relatively straightforward to identify disease genes in the cases where a single gene produces illness, as in the case of familial Alzheimer's disease and some very severe forms of autism. However, such situations are quite rare. Illness in the vast majority of people with Alzheimer's disease, autism, and epilepsy, and virtually all people with schizophrenia, results from the interaction of many small variations in the genetic code together with environmental risk factors. While it has long been recognized that identification of the precise genetic risk factors for these disorders would be extremely valuable in lighting the path to new treatments, such clues seemed out of reach. The human genome project changed that, providing technology and computing tools that would make it possible to identify the small genetic signals that contribute to disease, previously hidden a sea of healthy human DNA sequence variation.

Through its research support and wise policies that encouraged collaboration and sharing of data, NIH has played a central role in moving the genetic analysis of common brain disorders forward. Finding the "signal" in the "noise" required very large patient samples that took years to assemble. During the past year, important progress has been reported in identifying genomic regions involved in common forms of Alzheimer's disease, autism, epilepsy, schizophrenia, and multiple sclerosis. While there remains a challenging path if we are to transform these new understandings into effective new treatments, these important newly reported clues have had a galvanizing effect in universities, hospitals, and in industry. The result is many new ideas and efforts to attack these disorders.

*Navigating the World*

The most advanced surveillance system is built into the brain. It comes equipped with a system that maps the locations and the order of a lifetime of events. Through new research tools and insights, scientists are coming to understand how the brain permits us to navigate the environment. Recent discoveries show that finding the way in the world is inexorably linked to the brain structures and processes by which memories are stored. While the brain is making mental maps to help a person navigate, it is also overlaying remembered experience onto those maps. The very same cells and circuits that help us navigate is the one that is damaged first in Alzheimer's disease. One of the first symptoms of Alzheimer's disease is that its victims can no longer find their car, and often can no longer find their way home. Further insight into how the brain builds networks can potentially lead to interventions that spare millions of people from the debilitating effects of memory disorders.

The importance of this work is underscored by the fact that the 2014 Nobel Prize in Physiology or Medicine was awarded to three pioneering neuroscientists who study navigation. Their work on the very basic science of how individual brain cells code the body's position in space has opened the door for important translational research studies. Building on this groundbreaking work, NIH-funded researchers are currently investigating the computations cells perform to determine position in space; the relationship between spatial memory and decisionmaking; and novel interventions targeted at this system to improve cognitive abilities in a host of disorders that damage memory.

*Bypassing Barriers*

Studies funded by NIH are helping researchers understand the blood-brain barrier, which helps block harmful substances from entering the brain. Unfortunately, many life-saving drugs are also unable to cross it, and thus cannot reach their target. An estimated 98 percent of potential drug treatments for brain disorders are unable to penetrate the blood-brain barrier. Researchers are developing techniques to open this barrier and allow medicines to enter. These techniques resulted in successful delivery of chemotherapy to patients with brain tumors, anti-clotting drugs to stroke patients, and other important treatments.

Scientists are also developing new strategies for attaching drugs to molecules that naturally cross the barrier. This method has shown success in several animal models by allowing drugs for conditions like Parkinson's disease to enter the brain. Through this research, scientists are creating new ways to open the blood-brain barrier so that life-saving drugs can reach specific targets without also opening the barrier to substances that must be excluded. Researchers are hopeful that new knowledge of the blood-brain barrier function, and new methods for drug delivery to the brain, will one day lead to better treatments for some of the most challenging and intractable disorders.

*Neuroscience: An Investment in Our Future*

Despite the difficult funding environment, the last several years have been a tremendously exciting and productive time for neuroscience discoveries. Major research advances in genomics, brain development, brain circuitry and imaging, computational neuroscience, neural engineering, and many other disciplines have occurred. Progress in these areas is leading to new tools, new knowledge, and an understanding of the brain that was unimaginable even a few years ago. Consider what could be learned with a more favorable funding posture and how it could be applied to human health.

Sustained investment to stimulate and speed these discoveries is essential to American healthcare and economic well-being. First, major investment in basic and translational neuroscience is not only fueling an enduring and vital scientific endeavor; it is the essential foundation for understanding and treating diseases that strike nearly one billion people worldwide. At home, there are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year. This, in turn, produces severe hardship for millions of families and costs the U.S. economy at least $760 billion a year, with future expenses reaching the trillions looming for several conditions. Otherwise beneficial increases in life span may be may be profoundly undercut by neurodegenerative diseases such as Alzheimer's disease and other dementias. Advances made possible by publicly-funded research will help us maintain, and perhaps someday restore, healthy brain function. With funding from NIH, researchers can continue working towards lifesaving breakthroughs such as developing ways for paralyzed people to regain control of their lives by using thoughts to move a robotic arm or investigating the recently discovered set of ten blood compounds that might be used to identify older adults at risk for developing memory deficits. NIH's funding should reflect the effort needed to achieve these innovations.

Additionally, NIH funding is an investment in America's current economic strength. Funding for research supports quality jobs and increases economic activity. NIH supports approximately 400,000 jobs and $58 billion in economic output nationwide. Eighty-five percent of NIH's budget funds extramural research in communities located in every State.

Finally, without robust, sustained investment, America's status as the preeminent leader in biomedical research is at risk. Other countries are investing heavily in biomedical research to take advantage of new possibilities. Even with growing philanthropic support, the private sector cannot be expected to close the gap. The lag-time between discovery and profitability means that the pharmaceutical, biotechnology, and medical device industries need federally-funded basic (also known as fundamental) research to develop products and treatments. The foundation that basic research provides is at risk if federally-funded research declines.

*Conclusion*

We live at a time of extraordinary opportunity in neuroscience. A myriad of questions once impossible to consider are now within reach because of new technologies, an ever-expanding knowledge base, and a willingness to embrace many disciplines. To take advantage of the opportunities in neuroscience we need an NIH appropriation that allows for sustained, reliable and robust growth. That, in turn, will lead to improved health for the American public and will help maintain American leadership in science worldwide. Thank you for this opportunity to testify.

[This statement was submitted by Steven E. Hyman, President, Society for Neuroscience.]

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PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

The Society for Women's Health Research (SWHR) is pleased to have the opportunity to submit the following testimony to the Committee urging a renewed commitment to investment in scientific and medical research within the Department of Health and Human Services (HHS).

For 25 years, our organization has been widely considered the thought-leader in promoting research on biological differences in disease and is dedicated to transforming women's health through science, advocacy, and education. We believe that an appropriately funded, robust Federal research agenda, which is committed to furthering women's health research, is critical for the U.S. to meet the needs and expectations of its citizens.

SWHR calls on Congress to appropriate funds to our Federal health and research agencies that meet the needs of American women and men, and the scientific and

medical research community. We ask that the following agencies and programs be funded for fiscal year 2016 at the following levels:

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| Agency for Healthcare and Research Quality | $479.3 million |
| Centers for Disease Control and Prevention | $7.010 billion |
| Health Resources Services Administration | $10.4 billion |
| National Institutes of Health | $32 billion |
| Substance Abuse and Mental Health Services Administration | $3.7 billion |
| Office of Research on Women's Health at NIH | $42 million |
| HHS Office of Women's Health | $41 million |

REPLACE THE BCA SPENDING CAPS AND SEQUESTRATION

There is no question that one of the Federal Government's primary responsibilities is protecting the public health and investing in basic biomedical research to spur the way for the next generation of cures and therapies. Yet the spending caps set under the Budget Control Act of 2011 and sequestration have resulted in massive cuts to non-defense discretionary programs (NDD). While reducing the Federal deficit is important, SWHR remains deeply concerned with the extent of the cuts to NDD programs, particularly those that impact public health and medical research agencies. Many of the agencies and programs that fall under the NDD portion of the Federal budget have sustained cuts dating back to 2010, before implementation of the BCA or sequestration, and have consistently been asked to do more with less.

SWHR believes that the BCA spending caps and sequestration should be replaced with a consistent and balanced approach to deficit reduction that places equal value on the roles of nondefense programs, like our Federal health and research agencies, and defense programs in keeping Americans safe and secure. Efforts to reduce the deficit since fiscal year 2010 have disproportionately relied on spending cuts and on NDD programs. In fiscal year 2016, the sequestered spending cap for NDD is already 17 percent below fiscal year 2010 levels. As a share of our Nation's economy or GDP, these programs are on track to their lowest level on record in 1962.

We understand the focus on reducing the Federal deficit; however, we believe that Congress has a duty to provide the investment necessary to keep the U.S. the world leaders in biomedical research and fund our Federal agencies at a level that meet the needs and expectations of its citizens.

*Health and Human Services*

Funding levels for those agencies under the umbrella of the Department of Health and Human Services (HHS) have been significantly cut over the past several years, resulting in harmful impacts to the public health and its infrastructure, and scientific and medical research, which have a direct impact on women and men in every State. The recent Ebola outbreaks, both internationally and within the U.S., demonstrated the importance and necessity of a solid public health infrastructure in treating and preventing the spread of disease. Years of cuts to public health and medical research programs have greatly hindered our Nation's emergency preparedness and response capabilities at the national, State and local levels.

Arbitrary, across the board spending cuts will ultimately do little to remedy the U.S. Federal debt. Healthcare spending, by far, is the largest driver of U.S. Federal debt and is slated to account for nearly one-fifth of the economy by 2021. This spending is a result of an aging baby boomer population and chronic diseases that plague our Nation. It is imperative that Congress invests in our scientific and medical communities so that cures are accelerated to market, to provide better treatment to patients, and to study what treatments and delivery services serve patients best. This type of research will ultimately save valuable healthcare dollars, which are currently wasted on inappropriate and ineffective treatments. The President's budget prioritizes this type of research, and allocates increases for the Agency for Healthcare and Research Quality (ARHQ) and Health Resources Services Administration (HRSA). These agencies, often overlooked by the American public, serve a vital role in evaluating and improving access to our healthcare system. With millions of Americans newly insured under the Affordable Care Act, we must ensure that they receive the best care possible. SWHR urges the Committee to appropriate the President's request of $479.3 million to AHRQ, and 10.4 billion to HRSA.

Past investments in medical research have allowed scientists to begin unraveling the biologic and genetic underpinning of diseases. This research has shown that biological sex impacts every organ of the body, and plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex, gender, racial and ethnic diseases are evident in all major disease categories, including cancer, obesity, cardiovascular disease, and Alzheimer's disease. Science has demonstrated that being

biologically female or male impacts drug absorption, distribution, metabolism and elimination. Congress must ensure that all research conducted at or through funds provided by our Federal health agencies is utilized to its maximum benefit, and that data from this research is analyzed by sex, race, and other subgroup population demographics so that physicians can begin to tailor treatments to meet the needs of individual patients.

SWHR was pleased to see that the President's budget request provided substantial increases to Substance Abuse and Mental Health Services Administration (SAMHSA) and the Centers for Disease Control and Prevention (CDC). These two agencies function as safeguards to protect Americans, and have been chronically underfunded for years. SWHR supports the President's increase of $44.6 million for SAMHSA, bringing its fiscal year 2016 total to $3.7 billion, including $103 million for strengthening the mental health crisis system, addressing prescription drug and opioid abuse, expanding the behavior health workforce, and fostering tribal behavioral health. We know that there are many sex and gender difference that impact mental health, and support this increase for SAMHSA to allow them to work in collaboration with other agencies to further this type of research.

Similarly, the Centers for Disease Control and Prevention (CDC), serves as the Nation's first line of defense in protecting Americans from infectious diseases from Ebola to antibiotic resistance (AR). Additionally, CDC's Office of Women's Health has vital programs which increase the use of preventive services for women and children, and highlight programs relating to tobacco use, prescription drug overdose, sexually transmitted infections, cancer, cardiovascular disease, and reproductive health. SWHR supports the President's request of 7.010 billion for fiscal year 2016, and asks that the Office of Women's Health within CDC receive $600,000 for their work.

We realize that the current budgetary environment limits the amount of monies available for substantial increases; however, the benefit from every dollar invested in medical research outweighs the cost many times over and is, perhaps, the single most cost effective strategy in reducing our Federal deficit.

*Health and Human Services' Offices of Women's Health*

The HHS OWH is the government's champion and focal point for women's health issues. It works to address inequities in research, healthcare services, and public education gaps, which have historically placed the health of women at risk. Without OWH's actions, the task of translating research into practice would be only more difficult and delayed. Considering the impact of OWH's women's health programs on the public, we urge Congress to provide an increase of $1 million for this office, a total of $41 million for fiscal year 2016.

Additionally, each Agency within HHS, has an office or position that do critical work, both individually and in collaboration with other offices and Federal agencies, to ensure that women receive the appropriate care and treatments in a variety of different areas. Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the AHRQ, CDC, FDA, HRSA, Indian Health Service (INS), and SAMHSA. In a time of limited budgetary dollars, Congress should invest in these offices, which have a proven history of expertise, success, and working collaboratively with other agencies and offices. SWHR recommends that these offices be sufficiently funded to ensure that these programs can continue to provide much needed services to women and their families in fiscal year 2016.

*National Institutes of Health (NIH)*

The NIH serves as the America's premier medical research agency and is the largest source of funding for biomedical and behavioral research in the world. Many of the medical advances in recent decades are direct results from bipartisan investments in the agency. Unfortunately, years of austerity spending combined with sequestration has meant that NIH's overall budget has decreased by approximately 10 percent, and the rising cost of conducting research has caused the Agency's purchasing power to decrease by 23 percent.

This number does not just impact NIH's campus in Bethesda, Maryland; it impacts women and men in every single State. Approximately 85 percent of NIH funding is spent in communities across the country. NIH funding supports over 400,000 non-Federal scientists and technical personnel at more than 3,000 universities, medical schools, teaching hospitals, and research institutions.

A lack of proper investment in medical research also significantly impacts the next generation of scientists and researchers. As a result of stagnant Congressional appropriations, NIH grant funding has fallen to an all-time low of 15 percent. A shrinking number of available grants put American scientists out of work or forces

them to accept positions abroad resulting in the loss of skilled bench scientists and researchers to Africa, Asia, and Europe, who continue to heavily invest in research. Many recent graduates have no choice but to accept opportunities abroad and mid-career scientists whose funding is not renewed, meaning that NIH is losing the impact of previous research investments, as scientists are not allowed to finish projects which has warranted previous funding.

SWHR recommends that Congress set, at a minimum, a budget of $32 billion for NIH for fiscal year 2016. Further we recommend that NIH's mandate on the inclusion of women in basic research should be expanded to include women in all phases of basic, clinical and medical research and that NIH provide guidance on its new policy to balance the inclusion of male and female cells and tissues in pre-clinical basic research.

*Office of Research on Women's Health (ORWH)*

ORWH is the focal point for coordinating sex differences research at NIH, and supports innovative interdisciplinary initiatives that focus on women's health research. ORWH promotes opportunities for, and support of, recruitment, retention, re-entry and advancement of women in biomedical careers. The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) is an innovative, trans-NIH career development program that pairs junior faculty with senior investigators in an interdisciplinary mentored environment. Approximately 500 scholars, the majority of them female, have been trained at 39 centers and produced over 5,000 publications. The Specialized Centers of Research on sex and gender factors affecting women's health (SCOR) are designed to integrate basic and clinical approaches to sex and gender research across scientific disciplines and have resulted in over 650 articles, reviews, abstracts, book chapters and other publications. To allow ORWH's programs and grants to continue make their impact on the research community, Congress must direct that NIH continue its support of ORWH and provide it with a $1 million dollar budget increase, bringing its fiscal year 2016 total to $41 million.

In conclusion, Mr. Chairman, we thank you and this Committee for its support for medical and health services research and its commitment to the health of the Nation. We look forward to continuing to work with you to build a healthier future for all Americans.

[This statement was submitted by Leslie Ritter, Director of Government Affairs, Society for Women's Health Research.]

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## PREPARED STATEMENT OF THE SQUAXIN ISLAND TRIBE

On behalf of the Tribal Leadership and citizens of the Squaxin Island Tribe, I am honored to submit our requests to this Subcommittee for appropriations to continue the State-Tribal Education Partnership (STEP) and for Tribal Education Agencies/Departments (TEAs) authorized in the No Child Left Behind Act of 2002, Title VII, Section 7135 (20 U.S.C. § 7455), and Title X, Section 1140 (25 U.S.C.§ 2020 The development of Tribal infrastructure can also reduce the Federal burden in the long run.

Department of Education Requests:

—$198 million for Title VII (Indian Education Formula Grants) under No Child Left Behind
—$4 million would be for STEP and TEA
—$2 billion for Title VIII (Impact Aid) under No Child Left Behind Act
—$25 million for Title I, Part A Local Education Agency Grants

The Squaxin Island Tribe Supports the National Congress of American Indians and the National Indian Education Association.

### THE SQUAXIN ISLAND TRIBE

The Squaxin Island Tribe has been operating the Northwest Indian Treatment Center (NWITC) since 1994. Ingenious in creativity, the center offers a wide variety of cultural activities and traditional/religious ceremonies, making it a natural place to heal—body, mind and soul. Fittingly, the center was given the spiritual name "D3WXbi Palil" meaning "Returning from the Dark, Deep Waters to the Light." NWITC is a residential chemical dependency treatment facility designed to serve American Indians from Tribes located in Oregon, Washington and Idaho who have chronic relapse patterns related to unresolved grief and trauma. NWITC is unique in its integration of Tribal cultural values into a therapeutic environment for co-oc-

curring substance abuse and mental health disorders. It is a 28 bed, 30–60 day residential facility.

*Title VII (Indian Education Formula Grants)*

This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain parity with their non-Native peers. Currently, funding for Title VII only reaches 500,000 Native students leaving over 100,000 without supplementary academic and cultural programs in their schools. As Native students are far behind their non-Native peers in educational achievement, increased funding is necessary to address this substantial gap.

*STEP and TEA Funding*.—AI/AN education is in a state of crisis. The national dropout rate of AI/AN students is double that of their non-Indian peers. In some States the high school dropout rate of AI/AN students is over 50 percent. AI/AN students drop out of high school at a higher rate and score lower on achievement tests than any other student group. AI/AN 8th grade students are 18 percent more likely to read or perform in mathematics at a "below basic" level than their non-Indian peers. AI/AN students also have the highest rates of absenteeism, suspension, and expulsion.

Congress recognized the dire need to change the AI/AN education policy in 2012, when for the first time in history, Congress appropriated funding for TEAs in the Department of Education. The funding was used to support the STEP Program, in which Tribes and States through cooperative agreements combine resources to implement ESEA programs in public schools located on Indian reservations. Four Tribal-State partnerships were awarded STEP program grants to co-govern education. These projects support the type of Tribal-State-Federal partnerships Indian educators and Tribal leaders have long called for as a means to improve AI/AN education. The Department of Interior made a similar appropriation for the first time in fiscal year 2015, which has a priority for Tribes with Bureau of Indian Education schools. The funding will be used to expand the infrastructure of TEAs and to implement programs resembling STEP. These programs, working in concert, are crucially important to addressing the systemic problems in AI/AN education.

TEAs are in a unique position to halt and reverse the negative trend. TEAs will use funding to support more early education initiatives that many TEAs can provide, support more work in the area of Tribal-State education cooperative agreements, and to increase the role of TEAs in schools serving AI/AN students. Further, this funding will assist TEAs to become more self-sufficient by providing the means to develop or amend their education codes. Developing and strengthening TEAs lessen the burden on Federal appropriations in the future. This would begin to implement the policy of self-determination in American Indian education and further the United States' trust responsibility to AI/AN students.

TEAs will also coordinate education programs; develop and enforce tribal education codes, policies, and standards; develop culturally relevant curriculum and assessments; and, provide support services and technical assistance to schools and education programs on Indian reservations. This would include maintaining and sharing electronic data regarding AI/AN students, coordinate Federal education programs with schools and States, and institute programs to increase graduation rates and post-secondary school readiness.

Investment in TEAs is sound Federal policy. TEAs have already proven that they are capable of improving AI/AN student outcomes.

*Support $2 billion for Impact Aid, Title VIII funding under the No Child Left Behind Act Impact Aid*

With nearly 93 percent of Native students enrolled in public schools, Impact Aid provides essential funding for schools serving Native students. In fiscal year 2013, Impact Aid was cut by approximately $100 million dollars by sequestration from the fiscal year 2012 level of $1.1 billion, which forced school closures and school consolidation across many Native communities. In order to ensure Native students have access to education, Impact Aid must be fully funded at $2 billion.

*$25 Million for Title I, Part A Local Education Agency Grants*

Title I of the Elementary and Secondary Education Act (ESEA) provides critical financial assistance to local education agencies and schools with high percentages of children from low-income families that ensure all children meet challenging State academic standards. Currently, there are over 600,000 Native students across the country with nearly 93 percent of those students attending non-Federal institutions, such as traditional public schools in rural and urban locations.

*Self-Governance—An Efficient and Effective Use of Indian Self-Determination and Education Assistance Funds (ISDEAA)*

Self-Governance is the most successful policy in the history of Tribal—Federal relations and it inspires efficient and effective government spending. Through Self-Governance, Tribes are empowered, as sovereign nations, to exercise self-determination, redesign and reprogram funds. Within the statute, and provide services that are responsive to the needs of our communities and Tribal citizens.

The Tribal Self-Governance authority in 1988 excluded the Tribally Controlled Community College Assistance Act (Public Law 95–471 ) for elementary and secondary schools under the Indian School Equalization Formula pursuant to Title XI of the Education Amendments of 1978 (Public Law 95–561, as amended). We have always felt this was a hindrance for our people if we were to indeed achieve the full breadth of governing at the local level which included retaining our cultural and traditional languages and communication skills.

Tribal leaders and Tribal education agencies understand our children best and can more efficiently and effectively address our students' unique cultural and educational needs. Investment in Tribal Education Agencies is sound Federal policy. TEA have already proven that they are capable of improving American Indian and Alaska Native student outcomes through the recent STEP Grant and the Administration's acknowledgment, through Sovereignty in Education Grant, that TEA improve education.

We request that this Committee recognizes the success of Self-Governance and encourage all branches of the Federal Government to work with Tribes to make the most efficient and effective use of Federal appropriations for Tribal programs.

Thank you for this opportunity to submit written testimony.

[This statement was submitted by Councilman Jim Peters, Squaxin Island Tribe.]

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PREPARED STATEMENT OF DWIGHT STACHO

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF REBECCA STACHO

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PREPARED STATEMENT OF LAUREEN STENGLER

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Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF BONNIE M. SULLIVAN

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Blunt and Members of the Subcommittee: The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of critical HIV/AIDS and hepatitis programs as part of the fiscal year 2016 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

*CDC Viral Hepatitis Prevention*

Before detailing our HIV requests, we would like to highlight the critical importance of doubling funding for viral hepatitis at the CDC. The CDC estimates that 5.3 million people are living with hepatitis B and/or hepatitis C in the U.S., with as many as 75 percent unaware of their infection. With new treatment options available that lead to a cure, now is the time to increase hepatitis testing, surveillance and education programs. The President's proposal of $62.8 million for the CDC Division of Viral Hepatitis has the potential to reduce viral hepatitis transmission and prevent costly viral hepatitis-related illness and death. We urge you to support it.

*HIV/AIDS Programs*

HIV/AIDS remains one of the world's worst health pandemics. According to the CDC, in the U.S. over 658,000 people have died of AIDS and there are 50,000 new infections each year. A record 1.2 million people in the U.S. are living with HIV. Persons of minority races and ethnicities are disproportionately affected. African Americans, who make up just 12 percent of the population, account for 44 percent of new infections. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 200 percent of the Federal Poverty Level.

The U.S. Government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting domestic HIV/AIDS efforts are funded through this Subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the Federal interest as they protect the public health against a highly infectious virus. If left unaddressed, it will certainly lead to increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable healthcare and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent. Therefore, HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, and linked to and retained in care and treatment.

The National HIV/AIDS Strategy sets clear goals and priorities, and brings the Federal agencies addressing HIV together to ensure resources are well coordinated.

*The Ryan White Program*

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 536,000 low-income, uninsured, and underinsured individuals with HIV/AIDS. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 40 percent of people living with HIV in the U.S. are retained in HIV care, 37 percent have been prescribed antiretroviral treatment, and 30 percent are virally suppressed. We have a long way to go before we can realize the dream of an AIDS-free generation. With continued funding we can improve these numbers and health outcomes.

The AIDS Drug Assistance Program (ADAP), one component of the Ryan White Program, provides States with funds to pay for medications for over 200,000 people. While ADAPs continue to provide medications to Ryan White clients to keep them healthy, an increased amount of ADAP funding is being used to help low income enrollees afford insurance premiums, deductibles, and high cost-sharing related to the cost of their HIV medications. This is a cost-effective measure for ADAPs because patients not only can receive their HIV medications from the marketplace plans, but also full healthcare coverage.

We urge you to ensure that ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program.

As the Affordable Care Act (ACA) is implemented, there are expanded opportunities for healthcare coverage for some Ryan White clients. While the ACA will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Over 70 percent of Ryan White Program clients today have some sort of insurance coverage, mostly through traditional Medicaid and Medicare. Their coverage is not changing with health reform; the Ryan White Program will be needed as it is today.

Under the ACA, benefits differ from State to State as not all States are choosing to expand Medicaid, and there are many gaps being filled by the Ryan White Program. Plans do not offer all of the comprehensive essential support services, such as case management, transportation, and nutritional services, that are needed to ensure retention in medical care and adherence to medications. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes. In fact, 73 percent of those in the Ryan White Program are virally suppressed. Therefore, the Ryan White Program, while it may need to change in the future, must continue and must be adequately funded.

The AIDS Institute urges the Committee to reject the President's budget proposal to eliminate dedicated funding for Part D of the Ryan White Program and transfer it to Part C. Part D serves women, infants, children, and youth with HIV/AIDS and is a well-established system of care that has worked since 1988 in nearly eliminating mother to child transmission and providing medical care and family-centered support that helps ensure these vulnerable populations remain in care and adherent to their medications. While changes to the structure of the Ryan White Program might be needed in the future, it should not be done through the appropriations process and must include community input.

*CDC HIV Prevention*

As a Nation, we must do more to prevent new infections, but we only allocate 3 percent of our HIV/AIDS spending towards prevention. Care and treatment costs could be eliminated if we did not have new infections. Preventing just one infection would save an estimated $300,000 in future lifetime medical costs. Preventing all the new 50,000 cases in just 1 year would translate into an astounding $15 billion saved in lifetime medical costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing resources on those populations and communities most impacted by HIV and investing in those programs that will prevent the most number of infections. One group in particular that needs additional study and resources is young black gay men, who account for 53 percent of all new HIV infections in the black community.

With over 165,000 people living with HIV in the U.S. who are unaware of their infection, the CDC is also focused on increased HIV testing programs. Testing people early allows them to be diagnosed and referred to care and treatment earlier, which is critical to bettering individual health outcomes and preventing new infections.

The CDC estimates that in 2010, 26 percent of all new HIV infections occurred among youth ages 13 to 24. Nearly 75 percent of those infections were among young gay men. Clearly, we must do a better job of educating the youth, including gay youth, about HIV. Increasing funding to the HIV Division of Adolescent and School Health (DASH) will help address this need.

*HIV/AIDS Research at the National Institutes of Health (NIH)*

While we have made great strides, there is still a long way to go. Continued research at the NIH is necessary to learn more about the disease and to develop new treatments and prevention tools. Work continues on vaccine research and we look forward to an eventual cure.

Again, we thank you for your continued support of these programs. We have made great progress, but we are still far from achieving zero new HIV infections, an AIDS-free generation and eradicating viral hepatitis. We now have the tools, but we need continued leadership and the necessary resources to realize our goals. Thank you.

[This statement was submitted by Carl Schmid, Deputy Executive Director, The AIDS Institute.]

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES AND THE HUMANE SOCIETY LEGISLATIVE FUND

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2016.

RETIREMENT OF FEDERALLY OWNED CHIMPANZEES

The HSUS and HSLF request that the committee ask for information and updates from NIH on their progress towards retiring all but 50 of the government-owned chimpanzees from laboratories—a plan they announced in June of 2013 which will not only result in a better life for the chimpanzees but will also save taxpayer dollars. Further, we request that the committee push for the prioritization for retirement of the 20 government-owned chimpanzees at the Texas Biomedical Research Institute because of major concerns about the welfare of animals at the facility and the health and age of the chimpanzees housed there.

Further basis of our request can be found below.

*Slow Progress on Chimpanzee Retirement*

In June of 2013, the National Institutes of Health announced their plan to retire all but 50 government-owned chimpanzees to sanctuary, significantly curtail the use of chimpanzees in NIH funded studies and not revitalize breeding of chimpanzees for research. These decisions resulted from an Institute of Medicine study in 2011 which found that chimpanzees are not necessary for the vast majority of research.

Not including the 110 government-owned chimpanzees at the New Iberia Research Center who were already about halfway through the process of being transferred to sanctuary, approximately 360 government-owned chimpanzees remained in laboratories at the time of NIH's announcement—310 of whom should be slated for retirement to sanctuary per NIH's plan. However, according to a recent CNN news report, out of the 360 chimpanzees, only 6 have been retired to sanctuary thus far, and more than 20 have died in laboratories. Further, an NIH spokesperson noted the selection of the 50 chimpanzees could take "several years" and that it would happen before retiring more chimpanzees. It is unclear why it would take so long to choose the 50. Based on their timeline for protocol review, NIH should now have a good idea of what research (if any) this group of chimpanzees may be used for. It has been nearly 2 years since the plan was announced and we and other members of the public are becoming increasingly frustrated with the slow pace of progress on this issue.

*Sanctuaries are More Humane and Less Expensive Than Laboratories*

Accredited sanctuaries provide the highest welfare standards for chimps at a lower cost to taxpayers than housing chimpanzees in barren labs (see chart below). It is estimated that transferring those government-owned chimpanzees slated for retirement from the laboratories where they are currently housed to the national sanctuary would save taxpayers approximately $2.2 million per year in care and maintenance costs.

At Chimp Haven, the National Chimpanzee Sanctuary, chimpanzees are the sole focus of the facility and its staff. There, chimpanzees receive the very best care possible, including access to expansive outdoor habitats, large social groups and regular and varying enrichment. Conversely, the main mission of biomedical research laboratories is to conduct research and these facilities are often bound by limitations (i.e., mission, space, and research considerations). Thus, the laboratory environment suits the needs of researchers and not the animals. Laboratories simply cannot offer the high quality of care that sanctuaries do.

*Current Estimated Costs Related to Care and Maintenance of Government Owned Chimpanzees:*

GOVERNMENT OWNED CHIMPANZEES IN RESEARCH FACILITIES AND RESEARCH RESERVE FACILITIES

| Facility | Number of chimpanzees | NIH cost, millions in dollars/year | NIH cost, $/chimpanzee/day |
|---|---|---|---|
| Keeling Center for Comparative Medicine and Research | [1] 156 | [2] 2.56 | 44.97 |
| Texas Biomedical Research Institute, U42 grant [3] | [1] 20 | [2] 0.56 | 76.5 |

GOVERNMENT OWNED CHIMPANZEES IN RESEARCH FACILITIES AND RESEARCH RESERVE FACILITIES—Continued

| Facility | Number of chimpanzees | NIH cost, millions in dollars/year | NIH cost, $/chimpanzee/day |
|---|---|---|---|
| Alamogordo Primate Facility | [1] 154 | [1] 4.09 | 60.36 |
| Totals | 330 | 7.21 | Average: 60.61 |

[1] Based on information available on the NIH Web site regarding chimpanzee maintenance costs.
[2] Based on data available in NIH Research Portfolio Online Reporting Tools (RePORT).
[3] In addition to this grant, NIH also supports an additional 85 chimpanzees at the facility. These chimpanzees are owned by the laboratory and are not eligible for government funded retirement to sanctuary under the Chimpanzee Health Improvement Maintenance and Protection Act.

GOVERNMENT OWNED CHIMPANZEES IN SANCTUARY

| Facility | Number of chimpanzees | NIH cost, millions in dollars/year | NIH cost, $/animal/day |
|---|---|---|---|
| Chimp Haven | [1] 191 | [1] 2.73 | 39.23 |

[1] Based on information available on the NIH Web site regarding chimpanzee maintenance costs.

*Government Owned Chimpanzees at Texas Biomedical Research Institute*

There are currently 20 government owned chimpanzees at the Texas Biomedical Research Institute (TBRI). Most of these chimpanzees are elderly and have been infected with HIV, hepatitis C and/or hepatitis B and have been through countless invasive experimental procedures throughout their lives. These chimpanzees are clear candidates for retirement. Further, the U.S. Department of Agriculture has cited TBRI multiple times over the past few years for violations of the Animal Welfare Act that have resulted in death of five nonhuman primates, among other serious issues. The facility was cited for AWA violations as recently as February 2015 and the USDA is currently investigating the facility.

Given the age, history and health of these chimpanzees, the serious animal welfare concerns and the high cost of maintaining the chimpanzees at TBRI, we ask the committee to urge NIH to prioritize these 20 chimpanzees for retirement to Chimp Haven.

We respectfully request the following committee report language, which is supported by The HSUS and HSLF:

> The committee is aware of and commends NIH's stated commitment to retiring the vast majority of government owned chimpanzees to sanctuary, as it will provide these chimpanzees with the high quality care they deserve and save taxpayer dollars. However, the committee notes that the progress of chimpanzee retirement since the 2013 decision has been slow. It has been reported that since the announcement only 6 of the 360 government owned chimpanzees in labs have been retired and more than 20 have died in labs. The committee asks that NIH provide an update on the status of the process for determining whether chimpanzees will be retired or kept in the reserve colony of 50 and provide the committee with a list of government-owned chimpanzees that includes name, ID number, location, date of birth, sex and any designations made thus far regarding retirement or reserve colony for each individual. Please also provide any updates to the committee on whether or how many research projects using chimpanzees have been approved by NIH and/or the NIH's Chimpanzee Research Use Panel thus far. Finally, the committee has concerns about the welfare of the 20 government-owned chimpanzees at the Texas Biomedical Research Institute. This lab has been cited for numerous violations of the Animal Welfare Act in recent years. Further, many of these chimpanzees are elderly and infected with hepatitis and/or HIV. Given these issues and the high cost to maintain them in this laboratory, the committee requests that NIH prioritize their retirement to sanctuary.

We appreciate the opportunity to share our views on the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2016. We hope the Committee will be able to accommodate this request. Thank you for your consideration.

THE NATIONAL CENTER FOR ADVANCING TRANSLATIONAL SCIENCES

The National Center for Advancing Translational Sciences (NCATS) is one of 27 Institutes and Centers (ICs) at the National Institutes of Health (NIH). Established to transform and accelerate the translational research process, NCATS is all about getting more treatments to more patients more quickly. The Center complements other NIH ICs, the private sector and the nonprofit community; rather than concentrating on specific diseases, NCATS focuses on what is common among them.

*Translation* is the process of turning observations in the laboratory, clinic and community into interventions that improve the health of individuals and the public—from diagnostics and therapeutics to medical procedures and behavioral changes.

*Translational science* is the field of investigation focused on understanding the scientific and operational principles underlying each step of the translational process.

*Bridging the Gap*

Several thousand genetic diseases affect humans, of which only about 500 have any treatment. A novel drug, device or other intervention can take about 14 years and cost $2 billion or more to develop, and about 95 percent never make it past clinical trials. Even when a new drug or other intervention is developed and shown to be effective in clinical trials, many years may pass before all patients who could benefit from it are identified and treated.

Here are some areas the animal protection community and industry have supported:

—*Tissue Chip for Drug Screening (Tissue Chip) initiative*. This partnership with the Defense Advanced Research Projects Agency and the Food and Drug Administration (FDA) is designed to develop 3–D human tissue chips that model the structure and function of human organs, such as the lung, liver and heart, and then combine these chips into an integrated system that can mimic complex functions of the human body.

—*Toxicology in the 21st Century (Tox21) initiative*. Tox21 is a collaborative effort among NIH—including NCATS and the National Toxicology Program at the National Institute of Environmental Health Sciences—the Environmental Protection Agency and the FDA. Through Tox21, researchers are testing 10,000 drugs and environmental chemicals for their potential to affect molecules and cells in ways that can cause health problems. The compounds undergo testing in NCATS' high-speed robotic screening system.

We respectfully request the Subcommittee fund NCATS at the President's budget level which is $27,000,000 over the fiscal year 2015 request.

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PREPARED STATEMENT OF THE MARFAN FOUNDATION

Chairman Blunt and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the heritable connective tissue disorders community as you work to craft the fiscal year 2016 L-HHS Appropriations Bill.

ABOUT MARFAN SYNDROME AND HERITABLE CONNECTIVE TISSUE DISORDERS

*Marfan Syndrome*

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue holds all the body's cells, organs and tissue together. It also plays an important role in helping the body grow and develop properly.

Connective tissue is made up of proteins. The protein that plays a role in Marfan syndrome is called fibrillin-1. Marfan syndrome is caused by a defect (or mutation) in the gene that tells the body how to make fibrillin-1. This mutation results in an increase in a protein called transforming growth factor beta, or TGF-β. The increase in TGF-β causes problems in connective tissues throughout the body, which in turn creates the features and medical problems associated with Marfan syndrome and some related disorders.

Because connective tissue is found throughout the body, Marfan syndrome can affect many different parts of the body, as well. Features of the disorder are most often found in the heart, blood vessels, bones, joints, and eyes. Some Marfan features—for example, aortic enlargement (expansion of the main blood vessel that carries blood away from the heart to the rest of the body)—can be life-threatening. The lungs, skin and nervous system may also be affected. Marfan syndrome does not affect intelligence.

*Related Conditions*

There are disorders related to Marfan syndrome that can cause people to struggle with some of the same or similar physical problems. Some examples are Loeys-Dietz syndrome, Ehlers-Danlos syndrome, and Familial Thoracic Aortic Aneurysm and Dissection.

Disorders related to Marfan syndrome can also cut lives short, particularly when they go unchecked, and they can deeply affect the quality of life of the individuals and families who must cope with them. Just like people with Marfan syndrome, those affected by related disorders need early and accurate diagnosis to ensure they receive proper care and treatment.

Many of these disorders are genetic conditions that, like Marfan syndrome, cause the aorta (the main blood vessel that carries blood from the heart to the rest of the body) to enlarge, a problem that requires medicine and regular monitoring to determine appropriate treatment. Other features that may overlap with Marfan syndrome include those involving the heart, bones, joints and eyes. Related connective tissue disorders include:

—Loeys-Dietz Syndrome
—Ehlers-Danlos Syndrome
—Familial Thoracic Aortic Aneurysm and Dissection
—Mass Phenotype
—Ectopia Lentis Syndrome
—Beals Syndrome
—Bicuspid Aortic Valve
—Stickler Syndrome
—Shprintzen-Goldberg Syndrome

ABOUT THE FOUNDATION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

—We pursue the most innovative research and make sure that it receives proper funding.
—We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
—We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

ONE FAMILY'S STORY

Hector Roman was 36 years old when he died on June 25, 2012, of an aortic dissection caused by Marfan syndrome. He was never diagnosed with Marfan syndrome—despite being treated by several medical specialists for myriad health issues—and he did not know he was a risk of a sudden early death. He was in pain for days and didn't rush to the hospital because he was frustrated with the lack of help he was getting with his health concerns. He had no idea this delay would be deadly. After a few days in pain, he went into shock and a friend call 911. He died 3 days later during his third surgery.

Now, his partner, Teresita Mompeller, of Phoenix, AZ, is raising their three boys—Jovan, 5, Joel, 3, and Justus, 2—alone. After Hector died, Teresita learned about Marfan syndrome. Most alarming to her was that affected people have a 50 percent chance of passing it to their offspring. She had her sons checked immediately. Joel and Justus have been diagnosed with Marfan syndrome and already have aortic enlargement. While their condition is the same as their dad; their prognosis is better. The boys can live a normal life span because they have the diagnosis and are being monitored. They can avoid a fatal situation because they know.

Teresita, who has a Facebook page called "Do You Know Marfan?" (and a parallel page in Spanish) recently wrote: "Thanks to the work of The Marfan Foundation, I know that my boys have a greater chance of living a long life. I know first-hand what it is to be a mother with many questions and concerns about a rare disorder that nobody seemed to know anything about. The Marfan Foundation has guided me through all of my concerns. They have given me all the support and information needed to advocate for my children [so they receive] proper treatment. The Foundation has given me and thousands of other people, the peace of mind that they are working hard to better the lives of those affected."

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into heritable connective tissue disorders can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

—The number of competing research project grants (RPGs) awarded by NIH has also fallen sharply since fiscal year 2003. In fiscal year 2013, NIH made 8,283 RPG awards, which is 2,110 (20.3 percent) fewer than in fiscal year 2003.

—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a robust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

People with Marfan syndrome are born with it, but features of the disorder are not always present right away. Some people have a lot of Marfan features at birth or as young children—including serious conditions like aortic enlargement. Others have fewer features when they are young and don't develop aortic enlargement or other signs of Marfan syndrome until they are adults. Some features of Marfan syndrome, like those affecting the heart and blood vessels, bones or joints, can get worse over time.

This makes it very important for people with Marfan syndrome and related disorders to receive accurate, early diagnosis and treatment. Without it, they can be at risk for potentially life-threatening complications. The earlier some treatments are started, the better the outcomes are likely to be.

Knowing the signs of Marfan syndrome can save lives. Our community of experts estimates that nearly half the people who have Marfan syndrome don't know it. CDC and NCBDDD have critical programs that can help improve awareness and recognition of warning signs, which can save lives. Some of these programs include CDC's Million Hearts Campaign and NCBDDD's newborn screening activities.

Additionally, we support the establishment of a new sports screening program to fund awareness in high schools around the country and prevent Marfan syndrome-related thoracic aortic aneurysm and dissection, which claims the lives of young athletes across the country each year. A contemporary example of this need is Isaiah Austin, who was diagnosed with Marfan syndrome just 5 days before he was supposed to take part in the NBA Draft. Had it not been for the intense testing each potential draftee undergoes as part of the process, Isaiah may never have been diagnosed. He story might have ended by him collapsing on national television or years before while he was playing basketball in college. He is a prime example that more needs to be done. Meaningful funding increases will allow CDC to establish this new activity.

NATIONAL INSTITUTES OF HEALTH

NIH has worked closely with the Foundation to investigate the mechanisms of these conditions. In recent decades, this research has yielded significant scientific breakthroughs that have the potential to improve the lives of affected individuals. In order to ensure that the heritable connective tissue disorders research portfolios can continue to expand and advance, NIH requires meaningful funding increases to invest in emerging and promising activities.

*NHLBI*

After 4 years of recruitment and 3 years of follow-up evaluations the results of the first-ever multicenter clinical trial for our patient population conducted by the National Heart, Lung and Blood Institute's Pediatric Heart Network (PHN), were released at the November 2014 meeting of the American Heart Association. Patients, age 6 months to 25 years, were randomized onto either losartan or atenolol (a beta blocker that is the current standard of care for Marfan patients with an enlarged aortic root). The study found that there were no significant difference in the rate of aortic root dilatation between the two treatment groups over a 3-year period; in lay terms this means the study found another viable treatment for our patients. The Marfan Foundation thanks both NHLBI and NIAMS for their dedicated support and careful execution of this trial.

*NEI*

Ectopia lentis, dislocation of the lens, occurs in up to 60 percent of patients with Marfan syndrome. The central positioning of the lens depends on the zonule of Zinn, a fibrous structure which has fibrillin-1 as a major component. NEI-supported investigators are studying the protein interactions of fibrillin-1 in health and disease in the zonule of Zinn to understand the disease mechanisms that cause ectopia lentis. It is hoped that this research will provide therapeutic insights to better treat this complication of Marfan syndrome.

*NIAMS*

NIAMS continues to support the Consortium for Translational Research in Marfan Syndrome, which is investigating the disease process in MFS. These studies, building on previous advances, are aimed at identifying new biological targets for therapy, as well as predictive biomarkers of vascular and skeletal manifestations, which are the major causes of mortality and morbidity in MFS.

*ORDR*

The National Center for Advancing Translational Sciences houses ORDR and leads other important activities. In addition to the Rare Disease Clinical Research Consortia, translational treatment development programs hold promise for the heritable connective tissue disorders community.

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## PREPARED STATEMENT OF THE STURGE-WEBER FOUNDATION

Chairman Cole and distinguished members of the Subcommittee, thank you for your time and your consideration of the priorities of the community of individuals impacted by Sturge-Weber syndrome, Kippel Trenaunay, and Port Wine Birthmarks as you work to craft the fiscal year 2016 L-HHS Appropriations Bill.

### ABOUT STURGE-WEBER SYNDROME AND RELATED CONDITIONS

Sturge-Weber syndrome (encephelotrigeminal angiomatosis) is a congenital, nonfamilial disorder of unknown incidence and cause. It is characterized by a congenital facial birthmark ("Port Wine Birthmark") and neurological abnormalities; neurological concerns relate to the development of excessive blood vessel growth on the surface of the brain (angiomas). These angiomas can cause life-long seizures, a weakening or loss of the use of one side of the body (hemiparesis), as well as delay the development of motor and cognitive skills.

### ABOUT THE FOUNDATION

The Sturge-Weber Foundation is a 501c3 incorporated in 1987 by individuals affected by Sturge-Weber syndrome, Kippel Trenaunay, and Port Wine Birthmarks. Our mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port Wine Birthmark conditions through collaborative education, advocacy, research and friendly support. The Foundation and our nationwide network of dedicated volunteers continuously work to advance research, raise awareness, and provide empowerment.

The Vision of the Sturge-Weber Foundation is that in all areas of life—public, professional, personal—these goals will be achievable for our members.

In Awareness—when the public will be able to see past the disability to the person.

In Empowerment—when families and individuals will be able to obtain the medical care, employment, education, respect and personal achievement they seek

In Research—when the pace of discovery will not be hampered by lack of resources and will lead continually toward a cure and advances in treatment.

ONE PATIENT'S STORY

This is the first thing I've written in 3 years, except for graduate school papers and my thesis which don't really seem to count. It's not that I don't write. I just haven't had the courage to write since experiencing a psychotic break in 2011. This "break" was the culmination of clinical depression that was untreated because of insurance, an eye surgery to treat my glaucoma, 3 months of bed rest after my doctors took too much tissue out during the surgery, and the inability to see because the surgery was on my dominant eye. I've had great challenges in my life. I've been fighting for a quality life since I was born with Sturge-Weber Syndrome. My life long struggle to fight vision loss, depression, ostritization from my peers in school, and the supposition I would never have more function than a steamed vegetable has made me a fighter, but with every fighter there comes a breaking point. Mine just came the winter of 2011.

As an individual, and an advocate, with Sturge-Weber Syndrome I have fought with tenacity to provide hope for families and "patients" alike while providing education to doctors, news broadcasts, and even testify before Congress at age 13. Life isn't all bad all the time. I've been like almost every college student in America. I went away, I lived with roommates, and I've gone out to bars. After graduating in 2009, I too experienced the struggle of not being able to find a job in my field. I'm one of the graduates still living at home and not working to my full potential. Where I differ from the other millennials like myself is I have medical bills, co-pays, and medicine to pay for on a monthly basis. There are perhaps very few 28 year olds in the world that have to figure out how to pay a $2,000 deductable prior to receiving treatment for a port-wine stain which left untreated will lead to a more protruded and darker colored birthmark. Leaving it untreated would only further marginalize me. I have enough trouble finding a date as I am and there is no way I want to further allow myself to become a dog lady by not taking care of my health. Still the matter remains, how does one pay her 2,000 deductable for treatment when she only makes 25,000 before taxes?

There are days I have longed to be youthful and never worry about where the money for the next MRI will come from. I'd love to be one of those people that never need to go to the emergency room because of the migraines and ischemic strokes caused by the port-wine stain on my brain. I would SINCERELY love to have the non-functioning half of my brain back. Despite all the wishes, wants and dreams, I know I am blessed. Most people don't get to meet Congressmen and Julianne Moore, or be told they are an inspiration of courage and bravery by a favorite band. Granted, it's not winning the Betty Ford Award, like my mom when I was a baby, but through the years you learn to take each day with grace. That is until some 6 year old says "Eww! Mommy look at the pig!" That's that time when grace is challenging, but what makes medical research funding and education SO important!

SEQUESTRATION

We have heard from the medical research community that sequestration and deficit reduction activities have created serious issues for Federal funding opportunities and the career development pipeline. In order to ensure that research into Sturge-Weber syndrome and related conditions can continue to move forward, and, more importantly, to ensure that our country is adequately preparing the next generation of young investigators, we urge you to avert, mitigate, or otherwise eliminate the specter of sequestration. While the Foundation has anecdotal accounts of the harms of sequestration, the Federated American Societies for Experimental Biology has reported:

—In constant dollars (adjusted for inflation), the NIH budget in fiscal year 2013 was $6 billion (22.4 percent) less than it was in fiscal year 2003.

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—Awards for R01-equivalent grants, the primary mechanism for supporting investigator-initiated research, suffered even greater losses. The number awarded fell by 2,528 (34 percent) between fiscal year 2003 and fiscal year 2013.

The pay line for some NIH funding mechanisms has fallen from 18 percent to 10 percent while the average age for a researcher to receive their first NIH-funded grant has climbed to 42. These are strong disincentives to choosing a career as a medical researcher. Our scaling-back is occurring at a time when many foreign countries are investing heavily in their biotechnology sectors. China alone plans to dedicate $300 million to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Scientific breakthroughs will continue, but America may not benefit from the return-on-investment of a ro-

bust biotechnology sector. For the purposes of economic and national security, as well as public health, the Foundation asks that you work with your colleagues to eliminate sequestration and recommit to supporting this Nation's biomedical research enterprise.

CENTERS FOR DISEASE CONTROL AND PREVENTION

Recently it was discovered that Sturge-Weber syndrome occurs due to somatic mutation (a genetic mutation that occurs after conception). In this regard, the research being done at the Centers for Birth Defects Research and Prevention (CBDRP) at the NCBDDD is incredibly important to our community. Specifically, the National Birth Defects Prevention Study (NBDPS) and the Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS) are important steps into research that identify what causes birth defects and how to prevent them. NCBDDD and CDC as a whole need proportional and meaningful increases in their budget in order to continue the important research in this field.

NATIONAL INSTITUTES OF HEALTH

The Office of Rare Diseases Research (ORDR) housed at NCATS hosts a small research portfolio focused on Sturge-Weber syndrome and related conditions. This research has led to important scientific breakthroughs and is well positioned to vastly improve our understanding of the mechanism behind these conditions. Such programs as the Brain Vascular Malformations Consortium (BVMC) within the Rare Diseases Clinical Research Network (RDCRN) are incredibly important because they fund Sturge-Weber syndrome specific research. However, these continued advancements can only be made with stable increases in the overall NIH budget.

Additionally, Sturge-Weber syndrome falls under NEI, NIMH, NCI, NHLBI, NIAMS, and NINDS disciplines. In this regard, it is important to promote Sturge-Weber portfolios at these Institutes as cross-cutting information sharing is paramount in continuing the advancements in this field. In order to accomplish this goal increases in each institutions budgets are required.

Thank you for your time and your consideration of the community's request.

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PREPARED STATEMENT OF WILLIAM G. TOPERZER

I, William G. Toperzer, am the brother of Carol C. Toperzer a 69 year old profoundly mentally and physically disabled female. Carol has been a resident of the Hamburg Center, Hamburg, PA for 53 years—essentially her whole life—after being cared for at home by our now deceased mother, without assistance, up until age 16. Carol has never spoken, walked, or performed of any of her personal care and personal hygiene needs. She is fully dependent on others for all of her life needs. She is frail with essentially no muscle tone and weighs less than 90 pounds at best. She spends her entire time in bed, or in her special wheelchair.

Hamburg Center is an institutional facility operated by the Commonwealth of Pennsylvania, Department of Public Welfare. At the Center, Carol has received excellent care for the 53 years and I hope the Center remains in operation for the rest of Carol's days on earth. Some of her caregivers are the second generation of a family (daughters of women who originally cared for Carol). With her advancing age, Carol is now afflicted with a number of 'senior citizen' medical conditions. The list is long and I can only imagine her day-to-day suffering. She receives all of her nutrition, liquids and medications through a feeding tube imbedded directly into her large intestine to reduce the risk of prior acid reflux. Despite those precautions, she suffers from aspiration pneumonia incidents that have required being transported 20 miles to the Reading, PA hospital Emergency Room an average of six times per year for diagnosis and admission for antibiotic treatment. That disruption to her life—often in the middle of the night—is likely traumatic, despite providing additional care. Carol is now on constant oxygen administration. She has been permanently moved to the medical wing of the Hamburg Center where a full-time nurse is on duty 7x24.

I do NOT view the term institutionalization as a negative. Rather it is an indication of an orchestrated, highly monitored, and well administrated level of care from a number of specialists. Our government, our police, our public roads, public utilities and other similar entities are institutions, fully created to be uniform and to provide services. Institutions and institutionalization is good, not evil, despite the opinions and actions of some self-declared 'do-gooders' who broadly profess deinstitutionalization.

My deceased farther fully opposed any attempt at 'community-based placement' for Carol—even in her healthier days—because the level of care is not available in those small scale four-to-ten patient facilities where there his high staff turnover and little on-site supervision. In addition, those community facilities rely on obtaining the services of local medical personnel on an as needed basis, whereas Hamburg Center has primary care doctors, psychiatrists and nurses on staff. I recently hears an NPR radio story about the difficulty in staffing community-based centers citing things like employees who fail to show up for their scheduled shift because they want to stay home and watch a basketball game on TV instead. I carry forth our family's opposition to community placement for Carol and pray for her continued institutionalized residence at Hamburg Center.

I am certain that Carol's life—in her ever increasing frail state—would be threatened by deinstitutionalizing her. In 2014, loved ones of patients at Hamburg Center and other DPW run Centers in Pennsylvania were successful by court appeal to obtain a Revised Settlement in the case 'Benjamin (and others) versus DPW' that changed/reversed the intended DPW practices to place patients on a list of forced community placement candidates. We feel the outcome of that practice would have also created the 'slippery slope' to allow DPW to close their Centers. Patients who desire community place will be, and were previously able to select that change. However, those who are unable to express their desires will now be evaluated individually with the benefit of doubt given to continuing to give them the best care at the Centers.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Med-

icaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF TRACY THOMAS

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PREPARED STATEMENT OF THE TRANSPLANT ROUNDTABLE

Dear Chairman Blunt and Ranking Member Murray: On behalf of the Transplant Roundtable, a coalition of organizations representing organ transplant patients and professionals, we offer our strong support for increased Federal funding in fiscal year 2016 for the organ donation and transplantation programs administered by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA).

We applaud you and this Subcommittee for many years of unwavering commitment to these programs and ask again for your assistance. While we recognize the serious challenges regarding the Federal budget and annual appropriations, it is critical that the Federal Government retain its strong commitment to the Division of Transplantation ("DoT"). The President proposed a fiscal year 2016 appropriation of $23,549,000, the same level as the fiscal year 2015 appropriated amount.

Given the persistent need for donor organs and the many important programs administered and supported by the Division of Transplantation, we ask that you appropriate an increase of $3,000,000 for fiscal year 2016 to bring the budget to $26,549,000. This appropriation level would finally bring the DoT budget beyond the historical high of $25 million achieved back in fiscal year 2002.

The DoT serves a unique and irreplaceable function in helping to facilitate organ donation and transplantation, serving the needs of critically ill Americans in need of an organ transplant to survive. Programs supported and administered by the DoT save lives and improve the quality of life of thousands of Americans. DoT provides oversight and funding for the Nation's organ procurement, allocation, and transplantation system through the Organ Procurement and Transplantation Network (OPTN). It coordinates all organ and tissue donation activities and funds donation research.

Further, through the National Living Donor Assistance Center (NLDAC), it provides funding for travel and subsistence expenses of living donors whose low incomes may otherwise prohibit them from donating. The NLDAC program has helped facilitate organ transplantation for over 2,500 recipients since its inception, saving lives while saving the Medicare program over $60 million in dialysis services that were no longer necessary due to successful transplantation. These and other programs funded through DoT are very worthy of additional Federal investment as they produce a major return on this investment, year after year.

According to the Organ Procurement and Transplant Network (OPTN), there were 29,532 organ transplants performed from 14,412 donors in 2014. One organ donor can provide enough organs to save up to eight lives. And yet, demand for donor organs continues to outstrip supply by a wide, persistent margin. Every ten minutes a person is added to the transplant waiting list and 21 individuals die each day awaiting a donor organ, according to the OPTN. According to the United Network of Organ Sharing (UNOS), as of March 2015, the national patient waiting list for organ transplants contained more than 78,000 "active" patients and over 123,000 total patients awaiting donor organs. "Active" status refers to patients who are medically ready and able to receive a transplant when one becomes available.

Congressional, agency and private sector support has resulted in transplantation that has saved and enhanced the lives of well more than 600,000 people in the United States, helped to greatly reduce the number of deaths on the waiting list, and generated substantial savings to the Medicare program through foregone need for dialysis. As a country, we do very well in facilitating and providing these life-saving services, but we need sustained Federal commitment and resources to continue to meet the relentless, continuing need for donor organs.

Your leadership has been exemplary over many years on transplantation and organ donation activities. On behalf of transplant patients and their families, we ask that you to continue your leadership on Federal organ donation and transplantation programs by increasing Federal funding for the Division of Transplantation under the Health Resources and Services Administration.

Thank you for the opportunity to submit this testimony for the written record.

Division of Transplantation
Health Resources and Services Administration
U.S. Department of Health and Human Services

By the Undersigned Organizations of the Transplant Roundtable:

Alliance for Paired Donation; American Association of Kidney Patients; American Association for the Study of Liver Diseases; American Society of Nephrology; American Society of Pediatric Nephrology; American Society of Transplantation; American Society of Transplant Surgeons; American Transplant Foundation; Association of Organ Procurement Organizations; Coalition to Promote Living Kidney Donation; Dialysis Patient Citizens; Donate Life America; Eye Bank Association of America; NATCO, The Organization for Transplant Professionals; National Kidney Foundation; National Kidney Registry; Renal Physicians Association; Texas Transplant Society; Transplant Recipients International Organization; United Network for Organ Sharing; WaitList Zero.

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## PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing, comprising the American Nurses Association, the American Association of Colleges of Nursing, the American Organization of Nurse Executives, and the National League for Nursing, respectfully requests $244 million in fiscal year 2016 for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) and administered by the Health Resources and Services Administration.

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. The members of these respective organizations are acutely aware of the demand for nursing services due to a growing aging population, an increased focus on preventative care, and skyrocketing rates of individuals with multiple chronic conditions.

According to the U.S. Bureau of Labor Statistic's Employment Projections for 2012–2022, the employment of registered nurses (RNs) is projected to grow 19 percent from 2012 to 2022. BLS also projects job openings for RNs due to growing demand and replacement needs in the workforce will be over 1 million by 2022.

Increasing demand in the coming years will be driven by an aging population. According to the Pew Research Center, an estimated 10,000 people a day are turning 65 and that trend will continue until 2019. As such, the healthcare workforce will need to grow to keep up with demand for nursing care in traditional acute care settings and the expansion of non-hospital settings such as home care and long-term care. Further, more than one million of the Nation's 2.6 million practicing RNs are over the age of 50, according to the 2008 National Sample Survey of Registered Nurses.

Nurses continue to be the largest group of healthcare providers whose services are directly linked to quality and cost-effectiveness. The Tri-Council is grateful to the Subcommittee for its past commitment to Title VIII funding and respectfully asks that you continue to make the long-term investment that will build our Nation's nursing workforce.

*Nursing Workforce Development Programs* [1]

Since 1964, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. These programs have supported nursing education at all levels and supported institutions that educate nurses who practice in rural and medically underserved communities. A description of the Title VIII programs is provided below:

*Advanced Nursing Education (ANE) Programs (Sec. 811)* fund a number of grant activities—including several traineeships—that aim to increase the size and quality of the advanced nursing workforce. Supporting the preparation of RNs in master's and doctoral nursing programs, the ANE grants help prepare our Nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health nurses, and other nursing specialists requiring advanced nursing education. In Academic Year 2013–2014, these grants supported the education of 10,504 students.

Under the ANE program are two critical traineeship programs that are particularly relevant as the demand for primary and acute care services rises. The Advanced Education Nursing Traineeships (AENT) assist graduate nursing students by providing full or partial reimbursement for the costs of tuition, books, program fees, and reasonable living expenses. The Nurse Anesthetist Traineeships (NAT)

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[1] U.S. Department of Health and Human Services. (2015). Health Resources and Services Administration fiscal year 2016 Justification of Estimates for Appropriations Committees. Retrieved from: http://hrsa.gov/about/budget/budgetjustification.pdf.

support the education of students in nurse anesthetist programs. In some States, certified registered nurse anesthetists are the sole anesthesia providers in nearly 100 percent of rural hospitals. In Academic Year 2013–2014, the AEN Traineeship and the NAT supported 5,650 nursing students, exceeding the program's target of 2,910.

*Nursing Workforce Diversity (NWD) Grants (Sec. 821)* prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. This program awards grants and contract opportunities to schools of nursing for clinical training to address nursing educational needs. In Academic Year 2013–2014 the number of NWD student trainees was 6,691.

*Nurse Education, Practice, Quality and Retention (NEPQR) Grants (Sec. 831)* help schools of nursing, academic health centers, nurse-managed health clinics, as well as State and local governments strengthen nursing education programs, thereby increasing the size and quality of the nursing workforce. The purposes of the NEPQR grants are broad and flexible, allowing the program to address emerging needs in nursing workforce development. NEPQR supports infrastructure development to enhance the coordination and capacity building of inter-professional practice and education among health professions across the United States, and particularly in medically underserved areas.

*NURSE Corps (Sec. 846), (formerly the Nursing Education Loan Repayment and Scholarship Program)* provides support for nurses and nursing students to alleviate nursing shortages and ensure access to nursing services in underserved areas. The NURSE Corps Scholarship Program provides qualified individuals with tuition support and a stipend provided they serve at a Critical Shortage Facility upon graduation. Participants in the NURSE Corps Loan Repayment Program can have up to 85 percent of qualifying loans forgiven. Registered nurses and advanced practice registered nurses are eligible if they serve 2 or 3 years at Critical Shortage facilities and nurse faculty employed at accredited nursing programs also are eligible. In fiscal year 2014, the NURSE Corps Programs supported 1,334 nurses.

*Nurse Faculty Loan Program (Sec. 846A)* increases the number of qualified nurse faculty by creating a student loan fund within individual schools of nursing. Students agree to teach at a school of nursing in exchange for cancellation of up to 85 percent of their educational loans, plus interest, over a 4-year period. In Academic Year 2013–2014, this program supported a total of 2,401 nursing students pursuing a graduate-level degree as nurse faculty.

*Comprehensive Geriatric Education Program (Sec. 865)* provides support to nursing students specializing in care for the elderly. The program may also fund traineeships for individuals who are preparing for advanced education nursing degrees in geriatric nursing, long-term care, gero-psychiatric nursing, or other nursing areas that specialize in the care of the elderly population. In Academic Year 2013–2014, there were 14,200 trainees supported by these grants.

Nurses are the key to helping decrease healthcare costs, addressing the burden of disease, and improving the quality of care delivery. The funding of Federal programs that have proven their effectiveness over many years, such as Title VIII Nursing Workforce Development programs, helps ease the demand for RNs. The Tri-Council respectfully requests your support for $244 million in fiscal year 2016 for the Title VIII Nursing Workforce Development Programs. If our organizations can be of assistance, please contact ANA's Director of Government Affairs, Michelle Artz. Thank you in advance for providing these resources to bolster the Nation's nursing workforce.

Respectfully,

Pamela F. Cipriano, PhD, RN, NEA-BC, FAAN, President, Marla Weston, PhD, RN, FAAN, Chief Executive Officer, American Nurses Association; Eileen Breslin, PhD, RN, FAAN, President, Deborah Trautman, PhD, RN, Chief Executive Officer, American Association of Colleges of Nursing; Linda Burnes Bolton, DrPH, RN, FAAN, President, Pamela Austin Thompson, MS, RN, CENP, FAAN, Chief Executive Officer, American Organization of Nurse Executives; Marsha Howell Adams, PhD, RN, CNE, FAAN, ANEF, President, Beverly Malone, PhD, RN, FAAN, Chief Executive Officer, National League for Nursing.

## PREPARED STATEMENT OF THE THURGOOD MARSHALL COLLEGE FUND

### INTRODUCTION

Thank you Chairman Blunt and Ranking Member Murray and the entire Committee for accepting this written testimony. My name is Johnny C. Taylor, Jr., President and CEO of the Thurgood Marshall College Fund (TMCF). The Thurgood Marshall College Fund supports and represents more than 300,000 students attending the country's 47 publicly-supported Historically Black Colleges and Universities (HBCUs), medical schools and law schools. More than eighty percent of all students enrolled in HBCUs attend TMCF member schools. TMCF was established in 1987 under the leadership of Dr. N. Joyce Payne.

To date, TMCF has provided more than $200 million in scholarships, programmatic and capacity building support to students and member schools. The average in-State tuition at a TMCF school is $7,105 and is a desirable choice for diverse first generation college students. While the tuition rates of our member schools remain reasonable, the resources from key accounts across the Federal Government established to support students, HBCUs and minority serving institutions continue to shrink and jeopardize the likelihood of students obtaining a college degree. This is a national security issue.

It is with a sense of urgency that I submit written testimony to highlight TMCF's fiscal year 2016 education budget priorities and highlight the importance of increasing critical funding streams that support Historically Black Colleges and Universities (HBCUs). Specifically, our priority programs under the Labor HHS Appropriations Subcommittee include Title IIIB Strengthening Historically Black Colleges and Universities, Pell, and the Capital Financing Program.

As demographics change, HBCUs provide access and opportunities to an increasingly diverse population and remain committed to preparing America's future leaders in education, science and technology, law, medicine and public service to meet the workforce demands in a globally competitive world. In an effort to ensure that we are producing a pipeline of top talent, critical funding and other resources targeted to HBCUs must be preserved. We urge the committee to increase funding for priority HBCU programs and accounts to ensure students attending HBCUs have the resources to ensure they graduate with the skills and knowledge to be globally competitive.

*Enhance Title IIIB: Aid for Institutional Development*

*Title IIIB: Strengthening Historically Black Colleges and Universities*

TMCF urges the committee to maintain and consider increasing the fiscal year 2016 discretionary and mandatory funding levels for Title IIIB, Strengthening Historically Black Colleges and Universities program. This account has not kept up with inflation and sequestration resulted in real cuts to individual campuses. Please restore Title IIIB discretionary funding to fiscal year 2010 levels of $267 million. The account is currently funded at $227 million. Additionally, we ask the Committee to please protect the $85 million mandatory funding for fiscal year 2016.

An increase in funding levels for the Title IIIB programs are critical to enhance and sustain the quality of HBCUs, and to meet the national challenges associated with global competiveness, job creation and changing demographics. In particular, these funds support research opportunities for STEM students and professional development for faculty in the science and technology fields. These funds are also used to help build endowments.

TMCF also urges the Committee to approve $61 million for the HBCU Graduate program under Title IIIB, section 326. This would essentially result in level funding from fiscal year 2015. Additionally, the Master's Degree Program for HBCUs was last funded under the fiscal year 2014 budget at $10 million. We ask the Committee to please restore funding for this account to match the fiscal year 2014 enacted level.

*Increase Pell and Reinstate Summer Pell*

We respectfully request that the Committee approve $22.8 billion for the fiscal year 2016 Pell funding level. TMCF supports a $5,690 maximum Pell award. We also urge the Committee to reinstate summer Pell Grants.

The majority of students who attend HBCUs depend on some form of financial aid to complete their degree. Of all first-time, full-time undergraduate degree/certificate-seeking students who attend TMCF member-schools, 93 percent rely on financial aid in pursuit of a degree. While HBCUs provide a quality affordable education, many poor, low-income families continue to debate the return on a college investment if they are required to take out large amounts of loans. Year round Pell makes

it possible for many first-generation students to complete college on time. As a Nation, we want to provide as many avenues as possible for low-income students to enter and complete college with minimal amounts of college loan debt.

Though there have been modest increases in Pell, these increments have failed to keep up with inflation, caused a decline in enrollments at HBCUs and hindered many students from persisting and graduating. More should be done to ensure students entering college graduate with a degree and are prepared for the globally competitive workforce. This is a national security issue.

Traditionally, HBCUs have accepted first-generation, low-income students who often graduate from poor performing high schools and on average take longer to complete college. As a result, these students often attend HBCUs during the summer before their freshman year to get a jumpstart. Additionally, first generation students who attend summer school are more likely to complete their degree on time. TMCF strongly believes summer Pell should be reinstated.

*HBCU Capital Financing Program*

TMCF urges Congress to increase the HBCU Capital Financing Program by $5.6 million to $25 million for fiscal year 2016. This program provides low-cost capital to finance physical improvements on HBCU campuses by guaranteeing and administering loans. At a minimum, we recommend restoring the loan subsidy to pre-sequester level of $20.5 million. We also request appropriations language to remove the $1.1 billion loan guarantee statutory cap, which was recommended by the Department of Education in previous years.

Thank you for your consideration of the funding proposals offered by TMCF. Please let me know if you have questions or would like to meet in the future to discuss TMCF's fiscal year 2016 funding recommendations.

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PREPARED STATEMENT OF TRUST FOR AMERICA'S HEALTH

Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by working to make disease prevention a national priority, is pleased for this opportunity to provide written testimony on the State of public health funding. As this subcommittee works to develop a fiscal year 2016 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to ensure adequate funding for public health prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

Every American should have the opportunity to be as healthy as he or she can be. Every community should be safe from threats to its health. And all individuals and families should have a high level of services that protect and support their health, regardless of who they are or where they live. But right now, Americans are not as healthy as they could or should be. The lingering effects of sequestration and years of funding cuts have fundamentally eroded the country's ability to respond to disasters, prevent chronic diseases, reduce health disparities, and ensure the health of all Americans.

Chronic diseases such as cancer, diabetes, lung disease, heart disease and stroke are responsible for seven out of 10 deaths and cost $1.3 trillion in treatment costs and lost productivity every year. Two thirds of Americans are overweight or have obesity and nearly 20 percent of Americans smoke. There is a growing evidence base that demonstrates that the majority of chronic disease is preventable by addressing common risk factors. We have begun to see signs of success, with childhood obesity rates declining in cities and States that were among the first to adopt a comprehensive approach to obesity prevention. We must bring that knowledge to scale, so that Americans across the country have the opportunity to lead healthier lives. Over the past 2 fiscal years, we were pleased that Congress made important new investments in community prevention that will help continue our efforts to transform our healthcare system to one that values prevention and wellness, and we urge the Committee to build on those investments in the fiscal year 2016 bill.

Recent infectious disease outbreaks illustrated persistent gaps in the country's preparedness for diseases, disasters, and bioterrorism. In 2014 the Nation saw the first domestic cases of Ebola virus and chikungunya, multi-State cyclospora and measles outbreaks, severe cold and drought, wildfires, tornados, and mudslides. Each of these required a public health and healthcare response. However, previous Federal, State, and local budget cuts have threatened more than a decade of progress.

Finally, prescription drug abuse has quickly grown into a full-blown epidemic, with more than 6.1 million Americans abusing or misusing prescription drugs and

at least 60 American dying every day from overdoses. Overdose deaths from prescription drugs have quadrupled since 1999 and outnumber deaths from all illicit drugs—including heroin and cocaine—combined. Addressing this epidemic requires investments both in prevention and in treatment of those already suffering from substance abuse addiction.

Building a public health system prepared to meet the challenges of protecting Americans from natural and man-made threats and preventing disease can only occur with a strong and steady baseline of funding. Below are TFAH's recommendations for meeting that challenge:

*The Prevention and Public Health Fund (PPHF)*

TFAH was pleased to see Congress exercise its authority to allocate the Prevention and Public Health Fund in fiscal year 2014 and fiscal year 2015, and we urge the Committee to do so again in the fiscal year 2016 appropriations bill. To date, the Fund has invested $5.25 billion nationwide to support State and local efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, address healthcare associated infections, train the Nation's public health and health workforce, screen for and prevent cancer, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

*Centers for Disease Control and Prevention (CDC)*

Investments in our Nation's primary public health agency are not keeping pace with the growing challenges we face. From fiscal year 2010 to 2013, the CDC saw its budget authority cut by 18 percent. The fiscal year 2015 Omnibus Appropriations measure provided CDC with an increase of about $43 million, including $887.3 million from the Prevention and Public Health Fund, resulting in an overall near $13 million increase for chronic disease programs. However, that increase simply brings CDC funding back to fiscal year 2013 levels. Scarce resources means CDC will be forced to make extremely difficult, sometimes life and death choices. We urge the Committee to support the overall $110 million program level increase included in the President's budget for fiscal year 2016.

*National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)—CDC*

Our Nation's doctors and hospitals are our trusted front line when illness appears, but we must continue to engage not only health systems but sectors such as education, housing, business, planning, and faith-based institutions to transform communities to make the healthy choice the easy choice and prevent illness in the first place. CDC's Chronic Disease Center has made progress in moving away from the traditional categorical approach to funding disease prevention and toward more coordinated, cross-cutting strategies. We encourage the Committee to maintain funding for the Chronic Disease Center at fiscal year 2015 levels ($1.198 billion), building upon fiscal year 2015 investments in diabetes, heart disease and stroke, the Partnerships to Improve Community Health initiative, the Racial and Ethnic Approaches to Community Health program and the Preventive Health and Health Services Block Grant program. For the block grant in particular, TFAH calls upon the Committee to promote its use to modernize our public health system by supporting health department accreditation and other efforts to ensure the Nation's health departments can deliver foundational public health capabilities to all Americans.

*National Center for Environmental Health (NCEH)—CDC*

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. Yet it remains one of the most critically underfunded parts of CDC. We recommend that you fund NCEH at $212.460 million in fiscal year 2016 to maintain and grow the National Environmental Public Health Tracking Network (by $5 million), expand the Climate and Health program to all 50 States, fully restore the Childhood Lead Poisoning Prevention Program, and pursue other important priorities like asthma control and the built environment.

*Public Health Emergency Preparedness (PHEP) Cooperative Agreements—CDC*

The Public Health Emergency Preparedness (PHEP) cooperative agreements, administered by CDC, is the only Federal program that supports the work of State and local health departments to prepare for all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The grants fund nearly 4,000 State and local public health staff positions, and support 15 core capabilities including public health laboratory testing, surveillance and epidemiology,

community resilience, countermeasures and mitigation, and more. These funds are used for everyday preparedness activities, such as monitoring public health threats, and have been integral in expanding the response to full-scale disasters, such as domestic cases of Ebola virus and chikungunya, multi-State cyclospora and measles outbreaks, severe cold and drought, wildfires, tornados, and mudslides. TFAH recommends $675 million for the Public Health Emergency Preparedness Cooperative Agreements in fiscal year 2016, a $31 million increase from current levels, to help States and localities restore some of the core capabilities lost due to significant cuts to the program in recent years.

*Hospital Preparedness Program—ASPR*

The Hospital Preparedness Program (HPP), administered by the Assistant Secretary for Preparedness and Response (ASPR), provides funding and technical assistance to prepare the health system to respond to and recover from a disaster. HPP is building the capacity of 24,000 healthcare coalitions—regional collaborations between healthcare organizations, providers, emergency managers, public sector agencies, and other private partners—to meet the disaster healthcare needs of communities. Through the coalition planning process, facilities are learning to leverage resources, such as developing interoperable communications systems, tracking beds, and writing contracts to share assets.

HPP helped a prepared healthcare system save lives during recent events, including the Colorado wildfires, Boston Marathon bombings and tornadoes in Kentucky and Joplin, MO. HPP appropriations have decreased from $426 million in fiscal year 2010 to $255 million in fiscal year 2015, including a one third cut in the fiscal year 2014 omnibus. These cuts have resulted in reduced capabilities for most awardees in areas such as planning, exercises, planning for at-risk individuals, management of supplies, and preparedness training. TFAH recommends $300 million for fiscal year 2016 for HPP, an incremental step toward rebuilding the program.

*Combating Prescription Drug Abuse—CDC & SAMHSA*

TFAH was pleased that the President's budget included $133 million in new investments to address prescription drug abuse, heroin use and overdose deaths, including new funding for the Centers for Disease Control and Prevention (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA). TFAH strongly supports this cross-government initiative. In particular, we would like to highlight our support for these pieces of the initiative within the jurisdiction of the Labor-HHS bill:

—TFAH supports the President's budget request for $68 million (a $48 million increase) for the CDC Injury Center's Injury Prevention Activities line to enable the CDC to expand its work to all 50 States to help address the main drivers of the epidemic of prescription drug overdoses and provide those States with additional resources and scientific technical assistance for surveillance and prevention efforts. Prescription drug abuse is a national problem which requires a national response.

—TFAH supports the request for $12 million for SAMHSA to establish the Grants to Prevent Prescription Drug/Opioid Overdose Related Deaths (PDO) program. This new program will provide grants to 10 States to reduce significantly the number of opioid overdose-related deaths.

—TFAH supports the request for $25 million (a $13 million increase) for SAMHSA to expand access to medication assisted treatment, which is an effective tool to treat opioid addiction but is unavailable for many Americans who desperately need it due to restrictions in access.

Additionally, TFAH recommends a $25 million increase for the Substance Abuse Block Grant (SABG) to help expand access to substance abuse treatment. Substance abuse treatment has been underfunded for decades, and while there has been more than a five-fold increase in treatment admissions for prescription drug abuse in the past decade, millions more are going untreated. The SABG alone accounts for about 40 percent of spending by State substance abuse agencies, yet the SABG has been level funded at $1.8 billion for several years despite the increased burden of addiction.

*Conclusion*

Eighty-five percent of the CDC's annual budget flows to States, communities, tribes, and territories in the form of grants and contracts to State and local public health departments, and community partners, to give them the tools they need to conduct critical public health and prevention activities that every American relies on, such as protecting us from infectious diseases by combating healthcare-associated infections by delivering immunizations, ensuring adequate public health emergency preparedness, and conducting nonstop disease surveillance. Investing in dis-

ease prevention is the most effective, common-sense way to improve health and address our long-term deficit. Thank you for your consideration.

[This statement was submitted by Jeffrey Levi, Executive Director, Trust for America's Health.]

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## PREPARED STATEMENT OF TULSA CARES

We are pleased to submit this testimony to the Members of this Subcommittee on the urgency of continuing to support the Ryan White Program through the Appropriations process and increasing funding for the domestic HIV/AIDS portfolio in fiscal year 2016. This support and funding will be decisive for achieving the goals of the National HIV/AIDS Strategy (NHAS), the AIDS Free Generation and halting the devastating effects of the HIV Treatment Cascade.

Tulsa CARES is part of a nationwide coalition, the Food is Medicine Coalition, of over 80 food and nutrition services providers, affiliates and their supporters across the country that provide food and nutrition services to people living with HIV/AIDS (PLWHA) and other chronic illnesses. In our service area, we provide over 83,000 medically tailored meals through our grocery and prepared meal programs annually. Collectively, the Food is Medicine Coalition is committed to increasing awareness of the essential role that food and nutrition services (FNS) play in successfully treating HIV/AIDS and to expanding access to this indispensable intervention for people living with other severe illnesses.

*Why Food and Nutrition Services (FNS) Matter for PLWHA*

While adequate food and nutrition are basic to maintaining health for all persons, good nutrition is crucial for the management of HIV infection. Proper nutrition is needed to increase absorption of medication, reduce side effects, and maintain healthy body weight. Research has identified the virus as an independent risk factor for cardiovascular, liver and kidney disease, cancer, osteoporosis and stroke. Several HIV medications can cause nausea and vomiting and some can affect lab results that test lipids and kidney and liver function. These compounding health effects, caused by the virus and its medications, reinforce the important role a nutrient-rich diet plays in a patient's overall care plan. In addition, providing food and nutrition services can serve to facilitate access and engagement with medical care, especially among vulnerable populations.

The Food and Nutrition Services category within the Ryan White Program includes medical nutritional therapy (MNT) and food and nutrition services (FNS). MNT covers nutritional diagnostic, therapy, and counseling services focused on prevention, delay or management of diseases and conditions, and involves an in-depth assessment, periodic reassessment and intervention provided by a licensed, Registered Dietitian Nutritionist (RDN) outside of a primary care visit. The range of FNS provided through the Ryan White program complements the needs of PLWHA at any stage of their illness. For those who are most mobile, there are congregate meals, walk-in food pantries and voucher programs. For those whose disease has progressed, home-delivered meals and home-delivered grocery bags complement their medical treatment.

Since 2006, HRSA has included MNT and FNS, provided under the guidance of RDNs, as a clinically effective core medical service in the Ryan White Program. These services play a critical role in ensuring that PLWHA enter and continue in primary medical care, adhere to their medications, and ultimately achieve viral suppression.

*FNS as a Care Completion Service Unique to Ryan White*

Social and economic interventions, most often in the form of care completion service like food and nutrition services, are fundamental to making healthcare work for PLWHA. Support services for PLWHA are not covered in any comprehensive way by Medicaid or other public insurance initiatives that have been expanded by the Affordable Care Act. As the HIV epidemic in the United States increasingly impacts low-income individuals, support services help stabilize individuals living with or at risk of HIV. When needs are met, and life's emergencies are held at bay, PLWHA are poised to remain connected to care and treatment.

*Access to FNS and the Triple Aim*

Access to appropriate food and nutrition services (FNS) are increasingly recognized as key to accomplishing the triple aim of national healthcare reform for PLWHA.

*Better Health Outcomes*

When clients get effective FNS and become food secure, they then keep scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[1] Studies show both the health benefits of access to MNT and/or nutrition counseling for people with HIV infections[2] and the resulting decreases in their healthcare costs. Compare these outcomes to PLWHA who are food insecure, who have:

—Lower CD4 counts & lower likelihoods of having undetectable viral loads[3]

—More ER visits[4] & increased morbidity and mortality[5]

—More missed primary care appointments & reduced use of antiretroviral therapy.[6]

*Lower Healthcare Costs*

Millions of dollars in healthcare expenditures are saved through the provision of FNS to PLWHA. A recent study comparing participants in a medically-tailored FNS program vs. a control group within a local managed care organization found that average monthly healthcare costs for PLWHA fell 80 percent (more than $30,000) for first 3 months after receiving FNS.[7] If hospitalized, FNS clients' costs were 30 percent lower, their hospital length of stay was cut by 37 percent and they were 20 percent more likely to be able to be discharged to their homes rather than a more expensive institution.[8] Furthermore, FNS are a very inexpensive intervention. For each day in a hospital saved, you can feed a person a medically-tailored diet for half a year.

*Improved Patient Satisfaction*

Studies show nutrition counseling improves quality of life.[9] Members overwhelmingly report that our services help them live more independently, eat more nutritiously and manage their medical treatment more effectively.

*FNS and the National HIV/AIDS Strategy (NHAS)*

Access to FNS for PLWHA is fundamental to fulfilling the goals of the NHAS.

—NHAS Goal: Reducing new HIV infections: PLWHA who are food insecure are less likely to have undetectable viral loads in a statistically significant way. Undetectable viral loads prevent transmission 96 percent of the time,[10] thus, FNS is key to prevention.[11]

—NHAS Goal: Increasing access to care and improving health outcomes for people living with HIV: PLWHA who receive effective FNS are more likely to keep

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[1] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[2] Academy of Nutrition and Dietetics (formerly American Dietetic Association). HIV/AIDS Nutrition Evidence Analysis Project at http://www.adaevidencelibrary.com/conclusion.cfm?conclusion__statement__id=250707 Accessed 29 July 2012.

[3] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[4] Ibid.

[5] Anema A, Chan K, Yip B, Weiser S, Montaner JSG, Hogg RS. Impact of food insecurity on survival among HIV-positive injection drug users receiving antiretroviral therapy in a Canadian cohort. 141st APHA Annual Meeting, Nov. 2–6, 2013. Boston, MA. Abstract #: 290277.

[6] Aidala A., Yomogida M., and the HIV Food & Nutrition Study Team (2011).

[7] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[8] Gurvey J, Rand K, Daugherty S, Dinger C, Schmeling J, Laverty N. Examining Health Care Costs Among MANNA Clients and a Comparison Group. OMG Center for Collaborative Learning, Philadelphia, PA, USA. J Prim Care Community Health. 2013 Jun 3. [Epub ahead of print].

[9] Rabeneck L, Palmer A, Knowles JB, Seidehamel RJ, Harris CL, Merkel KL, Risser JMH, Akrabawi SS. A randomized controlled trial evaluating nutrition counseling with or without oral supplementation in malnourished HIV-infected patients. J Am Diet Assoc. 1998; 98: 434–438. Schwenk A, Steuck H, Kremer G. Oral supplements as adjunctive treatment to nutritional counseling in malnourished HIV-infected patients: randomized controlled trial. Clinical Nutrition. 1999; 18(6): 371–374.

[10] M. S. Cohen et al., "Prevention of HIV–1 Infection with Early Antiretroviral Therapy," N. Engl. J. Med. 365, 493–505 (2011). HPTN 052.

[11] Palar K, Laraia B, Tsai A, Weiser SD (2013). Food insecurity is associated with sexually transmitted infections and HIV serostatus among low income adults in the National Health and Nutrition Examination Survey (NHANES) (1999–2010). Presented at the American Public Health Association 141st Annual Meeting, Boston, MA, November 5, 2013.

scheduled primary care visits, score higher on health functioning, are at lower risk for inpatient hospital stays and are more likely to take their medicines.[12]

—NHAS Goal: Reducing HIV-related disparities and health inequities: By providing FNS to PLWHA who are in need largely because of poverty, we improve health outcomes, thereby reducing health disparities.[13]

*Conclusion*

We are deeply aware of the difficult decisions that face the members of the Subcommittee in the current fiscal environment. Yet, research shows that investment in FNS, with the great return in prevention and retention in HIV care, are vital to lowering the number of new infections in the domestic HIV epidemic and ultimately reducing healthcare costs and preserving healthcare resources for the future. A client's diet can literally have life and death consequences. When people are severely ill, good nutrition is one of the first things to deteriorate, making recovery and stabilization that much harder, if not impossible. Early and reliable access to medically-appropriate FNS helps PLWHA live healthy and productive lives, produces better overall health outcomes and reduces healthcare costs.

Most importantly, there remains a tremendous variation by State in coverage of food and nutrition services both inside and outside of Ryan White, making support for Ryan White all the more needed. Ultimately, if we are going to achieve a more coordinated national response to the HIV epidemic and our quest to reduce healthcare spending nationwide, FNS must be included in all healthcare reform efforts, including the Ryan White and the ACA.

Along with our colleagues, we appreciate the opportunity to offer testimony regarding the fiscal year 2016 Appropriations process. We are also pleased to offer our assistance and expertise, including information from our Research Library.

[This statement was submitted by R. Shannon Hall, Executive Director, Tulsa CARES.]

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## PREPARED STATEMENT OF REBECCA UNDERWOOD

Thank you for this opportunity to provide outside witness testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

I submit this testimony as a request that Congress prohibit the use of appropriated Federal funds by any DHHS program to support activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICD/IID) or any other Medicaid-licensed setting serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

I strongly object to the use of United States Department of Health and Human Services (DHHS) appropriations to achieve public policies of forced deinstitutionalization and to develop coercive and subversive methods of deinstitutionalization resulting in the eviction of individuals with severe, profound and extreme intellectual and developmental disabilities (IDD) from their HHS-licensed and funded homes, without regard to individual choice and need.

I am the mother and co-guardian of an adult son, aged 35 who, as the result of profound neurological damage at birth, functions at the level of a 4–12 week old infant with chronic and complex medical issues. After providing his 24/7 care in our home for several years, we accepted the reality that our son would benefit from the comprehensive, synchronized medical care available in a highly specialized intermediate care facility for individuals with intellectual disabilities.

Our parenting decisions and our son's continued residence in his current DHHS funded facility and receipt of the services uniquely suited to meet his extensive and complex physical and medical needs, which have proven beneficial for his survival, are under attack. A number of DHHS funded programs are targeting forced displacement of our most fragile constituency without regard to individual choice, need and safety.

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[12] Aidala A, Yomogida M, Vardy Y & the Food & Nutrition Study Team. Food and Nutrition Services, HIV Medical Care, and Health Outcomes. New York State Department of Health: Resources for Ending the Epidemic, 2014. Available at https://www.health.ny.gov/diseases/aids/ending__the__epidemic/docs/key__resources/housing__and__supportive__services/chain__factsheet3.pdf.

[13] Weiser SD, Frongillo EA, Ragland K, Hogg RS, Riley ED, Bangsberg DR. Food insecurity is associated with incomplete HIV RNA suppression among homeless and marginally housed HIV-infected individuals in San Francisco. J Gen Intern Med. 2009 Jan;24(1):14–20. doi: 10.1007/s11606–008–0824–5. Epub 2008 Oct 25.

Several DHHS agencies, including AIDD and its programs, NCD , and CMS use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, contrary to Federal law and causing human harm. These DHHS-funded deinstitutionalization activities include advocacy, lobbying, class action lawsuits, and other tactics, resulting in the downsizing and closure of DHHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These DHHS v. DHHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision as a mandate requiring deinstitutionalization to justify their policies and actions, forced deinstitutionalization is actually counter to *Olmstead* which only requires community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead*, 119 S. Ct. 2176, 2187 (1999) (majority)

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), Public Law 106–402, which authorizes AIDD programs for funding, such as Protection and Advocacy (P&A), DD Councils and University Affiliated Programs, does not support forced deinstitutionalization as it states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3) 2000).

Medicaid law and regulations requires that individuals eligible for the level of care provided in an ICF/IID must be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2) and 42 U.S.C. s 1392n(c)(2)(C).

*Administration on Intellectual and Developmental Disabilities (AIDD)* administers programs and grants created under Public Law 106–402, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). While the DD Act was last reauthorized in 2000 and authorizations for DD Act appropriations expired in 2007, Congress continues to fund these programs. DD Act programs, including Protection and Advocacy (P&A) and DD Councils, operate in every state. AIDD, now under the umbrella of the Administration for Community Living (ACL) within DHHS, administers the DD Act programs Federal funds. AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs. DHHS has been unresponsive to complaints from families of persons with severe, profound and extreme forms of developmental disabilities about AIDD policies. DHHS has turned a blind eye to the tragic, but predictable, results for many individuals when they are forced from their specialized Medicaid certified and funded congregate care homes. Independent oversight of Federal AIDD and DD Act programs is desperately needed.

*National Council on Disability (NCD)* is an independent Federal agency funded through DHHS appropriations. In October 2012 the NCD released a 300+ page policy paper and related "tool-kit" calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes of four or more people. This NCD policy paper and related toolkit calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes. Families and guardians of these affected individuals who lack the physical and cognitive ability to speak for themselves have repeatedly called upon NCD to reject their stance on forced deinstitutionalization. NCD has been unresponsive to these families. As an "independent Federal agency charged with advising the President, Congress, and other Federal agencies regarding policies, programs, practices and procedures that affect people with disabilities" NCD should not be taking any position which tramples on the rights of a portion of the disability community.

*CMS'* new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that CMS considers too large or too close to specialized care settings are at risk of no longer being eligible for Medicaid Home and Community Based Services (HCBS) funding, without regard for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/

DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

It will be a travesty if the Federal Government is successful in pigeon-holing disability policy into a one-size-fits-all, eliminating choice, while continuing to ignore Supreme Court clarifications within *Olmstead* regarding the care of those with the most severe forms of cognitive and developmental disabilities. We need an increasing array of viable options for services and support for our most vulnerable, not less.

In conclusion I call upon Congress, through appropriations' bill language, to prohibit the Department of Health and Human Services and their various programs use of Federal appropriations for deinstitutionalization activities that result in the eviction of eligible individuals with intellectual and other developmental disabilities from DHHS licensed and funded facilities and homes, without regard to individual choice, need, and safety.

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## PREPARED STATEMENT OF THE UNITED NEGRO COLLEGE FUND

Chairman Blunt, Ranking Member Murray, and Members of the Subcommittee, thank you for the opportunity to provide written testimony on behalf of UNCF (the United Negro College Fund) regarding our fiscal year 2016 appropriations priorities. I am the President and CEO of UNCF, and we are the Nation's largest higher education organization serving students of color, perhaps best known by the iconic motto—"A mind is a terrible thing to waste, but a wonderful thing to invest in®." We also represent the interests of 37 private Historically Black Colleges and Universities (HBCUs) that are members of UNCF.

In our 71-year history, UNCF has raised more than $4 billion in scholarship aid to help more than 400,000 students of color attend HBCUs and 900 other colleges and universities across the country to obtain the education they need to excel in the 21st century economy. UNCF's largest scholarship is the Gates Millennium Scholarship offered to high-achieving, low-income African American, American Indian/Alaska Native, Asian Pacific Islander and Hispanic American students. UNCF has awarded Gates Millennium Scholarships across the country, including $40 million to help 749 students from Missouri and Washington State, earn college degrees. We have awarded $239 million to 4,325 Gates Scholars to attend institutions in the States the Subcommittee represents.

UNCF's core priority, however, remains its partnership with the Nation's 37 private HBCUs. The money raised by UNCF has become even more important today as HBCUs have suffered from a "perfect storm" of Federal disinvestments since 2011. Limitations on Pell Grant eligibility requirements, sequestration cuts to the Title III HBCU Program and Parent PLUS Loan reductions have resulted in a severe loss of Federal resources to HBCUs. Specifically, Pell Grant funding to HBCUs fell by 17 percent ($172 million) between 2010 and 2013. In addition, Parent PLUS loan revenues to HBCUs decreased $269 million in just 2012 and 2013 alone. Accounting for the $39 million decline in investments to the HBCU Title III Institutional Aid program since fiscal year 2010, HBCUs, in the aggregate, have lost nearly $500 million in Federal education resources since fiscal year 2010. Despite these financial hardships, HBCUs still provide enormous value for students and the Nation.

HBCUs represent approximately 3 percent of all 2- and 4-year nonprofit colleges and universities; enroll 10 percent of all African American college students; confer 18 percent of bachelor's degrees awarded to African Americans; and generate 25 percent of the bachelor's degrees in science, technology, engineering and mathematics (STEM) awarded to African Americans. HBCUs accomplish this while serving students with greater need: 71 percent of students who attend HBCUs are low-income students who depend on Federal Pell Grants for their education, a substantially greater share than the 40 percent of students at other nonprofit colleges and universities. At the same time, total cost of attendance at HBCUs is 30 percent lower, on average, than other nonprofit institutions.

UNCF and its member institutions appreciate the efforts the Subcommittee has made to find the resources needed to restore some of the sequestration cuts impacting HBCUs and the students we serve. We hope that you will do more in the fiscal year 2016 budget cycle to restore the remaining sequestration cuts made since 2013, turn off the sequestration cuts that loom ahead, and make the additional investments in postsecondary education that are essential to our Nation's prosperity.

### FISCAL YEAR 2016 APPROPRIATIONS PRIORITIES

Looking to fiscal year 2016, a national strategy to produce more college graduates, boost our economy and enhance global competitiveness must include greater invest-

ment in HBCUs. UNCF strongly encourages the Subcommittee to support our highest priority items at the funding levels listed below.

—UNCF urges the Subcommittee to appropriate $267 million in discretionary dollars and sustain the already-appropriated $85 million in mandatory dollars for the Title III—Strengthening Historically Black Colleges and Universities Program. These are formula funds awarded to HBCUs for operating support and essential academic services, and they are being put to good use. For example, Spelman College received Title III funds to establish the SpelBots (Spelman's Robotic Team), a winning robotics initiative included in the National Science Foundation's technology showcase. Please reinvest in Title III and restore the $39 million in discretionary funds cut from the program since fiscal year 2010.

—The HBCU Capital Financing Program finances low-risk Federal loans to help HBCUs, especially private institutions, improve facilities, infrastructure and technology. Investing in capital projects not only enhances the educational environment for students but also reinvigorates our communities and provides much needed jobs. UNCF urges you to increase the appropriation for loan subsidies to $25 million, which would leverage $390 million in annual loans to meet the infrastructure needs of our institutions.

—Without Pell Grants, most HBCU students could not pay for the college education that is essential in today's economy. I urge you to fund at least a $5,960 maximum Pell award to help our students persist and complete college. UNCF's Frederick D. Patterson Research Institute has reported that need-based aid increases college completion among low- and moderate-income students. This aid is critical for African American students, 60 percent of whom rely on Pell Grants to attend college. In addition to increasing the maximum award, I encourage you to reinstate "summer" Pell Grants so students can earn their college degrees faster and at a lower cost.

—UNCF supports the President's fiscal year 2016 request to designate $60 million for Minority-Serving Institutions (MSIs) under the First in the World program to bolster academic outcomes. Given that half of the 459 fiscal year 2014 applications came from MSIs, we recommend that Congress reserve not less than $60 million for MSIs so that this amount is a floor, not a ceiling, on the resources for which MSIs may compete.

—I urge you to approve the College Opportunity and Graduation Bonuses proposed in the President's budget, which would reward institutions that enroll and graduate large numbers of low-income students. UNCF recommends, however, that both the numbers and percentages of low-income students graduating from institutions are taken into consideration.

—Restore the Supplemental Educational Opportunity Grants program to $748 million, provide $1.13 billion to Federal Work Study and invest in new capital and funding for loan cancellations in the Perkins Loan program. These campus-based aid programs support school choice; fill in financial gaps after students reach Direct Loan limits; leverage additional funds for financially needy students through institutional matching requirements; and reduce the amount of debt that low-income students must incur to attend college.

UNCF's mission is to build a robust and nationally-recognized pipeline of underrepresented students who, because of UNCF support, become highly qualified college graduates and to ensure that our network of member institutions is a respected model of best practice in moving students to and through college. The investments that the Subcommittee makes in the key programs I have outlined are critical to the ability of our member HBCUs to meet these goals.

Thank you for the opportunity to submit this testimony.

Sincerely.

[This statement was submitted by Dr. Michael L. Lomax, President and CEO, United Negro College Fund.]

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## PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

United Tribes Technical College (UTTC) has for 46 years, and with the most basic of funding, provided postsecondary career and technical education and family services to some of the most impoverished high risk Indian students from throughout the Nation. Despite such challenges, we have consistently had excellent retention and placement rates and are a fully accredited institution. We are proud to be preparing our students to participate in the new energy economy in North Dakota and to be part of building a strong middle class in Indian Country by training the next generation of law enforcement officers, educators, medical providers, welders, technicians, and administrators. We are governed by the five tribes located wholly or

in part in North Dakota. We are not part of the North Dakota State college system and do not have a tax base or State-appropriated funds on which to rely. The requests of the UTTC Board are:

—$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program. This is $2.3 million above the fiscal year 2015 level. These funds are awarded competitively and distributed via formula. We are seeking a change to the formula that is not so reliant on Indian Student Count to avoid dramatic swings in annual awards.

—Forward Funding. We ask that the Section 117 Perkins funds, like the other funds under the Carl Perkins Career and Technical Education Act, be put on a forward funded basis.

—$30 million as requested by the American Indian Higher Education Consortium for Title III–A (Section 316) of the Higher Education Act, $4.3 million above the fiscal year 2015 level.

—Support the scheduled increase in the maximum Pell grant award from $5,775 to $5,916.

*Section 117 Perkins Funding*.—We are extremely disappointed that neither the fiscal years 2014 nor 2015 Appropriations Acts restored the fiscal year 2013 sequestration to Section 117 Perkins even though funding for the rest of the Perkins Act was restored. Perhaps Section 117 was overlooked as a source of job training as it is in the Higher Education portion of the budget. We all realize the urgent need to better prepare a workforce to meet industry and other emerging needs. We are part of that undertaking, but need more resources to come closer to our potential.

Perkins funds are central to the viability of our core postsecondary education programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time targeted supplemental funds. Our Perkins funding provides a base level of support while allowing the college to compete for desperately needed discretionary funds.

We highlight several relatively recent updates of our curricula to meet job market needs. Indeed, the ramifications of the North Dakota Bakken oil boom are apparent as we have seen faculty and students leave education in pursuit of jobs in the Bakken region. We saw the need for more certified welders in relation to the oil boom and have expanded our certified welding program in response to the workforce need. We are now able to train students for good paying in-demand welding employment with a focus on career rather than just a job. Other courses reflect new innovative approaches on energy auditing and Geographic Information System Technology. UTTC is seeing increased interest in our online programs of study and short term skill building training at the UTTC Black Hills Learning Center, a distance learning site located at Rapid City, SD. We are also working toward the establishment of an American Indian Specialized Health Care Training Clinic on our established Bismarck, ND campus.

Funding for United Tribes Technical College is a good investment. We have:

—Renewed unrestricted accreditation from the North Central Association of Colleges and Schools, for July 2011 through 2021, with authority to offer all of our full programs on-line. We have 16 Certificate, 20 Associate, and three Bachelor degree program. Five programs are fully developed and available as online programs.

—Services including a Child Development Center, family literacy program, wellness center, area transportation, BIE-funded K–8 elementary school, tutoring, counseling, family and single student housing, and campus security.

—A projected return on Federal investment of 20–1 (2005 study).

—A semester retention rate of 68 percent and a graduate placement rate of 79 percent. Over 45 percent of our graduates move on to 4-year or advanced degree institutions.

—Students from 49 tribes; 73 percent of our undergraduate students receive Pell Grants.

—An unduplicated count of 605 undergraduate degree-seeking, 258 continuing education, and 42 dual credit enrollment students for a total of 905 for 2014–2015.

—A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.

—A critical role in the regional economy. Our presence brings at least $34 million annually to the economy of the Bismarck region. A North Dakota State University study reports that the five tribal colleges in North Dakota made a direct and secondary economic contribution to the state of $181,933,000 in 2012.

*Forward Funding*.—We ask that the Appropriations Committees provide one-time funding for Section 117 Perkins to put it on a forward funded basis. We do not know why it is not already forward funded, given that the rest of the Perkins Act is forward funded. A number of years ago Section 117 was moved to the Higher Education portion of the budget even though it is authorized through the Perkins Act. Perhaps that has something to do with it, although we note that many education programs are forward funded. Forward funding allows planning for vital education programs before the start of each school year, which is critically important when appropriations are delayed and the government is funded via Continuing Resolutions.

*Title III-A (Section 316) Strengthening Institutions*.—The Title III-A Strengthening Institutions funding is very important for all the tribal colleges. Funds are distributed via a formula with up to 30 percent of funds authorized to be set-aside for competitive funding for facility construction and maintenance. We share with other tribal colleges serious issues of inadequate physical infrastructure.

We are constantly in need of additional student housing, including family housing. With the completion of a Science, Math and Technology building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families. While we have constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of what was Fort Abraham Lincoln, as well as housing that was donated by the Federal Government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper than rehabilitating the old buildings that now house students.

*Pell Grants*.—We support maintaining the Pell Grant program and letting scheduled increases occur. We oppose the House Budget Resolution that calls for a 10-year freeze on the program. This resource makes all the difference in whether most of our students can attend college. As noted above, 73 percent of our undergraduate students receive Pell Grants.

*The Duplication or Overlapping Issue*.—As you know in March 2011, the Government Accountability Office issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO–11–474R and GAO–11–318SP). Funding from the BIE and the DOEd's Carl Perkins Act were among the programs listed in the reports. The full GAO report did not recommend defunding these programs; rather, the possibility of consolidation of these programs was proposed to save administrative costs. We are not in disagreement about possible consolidation of our funding sources, as long as program funds are not cut.

The Perkins funds supplement, but do not duplicate, the BIE funds. Both sources of funding are critical to frugally maintaining our institution. We actively seek alternative funding to assist with academic programming, deferred maintenance, and scholarship assistance, among other things. The need for career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding. There are only two institutions targeting American Indian/Alaska Native career and technical education and training at the postsecondary level—UTTC and Navajo Technical University. Combined, these institutions received less than $14.7 million in fiscal year 2015 Federal operational funds ($7.7 million from Perkins; $6.9 million from the BIE). That is not an excessive amount for two campus-based institutions who offer a broad array of programs geared toward the educational and cultural needs of their students and who teach job-producing career skills.

Thank you for your consideration of our requests.

[This statement was submitted by Leander "Russ" McDonald, PhD, President, United Tribes Technical College.]

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## PREPARED STATEMENT OF THE UNIVERSITY OF KANSAS MEDICAL CENTER

Mr. Chairman and Members of the Subcommittee; thank you for the opportunity to submit this statement regarding fiscal year 2016 funding for the National Institutes of Health's Institutional Development Award or "IDeA" Program. The IDeA program is funded by NIH's National Institute of General Medical Sciences (NIGMS), and was authorized by the 1993 NIH Revitalization Act (Public Law 103–43). I submit this testimony on behalf of the Coalition of EPSCoR/IDeA States [1], the

[1] Alabama, Alaska, Arkansas, Delaware, Guam, Hawaii, Idaho, Iowa, Kansas, Kentucky, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Mex-

Kansas IDeA program, and the University of Kansas Medical Center. The Coalition of EPSCoR/IDeA States respectfully requests that the Subcommittee provide $310 million for the IDeA program in fiscal year 2016.

I would first like to provide some basic information about the IDeA program. The IDeA program increases our Nation's biomedical research capability by improving research in States that have historically been less successful in obtaining biomedical research funds. Twenty-three States and Puerto Rico are eligible. The program funds only merit-based, peer-reviewed research that meets NIH's biomedical research objectives. While IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103–43), sizable increases in funding only began in fiscal year 2000. The IDeA program then grew rapidly, due in large part to the thoughtful actions of this Subcommittee. This initial funding permitted the launch of two initial program elements: the COBRE and BRIN/INBRE programs.

The first was the COBRE program or "Centers of Biomedical Research Excellence," which are research clusters targeting specific biomedical research problems. The COBRE program is designed to increase the pool of well-trained investigators in the IDeA States by expanding research facilities, equipping laboratories with the latest research equipment, providing mentoring for promising candidates, and developing research faculty through support of a targeted multi-disciplinary center, led by an established, senior investigator with expertise in the research focus area of the center.

The second IDeA program was BRIN or "Biomedical Research Infrastructure Networks," which targeted key areas such as bioinformatics and genomics, and facilitated the development of cooperative networks between research-intensive universities and primarily undergraduate colleges. The BRIN grants underwent competitive renewals in 2004 and were funded under the new name of "IDeA Networks of Biomedical Research Excellence," or INBRE.

The INBRE programs are designed to increase the pipeline of outstanding students and enhance the quality of science faculty in the IDeA States by research-intensive networking with undergraduate institutions. The INBRE program supports research infrastructure and mentoring of young investigators, and prepares students for graduate and professional schools as well as careers in the biomedical sciences at participating institutions. As you can see, these two programs play complementary roles in developing research capability and human capital in biomedical fields in the IDeA States.

Finally, the IDeA program has established a third mechanism named the IDeA-Clinical and Translational Research (IDeA–CTR) program. This program encourages and supports IDeA States to develop infrastructure for clinical and translational research, which is a key step in moving basic science discoveries forward into clinical treatments.

*Impact of the IDeA Program on Kansas*

Since the year 2000, Kansas has received more than $220 million in awards from the IDeA program. Those IDeA investments have greatly enabled our investigators to secure National Institutes of Health grants and more than double the amount of funding coming into Kansas. The IDeA program has resulted in funding of 570 biomedical research grants, supported 71 core biomedical research core facilities, and has resulted in 1,152 new research related jobs.

The Kansas INBRE (K–INBRE) program consists of three research-intensive universities and seven primarily undergraduate universities. Over its 14-year history, the K–INBRE has provided significant benefits to the State of Kansas, including training a skilled workforce and helping to drive scientific commercialization potential. Over $47.4 million from the NIH, numerous Kansas Universities, as well as philanthropies and industry support to the K–INBRE has benefitted Kansas Universities by significantly aiding Kansas's faculty to increase NIH funding from $50.3 million (2000) to $109.4 million (2014). The K–INBRE has significantly improved in the dissemination of knowledge throughout Kansas via videoconferencing, symposia and increased intra- and inter-State collaborations.

The K–INBRE was responsible in establishing the first bioinformatics cores in Kansas on three institutional campuses and been instrumental in preparing for new advances in increased medical informatics and translational research. The K–INBRE has also assisted with building the Kansas biomedical science industry by facilitating collaborations between academia and industry. This is critical, as the growth of the Kansas bioscience sector is climbing at more than twice the national rate.

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ico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Virgin Islands, West Virginia, and Wyoming

Finally, the K–INBRE has contributed to building a skilled workforce for Kansas by assisting with the building of the biomedical workforce in Kansas, and by supporting research training for over 900 undergraduates, numerous post-docs and new faculty investigators. Importantly, the K–INBRE has helped broaden student research participation of under-represented groups (rural and ethnic). In 2014 alone, 176 graduate and undergraduate students throughout the State of Kansas were supported by K–INBRE funds. More importantly, these funds have broadened research participation by under-represented rural and ethnic groups, and NIH-level research infrastructure has been initiated in seven of ten campuses within the K–INBRE network.

Overall, the implementation of the K–INBRE program facilitates the generation of new strengths in Cell and Developmental Biology in the State of Kansas, and ultimately contributes to the development of new tools and strategies for improving human health.

Kansas researchers are currently involved in six active COBRE awards. Three of these COBREs are located at University of Kansas Medical Center in Kansas City, KS. The Molecular Regulation of Cell Development and Differentiation COBRE has established a thriving multidisciplinary research group focused on the molecular regulation of cell development. This COBRE has been highly successful in helping numerous young faculty obtain NIH funding. The purpose of the Nuclear Receptors in Liver Health and Disease COBRE has been to establish a recognized center to study liver function in health and disease. This COBRE has also been very successful at aiding young faculty in obtaining NIH funding. It has also created a valuable "liver bank" from many strains of inbred mice. The objective of the Novel Approaches for Control of Microbial Pathogens COBRE is to promote and enhance the research capabilities of tenure track junior faculty members of participating institutions in the State of Kansas with an emphasis on inhibiting microbial pathogens. This COBRE has been critical in enabling Kansas faculty to obtain over $52 million in NIH funding and has established a highly utilized flow cytometry core facility at the University of Kansas Medical Center.

The remaining three COBRE programs reside in Lawrence, Kansas at the University of Kansas. The Center of Biomedical Research Excellence in Protein Structure and Function conducts basic research in health-related protein structure and function. By better understanding the structure, function, and interaction of proteins present in human cells, researchers are gaining a deeper understanding of how proteins carry out critical functions within cells. This COBRE has helped 13 faculty establish independent NIH funding and two faculty supported by this COBRE have gone on to receive national recognition for their research.

The Center for Molecular Analysis of Disease Pathways (CMADP) COBRE brings together junior and senior faculty from the physical, biological, and pharmaceutical sciences at the University of Kansas and other academic institutions in Kansas to conduct multidisciplinary research to develop and implement cutting-edge technologies for elucidating the genetic, chemical, and physical mechanisms of biological processes involved in disease. This COBRE has established a much needed Genome Sequence Core that provides state of the art sequencing capabilities for researchers in Kansas.

Finally, the Center for Cancer Experimental Therapeutics (CCET) COBRE brings together researchers from the University of Kansas Lawrence campus, Kansas State University and the University of Kansas Medical Center. The Center combines the resources and faculty of Kansas' institutions to create the infrastructure needed to pursue cancer-related research and experimentation at the interface between chemistry and biology. This is the oldest of the COBRE programs in Kansas and the CCET works to identify novel bioactive compounds that will be useful basic biomedical research tools and potential therapeutic agents. Scientists from the participating schools fight cancer through research projects focusing on specific types of cancer and the discovery of new anti-cancer drugs and therapies. This COBRE has established two important research cores associated with medicinal chemistry and high throughput screening, two key services that are important for drug discovery. The CCET was also instrumental in establishing a National Cancer Institute Designated Cancer Center at the University of Kansas Medical Center in 2012.

*Conclusion*

We request that this committee recommend the program be funded in fiscal year 2016 at $310 million. As you know, the EPSCoR/IDeA Coalition has maintained that the IDeA program should constitute at least 1 percent of the total NIH budget. This level of funding would continue funding for COBRE and INBRE, provide funding for the IDeA Program Infrastructure for Clinical and Translational Research (IDeA–

CTR) program, and provide co-funding which would allow researchers and institutions to merge with the overall national biomedical research community.

On behalf of the University of Kansas Medical Center, I express gratitude to this Subcommittee for the efforts it has made over the years to provide increased funding for IDeA, in particular this committee's work to ensure the successful inclusion of a $50 million increase for the program in fiscal year 2012. I hope that you will continue to invest in this biomedical research program, which is so important to almost half of the States in the Union. Every region of the country has talent and expertise to contribute to our Nation's biomedical research efforts—and every region of the country must participate if we are to increase our Nation's biomedical research capacity substantially. On behalf of the EPSCoR/IDeA Coalition, the University of Kansas Medical Center and our partner institutions across Kansas, I thank the Subcommittee for the opportunity to submit this testimony.

[This statement was submitted by Douglas Wright, Ph.D., Professor and Vice Chair, Principal Investigator, Kansas INBRE, Department of Anatomy and Cell Biology, University of Kansas Medical Center.]

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## PREPARED STATEMENT OF THE U.S. CHAMBER OF COMMERCE

Chairman Blunt and Ranking Member Murray, thank you for the opportunity to provide written testimony regarding fiscal year 2016 appropriations for the U.S. Department of Labor ("Labor Department" or "DOL"). The U.S. Chamber of Commerce is the world's largest business organization representing the interests of more than 3 million businesses of all sizes, sectors, and regions. Our members range from "mom-and-pop" shops and local chambers to leading industry associations and large corporations.

Businesses play an exceedingly important role in ensuring that Americans are able to enjoy a financially secure retirement. As private employers, businesses of every size seek to maintain a long-held commitment to providing voluntary benefits, such as defined benefit and defined contribution plans, that support the welfare of their workers. Financial sector businesses have also over the past several decades innovated in ways making access to tax-deferred investment vehicles—notably the individual retirement account ("IRA")—a reality for millions of American households. This private sector system has contributed significantly to the retirement needs of millions of seniors, and the Chamber and its members are committed to continuing the success of the system and ensuring the long-term retirement security of Americans.

It is precisely because of our commitment to protecting the retirement security of America's workers that we have such serious concerns about the Labor Department's impending rule re-proposal that would expand the definition of a "fiduciary" under the Employee Retirement Income Security Act ("ERISA") of 1974. We are concerned that the DOL's regulatory initiative will significantly increase costs and reduce access to much-needed financial education and advice for millions of workers and retirees.

It is hard to overstate the scope of the Labor Department's original proposal in 2010. As the Chamber and many other commenters noted at the time, the 2010 proposal would have seriously inhibited the ability of plan participants to obtain valuable investment education, and would have also had a particularly harmful impact on the IRA market. Specifically, the rule would have made it either impossible or cost prohibitive for a large number of investors with moderate retirement assets to open or maintain an IRA, and to be able to work with a financial professional on an ongoing basis. The limited information currently available from the White House and the Labor Department suggests that the re-proposed regulation will be similarly broad, and will likely elicit many of these same concerns.[1]

The Chamber believes that the DOL and the Administration have failed to properly take into consideration the effectiveness of the existing regulatory regime for broker-dealers and others who provide retirement products and services to workers and retirees. Of particular concern to us are the contents of an internal White House memo that was recently made public, in which senior Administration officials argue that "consumer protections for investment advice in the retail and small plan markets are inadequate and . . . the current regulatory environment creates per-

[1] See, e.g., White House Fact Sheet, "Strengthening Retirement Security by Cracking Down on Backdoor Payments and Hidden Fees," February 23, 2015 and "FAQs: Conflicts of Interest Rulemaking" at http://www.dol.gov/featured/ProtectYourSavings/faqs.htm.

verse incentives that ultimately cost savers billions of dollars a year."[2] Many of these same arguments were recycled in the President's recent comments.

The Chamber fundamentally disagrees with the conclusions reached in the White House memo regarding current regulation of market participants, in particular broker-dealers who play a large role in the IRA market. Indeed, we believe that the DOL and White House have failed to take into account the important roles played by the Securities and Exchange Commission ("SEC") and the Financial Industry Regulatory Authority ("FINRA") in their oversight of broker-dealers. A recent report lays out in detail the current comprehensive regulatory regime that oversees broker-dealers and other financial professionals.[3]

Despite the long-established roles of the SEC, FINRA, banking, and insurance regulators to govern the conduct of financial professionals, and of the Internal Revenue Service ("IRS") to enforce IRA requirements, the DOL on its own seeks to fundamentally alter the rules governing how investment advice is provided with respect to nearly $15 trillion in capital, roughly half of which is held in IRAs. On behalf of our members and their employees, we have serious doubts that the Department of Labor is the proper regulatory agency to attempt such broad regulation of financial services, especially for retail investors in IRAs.

This concern is especially significant given that many of the primary financial regulators are already focusing on areas in which the White House and DOL claim there are regulatory shortcomings, notably in the IRA rollover market. For example, FINRA issued new guidance less than 15 months ago expanding the requirements for determining the suitability of a rollover to an IRA.[4] SEC Chair Mary Jo White recently announced that the SEC could soon begin promulgating a regulation to harmonize the suitability and fiduciary standards under the securities laws, as authorized in the Dodd-Frank law.[5] The Labor Department is not acting to fill a void where there is insufficient regulation—rather, it is promulgating a regulatory standard that could well conflict with, or even trump, the actions of other regulators.

Indeed, SEC Commissioner Dan Gallagher expressed significant reservations about the DOL regulatory process in a recent speech, saying the reported coordination between SEC and DOL on DOL's fiduciary rule " . . . has been nothing more than a 'check the box' exercise by DOL designed to legitimize the runaway train that is their fiduciary rulemaking."[6] The DOL response to the Education and the Workforce Committee's letter requesting the Department specifically document its coordination efforts with the SEC did little to dispel this concern.[7] The DOL response indicated merely that Secretary Perez and SEC Chair White have had a handful of telephone calls and meetings over the past year and a half to discuss the DOL rule, and that staff have had "numerous" phone calls and meetings.[8]

We are deeply concerned that the approach taken by the Labor Department in the 2010 proposal, and presumably in the re-proposal, relies on the prohibited transaction exemptions ("PTEs") under ERISA and the Tax Code. These extremely blunt regulatory tools are ill-suited for nuanced regulation that preserves access to valuable investment advice while preventing abuse.

The Chamber recently issued a report entitled "Using PTEs to Define a Fiduciary Under ERISA: Threading the Needle with Rope" that discussed these concerns in detail.[9] The reality is that the prohibited transaction regime administered by the DOL is a very difficult and often unworkable method to effectively address the issues that arise with an overly broad rule. While the Labor Department and the Administration assure us that the re-proposal will provide some narrow "principles-

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[2] See White House memo from Council of Economic Advisers members Jason Furman (Chair) and Betsey Stevenson http://www.scribd.com/doc/253449711/WH-DOL-memo.

[3] See white paper from Morgan Lewis: "Department of Labor Retirement Initiative Fails to Consider Current Regulatory Regime, Which Comprehensively Protects Investors, Including IRA Investors, and Preserves Investor Choice." March 2015 http://www.morganlewis.com//media/files/publication/morgan%20lewis%20title/white%20paper/im__whitepaper__dolretirementinitiative__march2015.ashx.

[4] See FINRA Regulatory Notice 13-45, https://www.finra.org/sites/default/files/NoticeDocument/p418695.pdf.

[5] "SEC's Mary Jo White Says Agency Will Develop Fiduciary Rule Brokers" Investment News March 17, 2015.

[6] Speech of Commissioner Daniel M. Gallaher at "The SEC Speaks in 2015," February 20, 2015.

[7] March 4, 2014 letter to Secretary Perez from Chairman Kline and Subcommittee Chairman Roe.

[8] March 16, 2015 response from Assistant Secretary Jayaratne to Chairman Kline and Subcommittee Chairman Roe.

[9] The Chamber's report can be found at: http://www.centerforcapitalmarkets.com/wp-content/uploads/2013/08/White-Paper-Using-PTEs-to-Define-a-Fiduciary-Under-ERISA-2.19.15-FINAL.pdf.

based" exemptions to these rules,[10] real-world experience with PTEs suggests that these narrow exemptions will not prevent workers and investors from being denied access to advice.

For example, the DOL finalized prohibited transaction exemptions in 2011 that were intended to improve access to investment advice by retirement plan participants. However, the DOL's own economic analysis showed that even after the exemptions were adopted, participants would still lose approximately $100 billion every year due to investments errors from a lack of advice.[11] Even if the White House's dubious estimates are correct that "conflicted" advice results in $8–$17 billion of losses per year,[12] the economic harm to American workers and retail investors of being denied access to investment advice is five to ten times greater, a figure that would increase even further if the expanded fiduciary definition further restricts the availability of advice.

In summary, Mr. Chairman, we are deeply concerned that the Department of Labor's regulatory effort to expand the definition of a fiduciary may ultimately harm the very working Americans it purports to help by further limiting their access to, and choice of, investment advice providers. We ask that the Committee use its authority to require the Labor Department to provide detailed information on its coordination with the SEC as a condition of receiving the funding necessary to continue its work. On their current course, the DOL and SEC could very well end up promulgating regulations that are duplicative or conflict with one another. Additionally, given that the DOL will likely require a significant amount of funding in order to enforce an expanded definition of fiduciary, the Committee should also seek answers as to whether the DOL will require additional resources in future years in order to enforce these new rules. Active Congressional oversight of these regulatory processes will be essential to ensure American workers continue to benefit from our private retirement system.

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## PREPARED STATEMENT OF THE U.S. HEREDITARY ANGIOEDEMA ASSOCIATION

### SUMMARY OF FISCAL YEAR 2016 RECOMMENDATIONS

—Provide $32 billion for the National Institutes of Health (NIH)
—Support the NIH hereditary angioedema research portfolio
—Encourage the Centers for Disease Control and Prevention (CDC) to advance hereditary angioedema education and awareness

Thank you for the opportunity to present the views of the U.S. Hereditary Angioedema Association (U.S. HAEA) regarding fiscal year 2016 funding for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). On behalf of U.S. HAEA, I urge Congress to support hereditary angioedema research and public awareness.

U.S. HAEA is a non-profit patient advocacy organization dedicated to serving the estimated 6,000 HAE sufferers in the U.S. We provide a support network and a wide range of personalized services for patients and their families. We are also committed to advancing clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Hereditary angioedema (HAE) is a painful, disfiguring, debilitating, and potentially fatal genetic disease that occurs in about 1 in 30,000 people. Symptoms include episodes of swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. The majority of HAE patients experience their first attack during childhood or adolescence. Approximately one-third of undiagnosed HAE patients are subject to unnecessary exploratory abdominal surgery. About 50 percent of patients with HAE will experience laryngeal edema at some point in their life. This swelling is exceedingly dangerous because it can lead to death by asphyxiation. The historical mortality rate due to laryngeal swelling is 30 percent.

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[10] White House Fact Sheet, "Strengthening Retirement Security by Cracking Down on Backdoor Payments and Hidden Fees," February 23, 2015.

[11] See Investment Advice—Participants and Beneficiaries, 76 FR 66,136, 66,151–153 (October 25, 2011).

[12] Fact Sheet, February 23, 2015.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

U.S. HAEA recommends that Congress provide an overall funding level of $32 billion for NIH in fiscal year 2016. In addition. U.S. HAEA urges Congress to include recommendations in accompanying committee reports emphasizing the importance of advancing HAE research per the findings of the October 2014 scientific conference, Expanding Boundaries of our HAE Knowledge.

In October 2014, the NIH National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Sciences (NCATS), and U.S. HAEA partnered on the state-of-the-science conference, Expanding Boundaries of our HAE Knowledge. This conference brought together top HAE researchers as well as other medical researchers across disciplines in order to identify promising avenues for future research. NIH should capitalize on this conference by issuing requests for applications or other opportunities for HAE research based on the findings of the conference.

As a rare disease community, HAE patients are also stakeholders of the Office of Rare Diseases Research (ORDR) and may benefit from programs like the Therapeutics for Rare and Neglected Diseases (TRND) program. U.S. HAEA also urges Congress to robustly support NCATS and the NIH rare disease portfolio in fiscal year 2016.

CDC PUBLIC AWARENESS AND EDUCATION TO PREVENT HAE DEATHS

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in fiscal year 2016.

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, patients are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment, and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, the use of available treatments can help patients lead a productive life. Education and awareness is needed to reach patients and providers with this message.

Thank you for the opportunity to present the views of the HAE patient community. I hope Congress will support research and education on HAE.

[This statement was submitted by Anthony Castaldo, President, U.S. Hereditary Angioedema Association.]

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PREPARED STATEMENT OF JAMES VEACH

Based on our family experience with pressure on the guardian to agree to move a family member from an ICF/IID I support the testimony of VOR.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AAIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decision-makers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AAIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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## PREPARED STATEMENT OF MARY VIGIL

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

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VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF ALISSA VILAGI

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

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The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which authorizes for funding AIDD programs, such as Protection & Advocacy, DD Councils and University Affiliated Programs, does not support forced deinstitutionalization and states that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (42 U.S.C. 15001(c)(3)(2000).

Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care set-

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NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF MARY A. VITALE

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

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Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

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PREPARED STATEMENT OF VOR

*I. Introduction*

VOR is a national nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD).

VOR urges the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies Appropriations bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including but not limited to AIDD and its programs, NCD, and CMS.

As explained below, we strongly believe such forced deinstitutionalization activities are contrary to Federal law and cause human harm. These deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies that result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs. These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. Bill language prohibiting the very actions that lead to human harm and are contrary to Federal law is desperately needed.

*II. The Law: The Olmstead* Decision, Medicaid Law, and the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Protect Choice Based on Individual Need

HHS-funded organizations pursuing forced deinstitutionalization cite the landmark Supreme Court decision of *Olmstead* v *L.C.* (1999) as justification for its position to close HHS homes. Like many organizations that support deinstitutionalization, these Federal agencies misread and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the Americans with Disabilities Act (ADA) requires individual choice before community placement can be imposed and recognizes the need for specialized care:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead*, 527 U.S. 581, 601–02 (1999) (1999) (majority).
>
> "As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk . . . 'Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's *Amici Curiae* brief]." Id. at 605 (plurality).

Likewise, Medicaid law and regulation requires that ICF/IID residents be "[g]iven the choice of either institutional or home and community-based services." 42 C.F.R. § 441.302(d)(2); see also, 42 U.S.C. § 1396n(c)(2)(C) and 42 C.F.R. § 441.303.

The DD Act, which authorizes for funding AIDD programs such as Protection & Advocacy Agencies, DD Councils, and University Affiliate Programs, and related Congressional history, support residential choice and recognizes that individuals and their families are in the best position to make care decisions:

> "Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000).
>
> "[T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions" [H. Rep. 103–442 (March 21, 1994)].

*III. Using HHS Funds to Eliminate HHS-Supported Homes Causing Human Harm: The Administration on Intellectual and Developmental Disabilities (AIDD) and its State-based Developmental Disabilities Assistance and Bill of Rights Act (DD Act) Programs*

It has been 15 years since Congress last reauthorized the DD Act. Authorizations for DD Act appropriations expired in 2007; however, Congress continues to fund these programs. DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every State. AIDD, within HHS, administers the DD Act programs.

Independent oversight of Federal AIDD and DD Act programs is nearly non-existent.[1] DD Act programs are using their public funds to achieve dangerous deinstitutionalization, evicting vulnerable people with I/DD from Medicaid-certified homes, disregarding individual choice and the legal right to appropriate services, as required by the ADA (as interpreted by the *Olmstead* decision) and Medicaid law, as outlined above.

AIDD persists in its support for DD Act programs' deinstitutionalization activities and even proposed a recommendation to "[d]evelop and implement plans to close public and private institutions," and "[k]eep people with disabilities out of congregate institutions," in collaboration with DOJ and The Arc (2011). Hundreds of families and others objected; the recommendation has not yet been finalized. Likewise, the national organizations for the three DD Act programs have referred to families who select HHS-licensed homes (ICFs/IID) as "clueless" and "unaware,"[2] a view not shared by the Supreme Court (see, *Heller* v. *Doe*, 509 U.S. 312, 329 (1993) (". . . close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered during the involuntary commitment process.")).

With AIDD directive, State-level DD Act program deinstitutionalization activities continue, exacting great harm on the very people Congress entrusted these HHS-entities to protect.

In a recent example, Disability Rights Ohio (DRO), the State's designated P&A, cited *Olmstead* and threatened a class action lawsuit purportedly on behalf of thousands of Ohioans with intellectual and developmental disabilities who receive care and support in licensed State and private ICFs/IID, sheltered workshop, or day program settings (July 1, 2014 letter to State officials). Without consulting with what its authorizing legislation calls "primary decisionmakers"—the individuals and their families—DRO instead cites the experiences of three individuals with disabilities to make the case that "thousands" are equally unsatisfied with their present situations. DRO's allegations and threats of litigation, in part, prompted draconian budget proposals that will force thousands of individuals with profound disabilities from their homes, workplace, and day program settings.

In response to DRO allegations and threats, more than 18,000 families signed a petition objecting to the budget proposals and many have testified prompting legislators to ask "who does DRO speak for?"

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[1] See, VOR Federal Comments Urging Objective Performance—Not More Self-Reporting—of DD Act Programs (January 25, 2012) (vor.net/images/VORCommentDDActEvaluation Jan2012.pdf).

[2] June 14, 2010 and July 30, 2007 letters to Congress referring to families as "unaware" and "clueless," respectively.

Yet, as recently as March 26, 2015, DRO reiterated its threat, in spite of the families' petition and testimony which makes clear the widespread opposition to the budget proposals, writing, "Without the complete package of reforms laid out in the proposed budget, there would be no foundation for a future agreement and no alternative for class members but to pursue their claims in court." (March 26, 2015 letter to State officials).

Lawsuits have been a favorite tool of P&As over the years, so DRO's fear mongering comes as no surprise. Since 1996, more than fifteen (15) P&A class action lawsuits for closure (not relating to conditions of care) and other deinstitutionalization tactics have been pursued over the objection of residents and their families. The P&A class action lawsuits are a particularly egregious use of Federal funds; they equate HHS suing itself because the targets of these HHS-funded lawsuits are HHS/Medicaid-licensed ICFs/IID.

AIDD and its State-based programs persist in their ideological devotion to community placement despite reports of hundreds of deaths in Georgia (Augusta Chronicle, March 2015); 1,200 "unnatural and unknown" deaths in New York (New York Times, 2011–2012); a risk of mortality in community settings of up to 88 percent in California (peer reviewed studies, 1996–2005); more than 100 deaths in Connecticut (Hartford Courant, March 2013); 53 deaths in Illinois (Belleville News-Democrat, June 27, 2012); hundreds of deaths in the District of Columbia (Washington Post, reports since 1999); plus many more reports of abuse, neglect and death across the majority of all States (see e.g, Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities (VOR, 2015)).

*IV. Using HHS Funds to Eliminate HHS-Supported Homes: National Council on Disability*

The National Council on Disability (NCD) is an HHS-funded, independent Federal agency that advises the President, Congress, and other Federal agencies on issues affecting people with disabilities.

On October 23, 2012, NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. NCD spent nearly $150,000 in Federal funds to prepare and publish "Deinstitutionalization: Unfinished Business," calling on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

NCD did not consult with the individuals who could be evicted from their homes, nor their families and legal guardians. Instead, NCD accuses these caring families and guardians of violating their family members' civil rights for choosing a care setting of four or more people. NCD has since received more than 350 letters from families opposing forced deinstitutionalization.

NCD's support for deinstitutionalization is contrary to Federal law and reckless. ICFs/IID have an array of services not often available elsewhere (e.g., on-site medical care, dental care, other specialties, and involvement in their broader communities). As discussed above, tragedies are predictable when residents are separated from life-sustaining supports.

*V. Centers for Medicare & Medicaid Services (CMS) Rule on Eligible Home and Community-Based Settings (HCBS) Narrows Options and Runs Counter to the Americans with Disabilities Act (ADA)*

Last year, CMS finalized a new regulation ("rule") that defined settings which qualify as "home and community-based" for the purpose of receiving Medicaid HCBS funding. Individuals living in settings deemed too "congregate" or too close to ICFs/IID would not be able to continue to receive necessary HCBS supports. According to CMS, along with its overarching goal "to improve Medicaid HCBS, we seek to ensure that Medicaid is supporting needed strategies for States in their efforts to meet their obligations under the ADA and the Supreme Court decision in *Olmstead* v. *L.C.*, 527 U.S. 581 (1999)." [79 FR 11 (Jan. 16, 2014)].

The ADA, however, forbids public entities from excluding or denying individuals with disabilities equal opportunity to receive program benefits and services, and must provide services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. [*Olmstead* at 6, citing the ADA, 28 CFR § 35.130(d) (1998)]. The new CMS rule defines "community" so narrowly that it will disqualify certain community homes, essentially redefining them as "institutions" for the purpose of HCBS funding eligibility. In so doing, CMS has effectively denied individuals with disabilities access to the very services they want and need by disqualifying some community settings that are in fact "the most integrated setting appropriate to the needs of qualified individuals with disabilities," in direct violation of ADA.

*VI. Solution and Conclusion*

HHS-funded agencies should not be allowed to advance an ideological agenda in support of evicting eligible people from HHS-licensed homes, contrary to the DD Act, Medicaid law, and the ADA/*Olmstead*. Such actions are a cruel and absurd use of Federal funding that is exacting great harm on our Nation's most vulnerable citizens, and contrary to societal values which respect individual and family decision-making.

Please support language to prohibit the use of HHS appropriations in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed and funded homes. No Federal agency should define "choice" so narrowly and illegally as to disenfranchise the most vulnerable segment of our disabled population.

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PREPARED STATEMENT OF JOHN STEPHEN WALDO

I am an 84 year old man writing with personal but somewhat distant knowledge of my nephew aged 55 who was born in 1958 with a healthy body but with a brain damaged suchwise that the body continues to function well, but his thinking and social capabilities never developed beyond that of a two o to three year old child.

*With considerable effort his parents raised and cared for him, along with his six very capable siblings, till he approached the age to "go to school." Sadly but with determination to do the best for him, they placed him in a State Institution (Louisiana) while remaining his legal guardians. There, with their regular visits and less so those of his siblings, he lived along with other variously disabled residents a healthy, largely contented, busy within the limits of his abilities, and often enough clearly happy life. The parents were gratified to find that their son did so well in his new surroundings, clearly better than he had when still living in his home. The surroundings with the other "disabled residents" along with the staff's direction made possible many things not possible in their life at home.

When his parents passed away about 10 years back, an older sister (my niece) assumed his guardianship. Those siblings who remained in the local area were her back-up. Some 5 years back Federal and/or state legislation or regulations made it necessary to move him from this rather large institution to a much smaller community oriented setting. This placed much greater responsibility for management and presence on his guardian and family, as also occurred with the families of the other two other residents. The time of adapting was not easy, but apparently both the disabled and the families involved seem to have come to an acceptable way of managing and living.

I personally know of the above from my contacts with my disabled nephew over the years when he was brought to very occasional family reunions by his father, and in more recent years through phone calls or emails with my niece, his guardian, and also conversations with some of his other siblings. I have myself most of my adult life distant from Louisiana.

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

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PREPARED STATEMENT OF KAREN WEAVER

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PREPARED STATEMENT OF EDWARD D. WENTRCEK

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AIDD programs routinely ignore the DD Act, *Olmstead* and Medicaid law by pursuing lawsuits and lobbying in support of the elimination of specialized care settings, including ICFs/IID, other specialized facilities, sheltered workshops, and day programs.

NCD released a 300-page policy paper and related toolkit calling for the closure of residential homes for people with I/DD, arbitrarily targeting residential homes for four or more people. "Deinstitutionalization: Unfinished Business" calls on the broader advocacy community to engage in advocacy efforts and lawsuits to evict people with I/DD from their homes.

CMS' new Federal regulation defines "Home and Community-Based Services" so narrowly that specialized and innovative care settings that are deemed to large or too close to specialized care settings are at risk of no longer being eligible for Medicaid HCBS funding, without regard at all for individual choice and needs, as *Olmstead* and Medicaid requires.

Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-makers are routinely ignored. The Labor, HHS, and Education and Related Agencies appropriations bill must include language prohibiting the use of HHS funding for forced deinstitutionalization which separates individuals with I/DD from the specialized care and settings they require without regard to individual choice and need, contrary to Federal law and causing human harm.

VOR, a national nonprofit organization advocating for high quality care and human rights for all people with I/DD, has submitted written testimony for the record with a consistent request. I support VOR's testimony.

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PREPARED STATEMENT OF PATRICIA T. WENTRCEK

I am writing to urge that the Subcommittee to include language in its Labor, HHS, and Education and Related Agencies bill that expressly prohibits the use of appropriations for any HHS program in support of activities which attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) or any other Medicaid-licensed settings serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic abuse.

Several HHS agencies use some of their Federal funding in support of forced deinstitutionalization, the elimination of specialized services for people with I/DD, including AAIDD and its programs, NCD, and CMS, contrary to Federal law and causing human harm.

These HHS-funded deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics result in the downsizing and closure of HHS-licensed ICF/IID homes, some specialized group homes, sheltered workshops and day programs.

These HHS v. HHS deinstitutionalization activities are a cruel and absurd use of Federal funding.

Often citing the Supreme Court's *Olmstead* decision, forced deinstitutionalization is actually counter to *Olmstead* which only required community placement when such placement is not opposed by the individual. The Court also stated:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any Federal requirement that community-based treatment be imposed on patients who do not desire it."

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My brother has neither the mental or physical capabilities to exist in a group home with questionable supervision and lack of a staff trained in many disciplines. The State supported living center is the least restrictive and most humane situation for people with similar disabilities. It is their home in every sense of the word.

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PREPARED STATEMENT OF ROBERT L AND ALICE J. WHITE

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PREPARED STATEMENT OF SUE YACOVISSI

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with intellectual disabilities, unless the purpose of action is to remedy systemic abuse.

I believe they are misusing the intention of *Olmstead*—basically rewriting what the Supreme Court language intention was—so they can control the flow of the money into directions they approve. Forced deinstitutionalization is basically forced removal of specialized services for the most vulnerable of the DD population. It is placing a specific language of agenda—that if the DD population wants services—they can have "choice"—but only the "choice" that is dictated to them through funding and through idiotic legal suits.

I have a daughter that receives her highly specialized level of care services through an ICF. She spent quite a few of her earlier years in community waiver services. The "community" waiver services do not provide the level of care that she currently requires. That simple. I am her advocate—her voice. She requires a higher level of services—this is in her medical record over a period of time—She qualifies for the Medicaid-licensed facility where she receives an outstanding level of care. She also has a large degree of "self-determination rights" where appropriate. She has "choice" written into her plan of care how she spends her time in the evening and weekends. She has "choice" in whether she takes a bath each day or can space it out. These are just 2 simple examples of how she still has a level of "choice or self-determination" in her daily life—in her daily level of activities.

Please stop this foolishness of government agencies trying or actually redirecting the flow of money to the agenda that they see fit. I am the advocate for my daughter. These government agencies—they just want my daughters money for their own agenda. I disagree strongly with that. Waiver services are a good program—but to take government money and use legal means to take away specialized care of services to the most vulnerable of the developmental disability population is absurd. And to require these individuals to take a downsized version of their plan of services—because of civil rights—that civil right argument to me does not make a lick of sense.

Sue Yacovissi
mom

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PREPARED STATEMENT OF KEITH ZIMMERMAN

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