

LEGISLATIVE HEARING ON MISCELLANEOUS PUBLIC HEALTH LEGISLATION, H.R. 1852, CHILDREN'S HOSPITAL GME SUPPORT REAUTHORIZATION ACT OF 2011, AND H.R. 2005, COMBATING AUTISM REAUTHORIZATION ACT OF 2011

HEARING
BEFORE THE
SUBCOMMITTEE ON HEALTH
OF THE
COMMITTEE ON ENERGY AND
COMMERCE
HOUSE OF REPRESENTATIVES
ONE HUNDRED TWELFTH CONGRESS

FIRST SESSION

JULY 11, 2011

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2005, COMBATING AUTISM REAUTHORIZA-
TION ACT OF 2011**

MONDAY, JULY 11, 2011

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON ENERGY AND COMMERCE,
Washington, DC.

The subcommittee met, pursuant to call, at 2 p.m., in room 2123, Rayburn House Office Building, Hon. Joseph R. Pitts (chairman of the subcommittee) presiding.

Members present: Representatives Pitts, Burgess, Blackburn, Gingrey, Latta, Cassidy, Guthrie, Upton (ex officio), Pallone, Dingell, and Waxman (ex officio).

Also present: Representative Christensen.

Staff present: Jim Barnette, General Counsel; Brenda Destro, Professional Staff Member, Health; Andy Duberstein, Special Assistant to Chairman Upton; Debbie Keller, Press Secretary; Ryan Long, Chief Counsel, Health; Katie Novaria, Legislative Clerk; Heidi Stirrup, Health Policy Coordinator; Stephen Cha, Minority Senior Professional Staff Member; Alli Corr, Minority Policy Analyst; and Ruth Katz, Minority Chief Public Health Counsel.

Mr. PITTS. The subcommittee will come to order. The chair recognizes himself for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

Today's legislative hearing will focus on two bills: H.R. 1852, the Children's Hospital Graduate Medical Education Reauthorization Act of 2011, the bill that I introduced with Ranking Member Pallone; and H.R. 2005, the Combating Autism Reauthorization Act of 2011, introduced by Congressman Chris Smith. I will focus my remarks on the CHGME reauthorization.

In his fiscal year 2012 budget President Obama proposed eliminating the Children's Hospital Graduate Medical Education program, a program that provides more than \$300 million a year to 56 freestanding children's hospitals across the U.S. Three of these hospitals are located in my home State of Pennsylvania: the Chil-

dren's Hospital of Philadelphia, the Children's Hospital of Pittsburgh, and Saint Christopher's Hospital for Children. Due to its proximity many of my constituents travel to the Children's Hospital in Philadelphia to seek treatment for their children.

The CHGME program trains 40 percent of our Nation's pediatricians and 43 percent of pediatric subspecialists. More than 5,000 residents take part in this program every year. The 1990s saw a 13 percent decline in the number of pediatric residents. However, since 1999 when the CHGME program was enacted, the number of pediatric residents has increased 35 percent. During the program's lifetime, \$2 billion has gone to train the next generation of pediatricians and pediatric subspecialists.

The program's current authorization expires September 30, 2011, and that is why I and Ranking Member Pallone introduced H.R. 1852, to reauthorize the program at the current level of \$330 million over the next 5 years. This is a fiscally responsible bill which continues the CHGME program at its current authorization. We cannot simply zero out this important program, as the administration has requested, and hope that other Federal programs not specifically dedicated to pediatric health care will pick up the slack.

To date this bill has garnered over 90 cosponsors, including more than half of the members of this subcommittee. This is not a partisan issue; it is about children's health and lives. I urge my colleagues to support this bill.

I also support Representative Chris Smith's Combating Autism Reauthorization Act, H.R. 2005.

I will now yield to the chairman of the committee, Mr. Upton, for the remainder of my time.

[The prepared statement of Mr. Pitts follows:]

Opening Statement of Rep. Joseph R. Pitts
Energy and Commerce Subcommittee on Health Hearing on
“Legislative Hearing on Miscellaneous Public Health Legislation”
July 11, 2011
(Remarks Prepared for Delivery)

Today’s legislative hearing will focus on two bills: H.R. 1852, the Children’s Hospital Graduate Medical Education (CHGME) Reauthorization Act of 2011, a bill I introduced with Ranking Member Pallone, and H.R. 2005, the Combating Autism Reauthorization Act of 2011, introduced by Rep. Chris Smith.

I will focus my remarks on the CHGME reauthorization.

In his FY12 budget, President Obama proposed eliminating the Children’s Hospital Graduate Medical Education program, a program that provides more than \$300 million a year to 56 free-standing children’s hospitals across the U.S.

Three of these hospitals are located in my home state of Pennsylvania: the Children’s Hospital of Philadelphia, the Children’s Hospital of Pittsburgh of UPMC, and St. Christopher’s Hospital for Children.

Due to its proximity, many of my constituents travel to the Children’s Hospital of Philadelphia to seek treatment for their children.

The CHGME program trains 40 percent of our nation’s pediatricians and 43 percent of pediatric sub-specialists. More than 5,000 residents take part in this program every year.

The 1990s saw a 13 percent decline in the number of pediatric residents; however, since 1999, when the CHGME program was enacted, the number of pediatric residents has increased 35 percent.

During the program’s lifetime, \$2 billion has gone to train the next generation of pediatricians and pediatric sub-specialists.

The program’s current authorization expires September 30, 2011, and that is why I and Ranking Member Pallone introduced H.R. 1852, to reauthorize the program at the current level of \$330 million over the next five years.

This is a fiscally responsible bill, which continues the CHGME program at its current authorization.

We cannot simply zero-out this important program as the administration has requested, and hope that other federal programs, not specifically dedicated to pediatric health care, will pick up the slack.

To date, this bill has garnered over 90 cosponsors, including more than half of the members of this subcommittee.

This is not a partisan issue. It is about children's health and lives.

I urge my colleagues to support this bill, and also to support Rep. Chris Smith's Combating Autism Reauthorization Act, H.R. 2005.

OPENING STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. UPTON. Well, thank you. And certainly this legislative hearing gives this subcommittee an opportunity not only to review the progress of these two important bills, but also to demonstrate our ability to work in a bipartisan manner. And with the passage of CHGME in 1999, freestanding children's hospitals began receiving funds to support the pediatric medical residency programs. And as a result, the number of pediatricians in the U.S. has steadily grown.

Over 40 percent of pediatricians and pediatric specialists are trained in the 56 freestanding children's hospitals that receive funding. The program has enjoyed bipartisan support. It makes the Obama administration's decision to eliminate funding for this in their 2012 budget very troubling. Even Secretary Sebelius expressed regret about the decision to zero out funding while testifying before the Energy and Commerce Committee earlier.

We look forward to the testimony today and its impact on funding for pediatric medical residency programs in the future of the program.

I would also say that the Combating Autism Act of 2006 consolidated and intensified the Federal effort to understand and treat autism spectrum disorders. It also addressed the need to monitor the disorder and bring relief to the children and families who live with the challenge of autism. This year the Interagency Autism Coordinating Committee released its strategic plan for autism spectrum disorders research that provides a blueprint for researchers and a basis for partnerships for the public and private sector.

Recent results from research on early screening genetics and prenatal conditions are hopeful signs that the Federal effort is working. The interagency coordinating committee is something that I am particularly interested in. I want to hear from the witnesses on how this committee has worked and whether the improved coordination of the Department's activities is something that should be emulated elsewhere.

Too often I have visits from patient groups telling a story about how a particular agency's activities did not complement another's work. HHS is a unified Department and its differing agencies should have the same strategic vision that is coordinated to achieve maximum results.

I look forward to the testimony and look forward to working with Republicans and Democrats on this very, very important issue, and I yield back.

[The prepared statement of Mr. Upton follows:]

Opening Statement of Chairman Fred Upton
Subcommittee on Health Hearing on
“Legislative Hearing on Miscellaneous Public Health Legislation.”
July 11, 2011
(Remarks Prepared for Delivery)

This afternoon’s legislative hearing gives the subcommittee an opportunity not only to review the progress of two important bills, but also to demonstrate our ability to work in a bipartisan manner.

With the passage of CHGME in 1999, freestanding Children’s Hospitals began receiving funds to support their pediatric medical residency programs. As a result, the number of pediatricians in the US has steadily grown. Today, over 40 percent of pediatricians and pediatric specialists are trained in the 57 freestanding Children’s Hospitals that receive CHGME funding. The program has enjoyed bipartisan support that makes the Obama administration’s decision to eliminate funding for CHGME in the 2012 budget very troubling. Even Secretary Sebelius expressed regret about the decision to zero out CHGME while testifying before the Energy and Commerce Committee. We look forward to testimony from Dr. Janet Heinrich, Associate Administrator of the Bureau of Health Professions at the Health Resources and Services Administration (HRSA), on the impact of CHGME on pediatric medical residency programs and the future of the program.

The Combating Autism Act of 2006 consolidated and intensified the federal effort to understand and treat Autism Spectrum Disorders. It also addressed the need to monitor the disorder and bring relief to the children and families who live with the challenge of autism. This year, the Interagency Autism Coordinating Committee (IACC) released its Strategic Plan for Autism Spectrum Disorders Research that provides a blueprint for researchers and a basis for partnerships with the public and private sector. Recent results from research on early screening, genetics, and prenatal conditions are hopeful signs that this federal effort is working.

The Interagency Autism Coordinating Committee is something I am particularly interested in. I want to hear from the witness on how this Committee has worked and whether the improved coordination of the Department’s activities is something that should be emulated elsewhere. Too often I have visits from patient groups telling a story about how a particular agency’s activities do not compliment another’s work. HHS is a unified Department and its differing agencies should have the same strategic vision that is coordinated to achieve maximum results. I look forward to testimony by Thomas R. Insel, M.D. Director of the National Institute of Mental Health about the research effort at NIH and the IACC strategic plan.

Mr. PITTS. The chair thanks the gentleman, and now recognizes the ranking member of the subcommittee, Mr. Pallone, for a 5-minute opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you Chairman Pitts. I want to thank you for holding this hearing on two very important public health bills, and I welcome the bipartisan spirit that brings us together today.

Specifically, I am proud of the bill that you and I introduced together, H.R. 1852, the Children's Hospital Graduate Medical Education Support Reauthorization Act of 2011. The Children's Hospital Graduate Medical Education program is a true success story. As every parent knows, it is so important to have a trusted doctor to turn to when your child gets sick. Since 1999 the Children's Hospital Graduate Medical Education program has helped to make sure that the doctor is there and prepared to diagnose any symptoms our children face.

Today we are still experiencing a shortage of pediatric and specialty physicians in New Jersey and across the country. So you can imagine how disappointed I was to see that the President suspended funding for the GME program in this year's budget.

In 2009 the program supported the training of 5,361 resident positions nationally. When it was first created in the 1990s the program single-handedly reversed the declines in pediatric training programs which threatened the stability of the pediatric workforce. Continuing its critical program, it is certain to have the same major impact on promoting access to primary care and an access to specialty care for children.

The small class of hospitals that receive this funding, which includes the Children's Specialized Hospital in my district in New Brunswick represents about 1 percent of hospitals nationwide but trains approximately 40 percent of all pediatricians. In addition, the funding allows all 56 hospitals in 30 States who participate to enhance hospitals' research capabilities and improve hospitals' ability to provide care to vulnerable and underserved children.

Chairman Pitts, together, along with nearly 100 of our colleagues who are cosponsors, we recognize that this legislation will help keep doctors in the pipeline who are prepared to address the special health care needs of our Nation's children.

Now, today we are also considering the Combating Autism Reauthorization Act of 2011. Autism spectrum disorder affects so many children in the United States, including my State of New Jersey. In fact, CDC has estimated that one in 110 children are classified as having an autism spectrum disorder. In New Jersey that number is more prevalent, affecting one in every 94 children, the highest prevalence in the Nation. Despite the high numbers of cases and the growing focus on this disease, there are still many providers who are unaware of the best methods to diagnose and treat the disorder, and that is why autism awareness is so important.

We must treat autism as a condition of urgent public health concern and raise awareness in education of the disorder. As such, Congress recognized this public health crisis. In 2000 we passed

the Children's Health Act that included specific activities related to autism, such as research at NIH, other developmental disability surveillance and research, and information in education. Those programs have continued to be reauthorized, the last time in 2006, with the acknowledgement that unfortunately the prevalence of autism continues to grow.

And that is why I support H.R. 2005 which reauthorizes these programs until 2014. This critical bill will help educate, promote research, promote early screening and advanced early diagnosis of autism spectrum disorders and other developmental disabilities.

I just wanted to say I know we had a very short weekend, we were only home, I guess, Saturday and Sunday, but interestingly enough, without my constituents knowing that either of these bills were on the agenda today, I actually had people—you know, just regular constituents—who came up to me at various events and mentioned what I was going to do about both of these areas. And I said, well, in fact we are having a hearing Monday. We are going to address both of these problems. So thank you, Chairman Pitts, and thank you again for the bipartisan nature of this.

Mr. PITTS. Thank you.

Mr. PALLONE. Mr. Chairman, could I ask that these letters be admitted to the record—or I ask unanimous consent. I think you have them all. It is the National Association of Children's Hospitals, American Academy of Pediatrics, Association of American Medical Colleges, American Hospital Association and American Medical Association.

Mr. PITTS. Without objection, so ordered.

[The information follows:]

National Association of
Children's Hospitals

Champions for Children's Health



N · A · C · H

May 19, 2011

The Honorable Joe Pitts
Chairman
Subcommittee on Health
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20510

Dear Chairman Pitts,

On behalf of the National Association of Children's Hospitals, thank you for introducing H.R. 1852 to reauthorize the Children's Hospitals Graduate Medical Education program. We appreciate your unwavering resolve as an advocate for children. The future of pediatric health care cannot be compromised, and we are fortunate to have champions who recognize the need to ensure the adequacy of the pediatric workforce for our nation's children.

Your support for CHGME, and the tireless efforts of you and your staff, helps not only Pennsylvania's children and children's hospitals, it also helps to ensure that children throughout the nation can depend on the high-quality care they need and deserve from our children's hospitals. As you well know, the freestanding children's hospitals that receive CHGME train forty percent of all pediatricians, forty-three percent of all pediatric subspecialists, and the majority of pediatric researchers, even though children's hospitals represent only one percent of all hospitals.

We know that Congress faces a challenging agenda this year, and we deeply appreciate the opportunity to work with you to ensure that children's hospitals can continue to train the best and brightest doctors to treat our nation's children. Thank you again for your leadership and support.

Sincerely,

Jim Mandell, MD
Board Chair
National Association of Children's
Hospitals

Lawrence A. McAndrews
President and CEO
National Association of Children's
Hospitals

National Association of
Children's Hospitals

Champions for Children's Health



N • A • C • H

May 19, 2011

The Honorable Frank Pallone Jr.
Ranking Member
Subcommittee on Health
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20510

Dear Ranking Member Pallone,

On behalf of the National Association of Children's Hospitals, thank you for introducing H.R. 1852 to reauthorize the Children's Hospitals Graduate Medical Education program. We appreciate your unwavering resolve as an advocate for children. The future of pediatric health care cannot be compromised, and we are fortunate to have champions who recognize the need to ensure the adequacy of the pediatric workforce for our nation's children.

Your support for CHGME, and the tireless efforts of you and your staff, helps not only New Jersey's children and children's hospitals, it also helps to ensure that children throughout the nation can depend on the high-quality care they need and deserve from our children's hospitals. As you well know, the freestanding children's hospitals that receive CHGME train forty percent of all pediatricians, forty-three percent of all pediatric subspecialists, and the majority of pediatric researchers, even though children's hospitals represent only one percent of all hospitals.

We know that Congress faces a challenging agenda this year, and we deeply appreciate the opportunity to work with you to ensure that children's hospitals can continue to train the best and brightest doctors to treat our nation's children. Thank you again for your leadership and support.

Sincerely,

Jim Mandell, MD
Board Chair
National Association of Children's
Hospitals

Lawrence A. McAndrews
President and CEO
National Association of Children's
Hospitals

May 26, 2011

The Honorable Joe Pitts
Chairman
Subcommittee on Health
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Subcommittee on Health
Committee on Energy and Commerce
United States House of Representatives
Washington, DC 20515

Dear Chairman Pitts and Ranking Member Pallone:

On behalf of organizations dedicated to the health of all children, we write to share our strong support for your bill to reauthorize the Children's Hospital Graduate Medical Education (CHGME) program. As supporters of the CHGME program since its inception, we are proud to continue to support this important effort.

The funding from the CHGME program helps to address an unintended but serious inequity for pediatric workforce and children's hospitals. This program represents significant progress toward Congress' goal of providing a level of federal GME support to the independent children's teaching hospitals comparable to what other hospitals already receive through Medicare. The support CHGME offers is a much-needed investment in the future of pediatric medicine and children's health care.

Independent children's hospitals, with federal CHGME support, have played a key role in ensuring the continued growth of our nation's pediatric workforce, including pediatric subspecialists in short supply. CHGME has afforded children's hospitals the opportunity to sustain and improve their teaching programs, allowing them to expand and reverse a decline in pediatric residencies that began in the 1990s. Representing less than one percent of all hospitals, independent children's teaching hospitals train nearly 30 percent of all pediatricians and nearly half of all pediatric specialists. They also are the major pipeline for future pediatric researchers. Together, CHGME-recipient hospitals have accounted for more than 65 percent of the growth in pediatric specialist training.

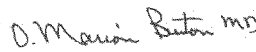
In a year where budget consciousness and fiscal responsibility have taken the spotlight in all policy discussions, we commend you for your continued effort to prioritize child health. Investments in the health of children will pay dividends well into the future.

Thank you for your life-long commitment to the health and wellbeing of children. We look forward to working with you to pass this important piece of legislation.

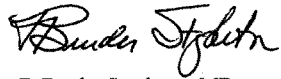
Sincerely,



Benard Dreyer, MD
Academic Pediatric Association
President



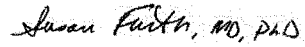
O. Marion Burton, MD, FAAP
American Academy of Pediatrics
President



F. Bruder Stapleton, MD
American Pediatric Society
President



Alan Cohen, MD
Association of Medical School Department Chairs
President



Susan Furth, MD
Society for Pediatric Research
President

cc: The Honorable Mike Burgess
cc: The Honorable Lois Capps



May 24, 2011

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The Honorable Joe Pitts
Chair, Subcommittee on Health
Energy and Commerce Committee
United States House of Representatives
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member, Subcommittee on Health
Energy and Commerce Committee
United States House of Representatives
Washington, DC 20515

The Honorable Robert Casey
United States Senate
Washington, DC 20510

The Honorable Johnny Isakson
United States Senate
Washington, DC 20510

Dear Chairman Pitts, Ranking Member Pallone, Senator Casey, and Senator Isakson:

On behalf of the Association of American Medical Colleges (AAMC), I write to thank you for authoring the *Children's Hospital GME Support Reauthorization Act of 2011* (H.R. 1852/S. 958). The AAMC represents all 134 accredited U.S. medical schools; nearly 400 major teaching hospitals and health systems, including 62 Department of Veterans Affairs' medical centers; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 128,000 faculty members, 75,000 medical students, and 110,000 resident physicians.

As you know, the Health Resources and Services Administration (HRSA)'s Children's Hospitals Graduate Medical Education (CHGME) program provides critical support for freestanding children's hospitals, for the future primary care workforce for our nation's children and for pediatric specialty care -- the greatest workforce shortage in children's health care. CHGME hospitals train 40 percent of all pediatricians (mostly in general pediatrics), 43 percent of pediatric specialists, and the majority of pediatric researchers. They also provide required pediatric rotations for residents in general internal medicine and family medicine.

Your leadership on this legislation will enable the program to continue to support these activities at institutions across the country. As the nation's supply of physicians shrinks and demand continues to grow, support for physician education and training will be essential to ensure patient access to care. Thank you again for championing this measure and for your commitment to education and training opportunities for the next generation of physicians. We look forward to working with you toward enactment and full funding for this critical program.

Sincerely,

A handwritten signature in black ink, appearing to read 'Atul Grover'.

Atul Grover, M.D., Ph.D.
AAMC Chief Advocacy Officer



Liberty Place, Suite 700
325 Seventh Street, NW
Washington, DC 20004-2802
(202) 638-1100 Phone
www.aha.org

July 8, 2011

The Honorable Joe Pitts
Chairman, Subcommittee on Health
Energy and Commerce Committee
United States House of Representatives
420 Cannon House Office Building
Washington, DC 20515

Dear Chairman Pitts:

On behalf of our more than 5,000 member hospitals, health systems and other health care organizations, and our 42,000 individual members, the American Hospital Association (AHA) wishes to express support for the *Children's Hospital GME Support Reauthorization Act of 2011* (H.R. 1852), which would reauthorize the Children's Hospitals Graduate Medical Education (CHGME) program at its current funding level for the next five years.

Congress created CHGME in 1999 to support graduate medical education programs at children's hospitals that train resident physicians, enhance research capabilities and care for poor and medically underserved children in rural and inner-city areas. The program provides funding to independent children's hospitals in more than 30 states to train primary care pediatricians. Children's hospitals treat very few Medicare patients; therefore, they do not receive Medicare funding to support medical training of residents. The CHGME program corrects this inequity. CHGME helps independent children's hospitals train more than 40 percent of general pediatricians, 43 percent of all pediatric specialists and the majority of pediatric researchers.

In the face of a nationwide physician shortage and in anticipation of the increased health care coverage provided under the *Patient Protection and Affordable Care Act*, the need for pediatricians is greater than ever. The AHA was dismayed that President Obama's fiscal year 2012 budget proposes to terminate CHGME. Eliminating the program will be detrimental to the mutual goals of strengthening the primary care workforce and ensuring timely access to critical, high-quality specialty care.

We appreciate your leadership on this issue and look forward to working with you to advance this legislation.

Sincerely,

Rick Pollack
Executive Vice President





Liberty Place, Suite 700
325 Seventh Street, NW
Washington, DC 20004-2802
(202) 638-1100 Phone
www.aha.org

July 8, 2011

The Honorable Frank Pallone, Jr.
Ranking Member, Subcommittee on Health
Energy and Commerce Committee
United States House of Representatives
237 Cannon House Office Building
Washington, DC 20515

Dear Congressman Pallone:

On behalf of our more than 5,000 member hospitals, health systems and other health care organizations, and our 42,000 individual members, the American Hospital Association (AHA) wishes to express support for the *Children's Hospital GME Support Reauthorization Act of 2011* (H.R. 1852), which would reauthorize the Children's Hospitals Graduate Medical Education (CHGME) program at its current funding level for the next five years.

Congress created CHGME in 1999 to support graduate medical education programs at children's hospitals that train resident physicians, enhance research capabilities and care for poor and medically underserved children in rural and inner-city areas. The program provides funding to independent children's hospitals in more than 30 states to train primary care pediatricians. Children's hospitals treat very few Medicare patients; therefore, they do not receive Medicare funding to support medical training of residents. The CHGME program corrects this inequity. CHGME helps independent children's hospitals train more than 40 percent of general pediatricians, 43 percent of all pediatric specialists and the majority of pediatric researchers.

In the face of a nationwide physician shortage and in anticipation of the increased health care coverage provided under the *Patient Protection and Affordable Care Act*, the need for pediatricians is greater than ever. The AHA was dismayed that President Obama's fiscal year 2012 budget proposes to terminate CHGME. Eliminating the program will be detrimental to the mutual goals of strengthening the primary care workforce and ensuring timely access to critical, high-quality specialty care.

We appreciate your leadership on this issue and look forward to working with you to advance this legislation.

Sincerely,

Rick Pollack
Executive Vice President





James L. Madara, MD
Executive Vice President, CEO

American Medical Association
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July 11, 2011

The Honorable Joseph Pitts
Chairman, Subcommittee on Health
U.S. House of Representatives
420 Cannon House Office Building
Washington, DC 20515

Frank Pallone, Jr.
Ranking Member, Subcommittee on Health
U.S. House of Representatives
237 Cannon House Office Building
Washington, DC 20515

Dear Chairman Pitts and Ranking Member Pallone:

On behalf of the physician and medical student members of the American Medical Association (AMA), I am writing in support of H.R. 1852, the "Children's Hospital GME Support Reauthorization Act of 2011," which would reauthorize federal funding to support graduate medical education (GME) for freestanding children's hospitals.

Leading authorities agree that by 2025 the United States will face a shortage of physicians to meet the needs of our U.S. population. While demand for access to physician services will be increasing, physician shortfalls up to 130,000 across all specialties are predicted. Pediatric subspecialists who train at children's hospitals are among the more than 20 specialty groups already experiencing severe shortages.

Furthermore, the Balanced Budget Act of 1997 capped the number of resident physicians each teaching hospital could claim for reimbursement under Medicare. While new U.S. allopathic and osteopathic medical schools are opening and many medical schools are expanding enrollments, core GME training programs are experiencing minimal growth due to limited funding.

Several important workforce programs, including Title VII and the Children's Hospitals GME program, rely on appropriations to fund the training of physicians. This important legislation would authorize the necessary funding to support this vital training program for pediatricians and pediatric subspecialists in children's hospitals.

Thank you for your support of residency programs that are critical for addressing our nation's physician workforce shortages. We look forward to working with you to see this program reauthorized and fully funded.

Sincerely,

James L. Madara, MD

Mr. PALLONE. Thank you.

Mr. PITTS. Thank you, Mr. Pallone. And at this time I yield 5 minutes to the vice chairman of the subcommittee, Dr. Burgess, for his opening statement.

**OPENING STATEMENT OF HON. MICHAEL C. BURGESS, A
REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

Mr. BURGESS. I thank the chairman for yielding. I thank you for holding the hearing on these two important reauthorizations.

Let me focus my time on H.R. 1852, the Children's Hospital Graduate Medical Education Support Reauthorization Act of 2011. I am grateful to have had the chance to help author and serve as a cosponsor of the Children's Hospital GME Support Reauthorization Act of 2011 with Chairman Pitts, Ranking Member Pallone, and Mrs. Capps.

In the decade since the program was first fully funded, it has proved to be a significant success. Graduate medical education levels the playing fields between adult and children's hospitals in regards to the training programs and provides a dedicated source of funding to train future doctors in cutting-edge pediatrics. According to the American Academy for Pediatrics, for most subspecialties there are, on average, 100,000 and 200,000 children per provider across hospital regions. There are only about 28,000 pediatric medical subspecialists and surgical specialists to care for over 80 million children in the United States.

Prior to the Children's Hospital GME enactment, the number of residents in Children's Hospitals' residence programs had declined by over 13 percent, but the passage of this bill has enabled, and the appropriate funding has enabled the Children's Hospitals to reverse this decline and increase their training by 35 percent.

Texas has an even greater need of more pediatricians and pediatric subspecialists. Texas currently has 60 pediatricians per 100,000 children, well below the national average of just under 90. But Children's Graduate Medical Education has helped close that gap through Texas Children's Hospitals. For example, Children's Medical Center Dallas is one example of a premier hospital whose mission has been greatly enhanced by the Children's Hospital Graduate Medical Education and has found that over 68 percent of the residents they train go on to practice within a 100-mile radius of the training facility.

Of course I am reminded that just a few years ago, probably 8 years ago in 2003, Children's Hospital in Dallas had that stunning success where they separated the two little Egyptian twins who had been born conjoined. And I saw a special on NPR a few nights ago about how their progress has continued now that they are back in their native country. But what an incredible day that was through that lengthy operation. It required the building of a special operating table, it involved all departments within the hospital. They all came together and worked diligently to save these two little boys. And it was an incredible story that was told in 2003 and still chokes you up when you see it many years later. But Children's adds a priceless asset to the region, and access to specialists and subspecialists across the north Texas area.

So I am grateful that our witnesses are here with us today. I am looking forward to hearing their testimony and how these programs are administered and how these reauthorizations will continue the great work that has already commenced.

Mr. Chairman, I would be happy to yield the balance of my time to anyone on our side who would seek recognition. If not, I will yield back.

Mr. PITTS. The chair thanks the gentleman.

We will proceed with the testimony at this time. I thank the witnesses for agreeing to appear before the committee. The first witness is Dr. Janet Heinrich. She is the Associate Administrator of the Bureau of Health Professions at the Health Resources and Services Administration. This is the entity that oversees the Children's Hospital Graduate Medical Education program.

Our second witness is Dr. Thomas Insel, the Director of the National Institute of Mental Health at the National Institutes of Health and the chair of the Interagency Autism Coordinating Committee.

Your written testimony will be made part of the official record. We ask that you summarize your opening statement in 5 minutes.

STATEMENTS OF JANET HEINRICH, ASSOCIATE ADMINISTRATOR, BUREAU OF HEALTH PROFESSIONS, HEALTH RESOURCES AND SERVICES ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND THOMAS INSEL, DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH, NATIONAL INSTITUTES OF HEALTH

Mr. PITTS. Dr. Heinrich, you may begin your prepared testimony.

STATEMENT OF JANET HEINRICH

Ms. HEINRICH. Chairman Pitts, Ranking Member Pallone and members of the subcommittee, thank you for the opportunity to testify today on H.R. 1852, the Children's Hospital GME Support Reauthorization Act of 2011. I am Jan Heinrich, Associate Administrator of the Bureau of Health Professions at the Health Resources and Services Administration. We appreciate your interest in our work and welcome the opportunity to discuss the Children's Hospital GME program with you.

First I would like to give you an overview of HRSA and give you an idea of our vision and mission. HRSA helps the most vulnerable Americans receive quality primary health care without regard to their ability to pay. The agency works to expand access to health care for millions of Americans—the uninsured, the underinsured and the vulnerable. HRSA recognizes that people need to have access to primary care, and through its programs and activities the agency seeks to meet these needs.

In addition to helping the most vulnerable Americans receive quality care, we also serve as a source of support for the Nation's health profession's education and training infrastructure through our work with medical schools, nursing schools, residency training programs and community-based training organizations. Our programs fund the full spectrum of training programs, from pipeline programs aimed at youth, hoping to interest them in health professions; to support for students and residents in health professions

training; to ongoing investments in the continuing education needed to maintain the workforce skills in a changing health care environment.

We also support the infrastructure for quality health professions training, including faculty development, innovations in training, curriculum changes and the development of community-based clinical training sites to expose students to the diverse needs of our communities. HRSA programs demonstrate our commitment to ensuring that the Nation has the right practitioners with the right skills working where they are needed most.

The focus of today's hearing is the children's GME payment program, and I would like to provide an overview for you. The CHGME Payment Program is authorized by section 340(e) of the Public Health Service Act through fiscal year 2011, as was stated, and is administered by the Bureau of Health Professions. The program provides Federal funding to the Nation's Children's Hospital to help them maintain the Graduate Medical Education programs that train resident physicians.

Since its implementation in 2000, CHGME has provided more than \$2.5 billion to children's hospitals to support residency training for general pediatrics, pediatric medical and surgical subspecialists, as well as pediatric experiences for adult medical and surgical specialists in other fields, as well as dentists. The CHGME funding is determined by annual appropriations. The size of the appropriation, the number of participating hospitals and the number of residents trained each year impact the amount of resources each participating children's hospital will receive from the program. Funds are distributed among eligible institutions based on statutory formulas that reflect direct and indirect Graduate Medical Education expenses. Payments are made to participating children's hospitals on a monthly basis. Much of what we know about the Children's Hospital Payment Program comes from annual reports to HRSA that participating children's hospitals are required by current law to submit.

Let me give you some basic statistics. In fiscal year 2010 the program supported 56 children's hospitals located in 29 States and Puerto Rico which were responsible for the training of about 5,800 FTE residents. To determine the CHGME support, a participating Children's Hospital may include in its calculation of full-time equivalent residents both its full-time residents and the portion of time associated with residents who rotate through the hospital.

In fiscal year 2010 the average award through the program was \$5.4 million. It is important, though, to help you understand that there is a wide range in the amounts that each hospital receives. That range is between \$21,000 to about \$22 million in a couple of facilities. This variation, again in dollars, is due to the variation in the size of the residency training program and the number of residents. The estimated overall average award per resident FTE is about \$71,000. In fiscal year 2011, \$268 million was appropriated for the CHGME program.

And, Mr. Chairman, I am happy to answer any questions.

Mr. PITTS. Thank you Dr. Heinrich.

[The prepared statement of Ms. Heinrich follows:]



Statement of

Janet Heinrich, Dr.P.H., R.N.

**Associate Administrator
Bureau of Health Professions**

**Health Resources and Services Administration
U.S. Department of Health and Human Services**

**Before the
Committee on Energy and Commerce,
Subcommittee on Health
U.S. House of Representatives**

**Washington, D.C.
July 11, 2011**

Chairman Pitts, Ranking Member Pallone, and Members of the Subcommittee, thank you for the opportunity to testify today on H.R. 1852, the Children's Hospital GME Support Reauthorization Act of 2011. I am Dr. Janet Heinrich, Associate Administrator of the Bureau of Health Professions at the Health Resources and Services Administration (HRSA), Department of Health and Human Services. HRSA appreciates your interest in our work, and welcomes the opportunity to discuss the Children's Hospital Graduate Medical Education (CHGME) program with you.

HRSA Overview

The Health Resources and Services Administration helps the most vulnerable Americans receive quality primary health care, without regard to their ability to pay. HRSA works to expand access to health care for millions of Americans—the uninsured, the underserved and the vulnerable. HRSA recognizes that people need to have access to primary health care and, through its programs and activities, the Agency seeks to meet these needs. The Agency collaborates with government at the Federal, State, and local levels, and also with community-based organizations, to seek solutions to primary health care problems. HRSA delivers on its obligation to address primary care access through the six Bureaus and thirteen Offices that comprise the Agency.

In addition to helping the most vulnerable Americans receive quality care, we also serve as a major source of support for the nation's health professions education and training infrastructure through our work with medical schools, nursing schools, residency training programs and community-based training organizations.

In all of these efforts, we collaborate with colleagues across the Federal government and with State and local governments, community-based organizations, health care providers and institutions, and a range of other partners. HRSA helps to train future nurses, doctors, and other clinicians, placing them in areas of the country where health resources are scarce. In fact, HRSA provides leadership and financial support to health care providers in every State and U.S. territory.

HRSA's Vision, Mission and Goals

HRSA's vision for the nation is healthy communities and healthy people. Our mission is to improve health and achieve health equity through access to quality services and a skilled health workforce.

We carry out our mission by working toward four major goals:

- Improve Access to Quality Care and Services;
- Strengthen the Health Workforce;
- Build Healthy Communities; and
- Improve Health Equity.

We are pleased to have the opportunity to share with you today some of the activities associated with our goal of strengthening the health workforce.

HRSA's Bureau of Health Professions

As the Associate Administrator of HRSA's Bureau of Health Professions, I have the opportunity to direct a range of programs designed to educate and train health professionals, including physicians, nurses, physician assistants, dentists, public health professionals, geriatric specialists, psychologists, home health aides and others.

Our programs fund the full training continuum -- from pipeline programs aimed at developing young people's skills and interest in health professions; to support for students and residents in health professions training; to ongoing investments in the continuing education needed to maintain the workforce's skills in a changing health care environment.

We also support the important infrastructure needed to ensure the quality of health professions training, including faculty development, innovations in training curricula and the development of community-based clinical training sites to expose residents and students to community needs. Throughout these programs, we aim to continuously demonstrate our commitment to ensuring that the nation has the right practitioners, with the right skills, working where they are needed.

Bureau priorities to help achieve this goal include the following:

- Increase the capacity and distribution of the primary care workforce supply through education and training opportunities;
- Develop new team-based models of care based on interprofessional education and clinical training experiences;
- Reduce health disparities by training the health workforce to provide culturally- and linguistically- appropriate care, as well as increasing workforce diversity;
- Assure the health workforce is trained to provide high quality, culturally and linguistically appropriate care;
- Enhance geriatric/elder care training and expertise; and
- Improve workforce data collection and analysis to better inform decision-making on the health workforce.

Children's Hospital Graduate Medical Education (CHGME) Payment Program

The CHGME Payment Program is authorized by Section 340E of the Public Health Service Act through Fiscal Year 2011 and is administered by HRSA's Bureau of Health Professions.

The program provides Federal funds to the Nation's children's hospitals with graduate medical education programs that train resident physicians. CHGME funding is determined by annual appropriations.

The CHGME Payment Program was originally authorized by Congress in 1999 and subsequently reauthorized in 2006. Since its implementation began in 2000, it has allocated more than \$2.5 billion dollars to children's hospitals that support residency training. Children's hospitals supported through the program train general pediatricians, pediatric medical subspecialists, pediatric surgical subspecialists, adult medical subspecialists, adult surgical subspecialists, and dentists.

Determining Payments

The size of the annual appropriation, the number of participating hospitals and the number of residents trained each year impact the amount of resources each participating children's hospital receives from the program each year.

Family and internal medicine residents also do rotations in Children's Hospitals to increase their exposure to pediatric practice environments. A participating children's hospital may include both its full-time residents and the portion of time associated with residents who rotate through the hospital in its calculation of FTE residents – or full-time equivalent residents – to determine CHGME support.

Funds are distributed among eligible institutions based on a formula outlined in statute that takes into account the number of residents trained in the hospital, the number of hospital beds, the number of patients discharged, and the hospital's case-mix. Approximately one third of the CHGME payment is for direct graduate medical expenses and two thirds are for indirect graduate medical expenses.

Monthly payments are made to participating children's hospitals. Hospitals are audited, as required by law, to validate the number of FTE residents claimed. Once final payments are reconciled at the end of each fiscal year, HRSA displays payments per hospital for the fiscal year in a table posted on our Web site.

Participating children's hospitals are required to submit an annual report on the status of and changes to graduate medical education training in their institutions.

Residents and Awards

In Fiscal Year 2010, the program supported 56 children's hospitals located in 29 states and Puerto Rico, which were responsible for the training of about 5,800 full time equivalent – or FTE – residents on- and off-site.

In Fiscal Year 2010, the average award through the program was \$5.4 million. Data indicate that awards ranged in size from \$21,000 to \$21.7 million. The estimated overall average award per-resident FTE is about \$71,000. In Fiscal Year 2011, \$268 million was appropriated for the CHGME Payment Program.

Conclusion

H.R. 1852, the "Children's Hospital GME Support Reauthorization Act of 2011", would amend current law to extend the CHGME program through fiscal year 2016, and would also make a conforming date change regarding when the report to Congress is due. The Department has no technical comments on the bill as written.

Thank you for the opportunity to provide an overview of the CHGME Payment Program as Congress considers reauthorizing the program.

Mr. PITTS. Dr. Insel, you are recognized for 5 minutes for your opening statement.

STATEMENT OF THOMAS INSEL

Mr. INSEL. Thank you. Good afternoon, Chairman Pitts and Ranking Member Pallone, members of the committee. I am Tom Insel. I am the Director of the National Institute of Mental Health at the NIH, and I have served as the Chair of the Interagency Autism Coordinating Committee, which I will call the IACC, which was originally created by the Children's Health Act of 2000 and then reestablished by the Combating Autism Act of 2006. I have been Chair since my arrival at NIH in 2002, so I have been doing this for quite a few years.

First I would like to express my appreciation for the opportunity to give you some background on how the existing act has facilitated unprecedented collaboration between Federal agencies and private organizations, enabling what I think is really amazing progress in the field of autism research and serving to sharpen our focus as well on the need for better services for people with autism and for their families.

At NIH we are very grateful for the strong support that you in Congress have always shown for us and the thousands of researchers around the country that we support. And as Chair of the IACC, I also would like to express the gratitude of all the Federal agencies—and there are many that are members of the committee—for your continued interests and encouragement.

The Combating Autism Act, which I will call the CAA, had five general provisions: centers of excellence; surveillance; education for early detection and intervention; the IACC, that is, this coordinating committee; and then a section on authorization for funding.

The 11 autism centers of excellence, the surveillance efforts at the CDC, the programs for early detection and intervention and funding for all of these programs is authorized to continue with or without reauthorization of the Combating Autism Act. The one provision that requires reauthorization to continue is this IACC, this coordinating committee. And that is scheduled to sunset on September 30, 2011. That is basically precisely what it says within the act.

For this reason let me just focus for a few moments on this coordinating committee and what it has accomplished. I will be happy to take questions from you later about other provisions if you have interest in any of them.

A word about autism for those of you who aren't close to this area, although I appreciate the comments from Mr. Pallone that most people are hearing more about autism than they might have ever imagined. Autism is now called autism spectrum disorder, meaning that it is a diverse collection of disorders that share in common impairments in verbal and nonverbal communication skills and social interactions, as well as, restricted, repetitive and sometimes stereotype patterns of behavior.

By definition the disorder starts by age three. The degree and specific combination of impairments can vary from one individual to the next, creating a heterogeneous disorder that can range in

impact from actually quite mild to severely and significantly disabling.

Two decades ago, Dr. Burgess, when you were in medical school and I was in medical school, we probably didn't hear much about it, but at this point we are amazed by how frequent we are seeing autism in clinics, particularly in pediatric clinics, in neuropsychiatric clinics, where the CDC's latest prevalence estimates are 1 in 110 children, that is 1 in 70 boys, that is amongst the 8-year-old cohort today being diagnosed with autism spectrum disorder. And it is therefore that the disorder has become an urgent national health priority.

In 2006 Congress passed the Combating Autism Act to strengthen Federal coordination around this issue and to enhance public-private collaborations in order to accelerate research to improve the lives of people with ASD and their families.

The CAA, the act itself, outlines the membership of this committee. This IACC includes both representatives of Federal agencies and public members representing a diverse set of stakeholder groups within the community. Currently the IACC includes two people with autism spectrum disorder, several parents of children and adults with ASD, members of advocacy research and service provider communities, and officials from several Federal agencies.

There are actually six parts of the Department of Health and Human Services: Department of Education, and, in addition to that, five NIH institute directors, as well as Francis Collins, the Director of the NIH, who also serves on this committee. You can imagine the challenge of trying to chair such a committee, but it has actually been quite inspiring to have this group of people around the table.

The major autism research and service organizations represented on this committee include Autism Science Foundation, Autistic Self-Advocacy Network, Autism Speaks, Safe Minds, the Simons Foundation, the Southwest Autism Research and Resource Center, and the UC Davis MIND Institute. So it is a very diverse, very experienced, and I think very committed group.

In addition to the voices and perspectives added by the members of the IACC, the committee has fostered public participation by having public comment periods at every full meeting, regularly inviting written public comments, conducting formal requests for information from the public and holding town hall meetings. And it has provided a high level of transparency for the public by actively disseminating information about the IACC activities via email, the IACC Web site, Webcasts and even Twitter. By including both Federal and public members on the committee and by fostering public engagement through a variety of means, the IACC ensures that a diversity of ideas and perspectives on ASD are brought to the table to inform the activities and recommendations of the committee. This is a committed group, by all measures; while the law only requires the committee to meet twice a year, since 2007 the committee has met around 16 times per year, including full committee and subcommittee meetings, workshops and town hall meetings, the most recent of which was a subcommittee meeting this morning at 8:00 a.m. So this is a very, very active group.

I think given the time and the number of questions I hope you will have, I am not going to go into a great deal of detail about some of the research and some of the efforts that this committee has accomplished. There is actually quite a bit we could talk about. All of this is in the written testimony, and I would just steer you towards that.

Let me say that looking back over the past 5 years since the passage of the act, I think that this committee has really served to focus efforts across the Federal Government, bringing these Federal agency representatives for research services and education, bringing parents, people with ASD, scientists, clinicians and others together to work as a team to address the issues that face everyone, and bringing a wide variety of expertise to what is really a difficult and, I must say, evolving area. In doing so it has produced a strategic plan to guide and focus Federal research efforts and to catalyze public-private partnerships.

And hopefully at this time we can talk a bit about what some of those are, while also providing a forum for public discussion and identification of additional needs from the community. And those needs continue to emerge and have been something that the committee has continued to adapt to. I think we have seen some remarkable progress in the identification of how common ASD is within communities, how ASD develops, how we can detect it at increasingly earlier ages, and what types of interventions, most importantly, the interventions that are most effective, especially in very young children.

The research is moving rapidly towards translation into practical tools that can be used in the clinic and community settings to change outcomes for people with ASD. In this time span, Federal agencies have coordinated efforts to enhance critical service programs, identify best practices to support the education, health, and employment needs of people on the spectrum, and to develop new mechanisms and strategies to enable broad access to health care services and supports, all leading towards improvement in the quality of life for people with ASD.

Mr. PITTS. All right. If you can wrap up.

Mr. INSEL. I will. The CAA established the IACC to provide advice to the Secretary of HHS regarding matters related to ASD to create a forum where the public could be actively involved in the process and to develop a strategy to guide national research efforts. While there has been unequivocal progress, much work remains to be done. The reauthorization will be critical for continuing this momentum and the stability over the IACC over the next 3 years.

I look forward to your questions. Thank you.

Mr. PITTS. OK. Thank you, Doctor.

[The prepared statement of Mr. Insel follows:]



TESTIMONY OF DR. THOMAS INSEL
DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH
NATIONAL INSTITUTES OF HEALTH

ON

THE COMBATING AUSTIM ACT

BEFORE THE

COMMITTEE ON ENERGY AND COMMERCE
US HOUSE OF REPRESENTATIVES

Good morning Chairman Pitts, Ranking Member Pallone and members of the Committee. I am Tom Insel, Director of the National Institute of Mental Health (NIMH) at the National Institutes of Health (NIH). I have served as the Chair of the Interagency Autism Coordinating Committee (IACC), created by the Children's Health Act of 2000 and re-established by the Combating Autism Act of 2006 (CAA), since my arrival at NIMH in 2002.

First, let me express my sincere appreciation for the opportunity to give you some background on how the existing CAA has facilitated unprecedented collaboration between federal agencies and private organizations, enabling amazing progress in the field of autism research and serving to sharpen our focus on the need for better services for people with autism and their families. We at NIH are very grateful for the strong support that you in Congress have always shown for NIH and the thousands of researchers around the country that it funds. As chair of the IACC, I'd like to express the gratitude of all the federal agencies that are members for your continued interest and encouragement.

The CAA dealt with five general provisions: centers of excellence, surveillance, education for early detection and intervention, the IACC, and authorization of funding. The 11 Autism Centers of Excellence, surveillance efforts at the Centers for Disease Control and Prevention (CDC), programs for early detection and intervention, and funding for all of these programs is authorized to continue with or without reauthorization of the CAA. The one provision that requires reauthorization to continue is the IACC, which is scheduled to sunset on September 30, 2011. For this reason, I will focus my remarks today on the IACC, but I welcome your questions about other provisions of the CAA.

In order to give you the most comprehensive yet concise background, I'll briefly describe the IACC, its membership, its transparent process, its collaborative activities, the influential Strategic Plans that it has developed, and its various areas of intense interest. In short, this description will let you know that the IACC has fulfilled each and every requirement of the CAA. It has provided both an important forum for public discussion of autism issues and a framework for a research agenda that is optimized to take full advantage of scientific

opportunities. As time permits, I also hope to share some examples of the very recent research advances that are so exciting in this field, and how these advances have been facilitated by the existence of the Strategic Plans developed by the IACC with considerable public input. Finally, I'll discuss how the IACC has focused on the need to enhance services for people with autism.

Autism spectrum disorder (ASD) is a diverse collection of disorders that share in common impairments in verbal and nonverbal communication skills and social interactions, as well as restricted, repetitive, and stereotyped patterns of behavior. The degree and specific combination of impairments can vary from one individual to the next, creating a heterogeneous disorder that can range in impact from mild to significantly disabling. Two decades ago, ASD was considered a rare disorder. Today, with CDC's latest prevalence estimates of 1 in 110 children in the U.S. being diagnosed with ASD, this disorder has become an urgent national health priority. In 2006, Congress passed the CAA to strengthen federal coordination around this issue and, to enhance public-private collaborations in order to accelerate research to improve the lives of people with ASD and their families.

The CAA outlines the membership of the IACC, which includes both representatives of federal agencies and public members representing a diverse set of stakeholder groups within the autism community. Currently, the IACC includes two people with ASD, several parents of children and adults with ASD, members of the advocacy, research, and service provider communities, and officials from the following federal agencies and offices that are involved in ASD research or services provision: Department of Education (ED), HHS's CDC, Centers for Medicare & Medicaid Services (CMS), Office on Disability (OD), Substance Abuse and Mental Health Services Administration (SAMHSA), Administration on Developmental Disabilities (ADD) in the Administration for Children and Families (ACF), Health Resources and Services Administration (HRSA), five institutes of NIH, and the NIH Director. Major autism research and services organizations represented on the IACC include Autism Science Foundation, Autistic Self Advocacy Network, Autism Speaks, SafeMinds, Simons Foundation, Southwest Autism Research & Resource Center, and the U.C. Davis M.I.N.D Institute.

In addition to the voices and perspectives added by the members of the IACC, the IACC has fostered public participation by having public comment periods at every full IACC meeting, regularly inviting written public comment, conducting formal requests for information from the public and holding town hall meetings, and has provided a high level of transparency for the public by actively disseminating information about IACC activities via e-mail, the IACC website, webcasts and even Twitter. By including both federal and public members on the committee, and by fostering public engagement through a variety of means, the IACC ensures that a diversity of ideas and perspectives on ASD are brought to the table to inform the IACC's activities and recommendations. The IACC is a committed group—while the law only requires the committee to meet twice a year, since 2007, the committee has met around 16 times per year, including full committee and subcommittee meetings, workshops and town hall meetings.

Under the CAA, the IACC is charged with developing and annually updating a strategic plan for ASD research. In fulfilling these requirements, the committee produced its first strategic plan in January 2009 and has issued updates in 2010 and 2011. The IACC developed its Strategic Plan with a great deal of input from the public, gathered through planning meetings, town hall meetings, and requests for information. This tremendous public input, combined with that of scientific and subject matter experts and all the major federal agencies and private funders resulted in a plan that provided a clear path to move autism research forward in targeted, innovative ways to help public and private agencies prioritize activities as soon as it was released. The first IACC Strategic Plan was organized into six chapters that reflect the needs expressed by the community: early and accurate diagnosis, better understanding how autism develops, enhanced ability to identify risk factors, development of new and more effective interventions and treatments, more research needed to inform and enhance services, and the development of better approaches to meet the changing needs of people with ASD over the entire lifespan. In 2010, the committee also added a chapter on the infrastructure needed to support a robust research effort. As you can tell, our strategic plan has a broad scope, in part because it was developed through the cooperation of both research and services-focused agencies and private organizations. While the Plan is a research plan, as the law directs, it encompasses a range of research that goes from fundamental biology of ASD to inform new diagnostics and

therapies, to the actual development of those needed tools and approaches, and finally to research that can inform and enhance services programs to meet the needs of people with autism across the lifespan.

Fortuitously, the first strategic plan was completed just as NIH received significant additional funding from the American Recovery and Reinvestment Act to help stimulate the economy through the support and advancement of scientific research. With a strategic plan in place to guide priorities, NIH allocated over \$122 million of additional funding between FY09 (\$64 million) and FY10 (\$58 million) to autism research, supporting a variety of projects addressing the most critical research needs highlighted by the IACC. This was in addition to NIH's investment of base annually appropriated funds for autism research, which was \$160 million in 2010. The overall NIH investment in autism research was an unprecedented \$218 million in 2010, more than double the funding prior to the CAA.

The IACC has also fulfilled the CAA requirements to produce an annual summary of advances in research and to monitor federal research activities. Since 2007, the IACC has issued four Summary of Advances documents, which describe what the committee felt were some of the most exciting advances in autism biomedical and services research each year. The IACC has also been actively monitoring not only federally-funded research, as the CAA requires, but has also tracked the research funded through private organizations, making for a much more complete picture of the research landscape across the U.S. All of the private organizations on the IACC that conduct research provided their data, and we have also collected data from all U.S. federal agencies and additional private groups. The result has been the IACC's annual "portfolio analysis." The first year, the data were presented at IACC meetings, but in subsequent years the IACC issued full reports on fiscal years 2008 and 2009 funding; the analysis of 2010 data is currently underway. These portfolio analysis reports have provided the first comprehensive look at autism research being conducted in the U.S. They also have facilitated a better understanding of how current research aligns with the IACC Strategic Plan. The committee has found both the summary of advances and portfolio analysis reports to be valuable tools for updating the Strategic Research Plan and determining the greatest areas of need for further action.

This year, the HHS/NIH office that supports the IACC, the Office of Autism Research Coordination (OARC), published a comprehensive Report to Congress, as required in the CAA, on federal activities that have taken place since the passage of the CAA. That report contains rich information about the programs and projects going on across HHS and the ED to meet the needs of people with autism. I urge you to take a look at this report because it provides the most comprehensive picture to date of how federal agencies are responding to the urgent needs of the autism community. The report contains details of the wide array of autism research, services and supports activities conducted by federal agencies, including biomedical and services research, public health activities, education initiatives, early screening, diagnosis and intervention services, provider training, healthcare delivery, social supports, and vocational training. We have copies of this and the other most recent reports mentioned with us and will be happy to give you copies.

Now I'd like to share with you some of the exciting advances we have seen in ASD research. Since the passage of the CAA in 2006, there has been a groundswell of activity on multiple fronts, from game-changing scientific discoveries reshaping the field of autism research to real-world applications that can help people with ASD and their families now.

As I mentioned earlier, one of the main provisions of the CAA was support for early diagnosis and intervention. CDC reports that the median age for autism diagnosis is 4 and half years of age and varies widely by sociodemographic group and geographic location. With recent advances, diagnosis by age 14 months is now a realistic possibility, and researchers are actively pushing the detection window to even younger ages. In April 2011, NIH-funded researchers demonstrated that a simple, low-cost, practical screening tool that takes only five minutes to administer can be implemented by doctors' offices to detect ASD around one year of age for many children. More than 100 pediatricians in San Diego County, CA participated and screened over 10,000 one year old children using the checklists. Impressively, all pediatricians who participated in the study are continuing to use the tool because they recognized the tremendous potential it provides to identify autism earlier and direct families toward interventions that can result in significant positive outcomes earlier in life. Another promising diagnostic tool is a

simple test that detects eye gaze patterns specific to infants with autism. A group of researchers at University of California, San Diego who have received funding from NIH to develop such a test recently reported that they could identify 1-3 year old children with autism with nearly 100 percent specificity. These promising diagnostic tools, combined with CDC's health education campaign, "Learn the Signs. Act Early.", to improve early identification, provide great potential for reducing the age of diagnosis and allowing children and their families to get the services and support they need when it can help the most.

Of course, early diagnosis is only valuable if effective interventions are available. Recently published results from several successful trials of early interventions have validated approaches that are effective in young children, creating real promise of improved health outcomes, and quality of life for children with ASD. In 2010, NIH investigators reported that children with ASD who receive a high intensity behavioral intervention starting by age 18-30 months show improvements in IQ, language, and adaptive behavior, to the point where the autism diagnosis no longer applies to some children who receive treatment. Soon after that groundbreaking study, a group of investigators jointly funded by HRSA and NIH reported that an intervention designed to enhance social engagement in toddlers indeed improved social, language, and cognitive outcomes. Early interventionists have noted an encouraging "problem" – new approaches that are being proven effective are being taken up so quickly by the community that it is difficult to find "control groups" for behavioral intervention trials. While this can complicate efforts to conduct randomized control trials, the real story is that parents and community practitioners are putting innovative strategies into practice quickly. Many of these recent advances in early diagnosis and intervention can be credited to NIH's Autism Centers of Excellence (ACE), which were expanded under the CAA and now comprise 11 research centers at major research institutions across the country.

We do not know the causes of ASD, but very recent findings comparing identical and fraternal twins suggest the importance of focusing on both environmental and genetics factors. NIH and CDC are continuing to strengthen research investigations into possible environmental causes of autism, establishing expansive research networks with the capability to collect large sets of data

on environmental exposures and health outcomes, and to conduct powerful analyses to determine which risk factors may be contributing to the development of autism. Population-based studies are the gold standard in epidemiology research. Large sample sizes and rigorous study designs allow researchers to examine many variables at once. Such networks, like NIH's Childhood Autism Risks from Genetics and the Environment (CHARGE) and Early Autism Risk Longitudinal Investigation (EARLI) and CDC's Study to Explore Early Development (SEED), will utilize data from medical records, interviews, questionnaires, developmental assessments, and physical exams to explore a host of possible risk factors, focusing heavily on factors in the environment before, during, and after pregnancy. It will take a few more years for these research networks to fully mature, but already, published findings are helping establish the evidence-base for ruling in and ruling out possible environmental triggers. In the first half of 2011 alone, the CHARGE study has implicated air pollution, mitochondrial dysfunction, and immune dysfunction as potential mechanisms for ASD. Just this month, CHARGE investigators reported that use of prenatal vitamins may reduce the risk of having children with autism. In the past week, another study, funded by CDC and a private group, showed that widely-used antidepressant medications taken during pregnancy can significantly raise the risk of having children with autism. In addition to their work on identifying risk factors for ASD, CDC also continues to provide the most comprehensive estimates to date of the prevalence of ASD in multiple areas of the U.S. through its Autism and Developmental Disabilities Monitoring (ADDM) Network. While great progress is being made for autism, CDC's prevalence estimates have documented significant increases in autism in the US, which highlights the need to continue research efforts and service advances being made with facilitation by the IACC activities.

With the pace of research moving so rapidly, I am confident that our continued investments in novel and innovative biomedical research in ASD will pay large dividends in the future. But there's a strong imperative to push the best of what we know now out into the community as rapidly as possible.

HHS's OD and the Assistant Secretary for Planning and Evaluation are creating the infrastructure to support and conduct patient centered research on health services and supports

for people with disabilities, including autism. Their new Center of Excellence, authorized under the American Recovery and Reinvestment Act, is part of a national strategy for quality improvement in health care and the expansion of health care delivery system research with a focus on person-centered outcomes research. Expanding on that effort, CMS is testing and implementing family-driven, person-centered and home and community-based service provision models for people with autism.

A common goal across many federal agencies is to support and empower people with autism to live more independently and enjoy an enhanced quality of life. Informed by the IACC Strategic Plan, NIH is making non-traditional investments in novel service and health delivery models, aided by the infusion of additional funds from the Recovery Act. Both the ED's Rehabilitation Services Administration (RSA) and HHS's SAMHSA "Supported Employment Toolkit" are helping people with autism secure and maintain jobs in the community. Medicaid continues to fund supported employment and habilitation services through States' home and community-based waiver programs, which pay for such services for many people with intellectual and developmental disabilities across the nation.

There are also interventions and supports that can help people with autism and their families today. HRSA is helping to pave the road from research to practice. Through funds provided by the Combating Autism Act Initiative (CAAI) under the CAA, HRSA has invested substantially in autism interventions to improve physical and behavioral health of people with ASD, practitioner training, and service provision models. HRSA-funded investigators are examining critical questions, such as the impact of co-occurring health conditions in autistic individuals and the effectiveness of parent-mediated and peer-mediated behavioral interventions. HRSA's health professionals' training programs are designed to reduce barriers to screening and diagnosis by increasing professional capacity and raising awareness about ASD among providers in the community. HRSA's State Implementation Grants represent nearly \$2.7 million in funds to assist nine States with improving services for people with ASD. These grants promise to help identify best-practices at the individual, community, and policy level. When possible, partnerships between agencies are being formed -- HRSA and CDC have joined to sponsor "Act

Early” Summits in all regions of the US and to facilitate the development of professional and community teams to improve the early identification of children with autism at a local level.

The coordination in the autism research community is unparalleled, and the IACC has played a critical role in fostering the growing list of promising public-private partnerships. Last fall, the mother of a child with autism spoke at an IACC meeting about the need to examine the high prevalence of autism in the Somali community in Minnesota reported in a state-funded study based on school data. Working collaboratively, several NIH Institutes, CDC, and Autism Speaks put together a research initiative to support investigation of the reported increase in ASD prevalence in the Minnesota Somali community and to identify the diverse service needs of these Somali-American children and their families.

As the Somali study illustrates, federal agencies recognize the autism challenge is not one we can tackle alone. There are a host of private organizations funding cutting-edge research, including four that hold a seat on the IACC – Autism Science Foundation, the Southwest Autism Research & Resources Center (SARRC) and the organizations identified by the recent IACC Portfolio Analysis as being the 2nd and 3rd largest private funders of research after NIH, Simons Foundation and Autism Speaks. Jointly, NIH, Autism Speaks, and Simons Foundation are driving several significant initiatives poised to accelerate the pace and quality of autism research. By developing the infrastructure and appropriate incentives, these public-private partnerships are encouraging data-sharing on an impressive scale, enabling scientists to do more with less. Additionally, NIH’s National Database for Autism Research (NDAR) is federating with several other autism data repositories such as the Autism Speaks’ Autism Genetic Resource Exchange (AGRE) and the public/private-funded Interactive Autism Network (IAN) to enhance researchers’ access to data. And in the community, programs like AGRE, IAN and the Autism Treatment Network (ATN), that involve direct outreach to and collaboration with the patient community, are bringing together hundreds of researchers and clinicians with tens of thousands of people nationwide affected by ASD in a search for answers.

Federal IACC member, ADD, with the help of non-profit organizations, including the Arc of the United States, the Autistic Self Advocacy Network (ASAN), and the Autism Society, recently launched the AutismNOW Project, an innovative dissemination network to provide access to high-quality resources and information on community-based services and interventions for people with ASD and their families. AutismNOW offers a call center, web-based clearinghouse of resources, twice-weekly webinars on a variety of topics related to autism, and regional events for the community to connect in-person.

Looking back over the past five years since the passage of the CAA, we can see how the establishment of the IACC has served to focus efforts across the federal government, bringing federal agency representatives (research, services, and education), parents, people with ASD, scientists, clinicians and others together to work as a team to address the issues, and bringing a wide variety of expertise to a difficult area. In doing so, it has produced a strategic plan to guide and focus federal research efforts and catalyze public private partnerships, while also providing a forum for public discussion and identification of additional needs from the community.

We have also seen some remarkable progress in the identification of how common ASD is within communities, how ASD develops, how we can detect it at increasingly earlier ages and what types of interventions are most effective, especially in young children. This research is rapidly moving toward translation into practical tools that can be used in the clinic and community settings to change outcomes for people with ASD. In this time span, federal agencies have coordinated efforts to enhance critical services programs, identify best practices to support the education, health and employment needs of people on the spectrum, and develop new mechanisms and strategies to enable broad access to healthcare, services and supports – all leading toward improvement in quality of life for people with ASD and their families.

The CAA established the IACC, to provide advice to the Secretary HHS regarding matters related to ASD, to create a forum where the public could be actively involved in the process, and to develop a strategy to guide national research efforts. While there has been unequivocal progress, much work remains to be done. The reauthorization will be critical for continuing the

momentum and stability of the IACC over the next 3 years. It is crucial that members of the IACC—individuals, federal agencies and member private organizations—have stable support to continue their efforts to work together on autism issues.

I thank you for this opportunity to speak with you and look forward to addressing any questions that you may have.

Mr. PITTS. I will begin the questioning now, and I recognize myself for 5 minutes for that purpose.

The Interagency Autism Coordinating Committee has been praised because it has brought together various HHS agencies that work with autism. Can you explain how the agencies interacted before the creation of the IACC?

Mr. INSEL. Well, I actually wasn't around prior to that time. And I must, say since we have been operational since 2000 as a committee, it is probably fair to say that prior to 2000 there was a fairly meager investment from most of the agencies in autism. There was certainly less than one-fourth of the NIH commitment that we have today. There was activity at the CDC in terms of epidemiology, but autism was not seen at that point as quite the priority it is today.

Mr. PITTS. The Combating Autism Act consists of the function of the CDC, HRSA, NIH and the Interagency Coordinating Committee. If the Combating Autism Act is not reauthorized, would NIH, CDC, and HRSA be able to continue its activities related to autism?

Mr. INSEL. It will be able to continue its activities contingent on appropriations. So I often like to say that authorization here is essentially a driver's license. Agencies serve as our vehicle. We have got a great road map through the strategic plan that the IACC has put together, but at the end of the day, whether we have got gas in the car or not depends on the appropriators.

Mr. PITTS. Let me ask a few questions about the strategic plan in 2011. What have you learned about risk factors for autism spectrum disorders, especially in light of recent news of an elevated risk of autism in children whose mothers took antidepressants in the year before delivery?

Mr. INSEL. Well, we have got a number of things that are emerging through the studies that are longitudinal to look at exposures that may increase risks. We also have increasing evidence for the importance of genetics as a risk factor. Perhaps 15 percent of children with a diagnosis of autism spectrum disorder are found today to have a genetic mutation. Many of these we didn't know about even 6 months ago. So that is an emerging area of risk as well.

Probably the most important area going forward is understanding how these genetic and environmental effects interact and to put people at the greatest risk.

Mr. PITTS. Would you describe, please, the new diagnostic tools for early screening and diagnosis of autism spectrum disorders?

Mr. INSEL. What is the most exciting on the diagnostic front is the possibility that we could begin to detect autism, not at age 4-1/2 or 4 and 3 months, but before the second birthday. And the way in which that is happening, really it happens—the most recent data comes from two fronts. One is just a simple 5-minute screening device that is available in the pediatrician offices that would be done at 12 months. And we are seeing that that picks up about 30 percent of the cases.

In fact, where this was piloted in San Diego, those pediatricians who agreed to do it as part of the pilot have continued to take this on, and we now have over 1,000 pediatricians in San Diego County

who are continuing to work with this possibility of actually extending that much more broadly.

But I think where we are getting even more traction is from the possibility that we could detect autism through sort of a biomarker; that is, looking at things like eye scanning, look at other very subtle behavioral changes that might not show up with a simple checklist coming from parents. Doing that, it looks like we have got about 100 percent sensitivity—I am sorry, 100 percent specificity, as early as 14 months by using a simple video monitor task to detect who will look at faces versus who will look at geometric shapes as a preference. And we have been able to now show the power of that to detect autism very quickly and very early on.

Mr. PITTS. Are there any significant gaps in the research plan that need to be filled?

Mr. INSEL. There certainly are. I think the two places that we are seeing the greatest emerging need is watching the transition to adulthood. And this was a place that the IACC hadn't really been focused in 2008 and 2009. But as time has gone on, what we have heard from the public and what we are hearing from in meetings that we have in the IACC, is this aging cohort. Here, aging means becoming adults, going from being children with autism to being young adults, and the fact that many of the social supports and the service resources that are available to students and to children with autism are no longer available as people with autism become adults. It is important for us to look at that and to think about both the research and service needs at that point.

The second I would say is, much more broadly, how services are provided throughout the country. There is an amazing amount of heterogeneity, not only in the needs of people with autism, but in the way that those needs are met across various States. You and Mr. Pallone happen to come from States that are particularly enlightened in their policies for what they do for people with autism, but that is not true in all 50 States, and the need to think about creating some standards that will be helpful as best practices I think is an emerging and actually an urgent need for people on the spectrum and for their families.

Mr. PITTS. Thank you. My time is expired. The chair recognizes the ranking member for 5 minutes for questioning.

Mr. PALLONE. Thank you, Mr. Chairman. I am trying to get in half of Dr. Heinrich and half of Dr. Insel. We will see how I do.

Dr. Heinrich, I wanted to ask about the children's GME. We know it is critical to physicians that—you know, to pediatric physicians. But I wanted to clarify the difference between this program and Medicare GME. Can you briefly explain the obstacles for free-standing children's hospitals to access Medicare GME for training pediatricians?

Ms. HEINRICH. Sure. The Medicare GME formulas that are used to reimburse hospitals really are heavily dependent on the services provided to the Medicare population, which usually are people 65 and over with various acute chronic conditions. With the free-standing children's hospitals, you do not have that 65-and-over population for the most part, you have children. So it disadvantages the Children's Hospital immediately. There also is a section

of the law that makes it more difficult for children's hospitals, actually.

Mr. PALLONE. Can I ask you, are we still seeing a decline in the number of pediatricians trained now that we have the program?

Ms. HEINRICH. Are we seeing a decline?

Mr. PALLONE. Yes. I mean, I know that at one time before the program began there was a decline, but is that still true?

Ms. HEINRICH. To the best of our knowledge we are continuing to see that residency positions are expanding for pediatricians overall. And as we look at numbers of providers, it looks like the number of pediatricians are continuing to expand. Whenever we talk about the numbers, though, we always have to be worried about that retiring population, because just as our overall population is aging, so are the health care providers.

Mr. PALLONE. I mean, when I talk to physicians—and I know there were some recent reports by your agency for pediatrics—they usually complain that the subspecialists are what we need more; in other words, that we need more people going to certain subspecialties. And I know in February 2000, there was a report by HRSA that concluded there was a shortage in pediatric rheumatologists. And then we expanded the number by 75 percent. In December 2008, expert work group on pediatric subspecialty capacity HRSA recommended that we expand graduate medical education for pediatric subspecialists. Do you agree with the findings of these reports in terms of the subspecialists?

Ms. HEINRICH. Congressman Pallone, I am not familiar with those particular reports. But anything from 2007 that we have published would have been based on even earlier data, so I would consider that old data. I prefer actually to see those reports and get back to you on whether or not we agree or disagree.

Mr. PALLONE. But you agree that the subspecialists in general need more support, right? In other words, that that is a problem, the subspecialties per se?

Ms. HEINRICH. You know, we have heard as you have from the professional associations, that there are shortages in these various subspecialties. It is just always very difficult to determine the demand for the program.

Mr. PALLONE. I am going to cut you off only because I want to go to Dr. Insel, but thank you.

Let me just ask you these—a couple of these questions. In your remarks you mentioned a recent study involving twins which found that environmental factors, not just genetic factors, may be at play. And these findings are somewhat controversial, as you know.

So I had three questions.

First, would you explain these findings in more detail? Would you give us a brief summary of what the research shows in terms of the role of genetics? And to the extent—the third one—to the extent environmental factors may be involved, what kind of environmental factors are we talking about? I am jumping right in because we don't have a lot of time.

Mr. INSEL. Sure. I know.

Let me give you the numbers because this has gotten quite a bit of press and it is easy to misunderstand or over-interpret what they mean. This was the largest study done to date on twins. And

we divide twins into those who are identical, where they share 100 percent of their DNA, and those who are fraternal, sharing 50 percent of their DNA, which is the same as you would expect from siblings.

So just to cut to the chase, in the general population it rates about 110, so you can imagine sort of a 1 percent risk in the general population. If you have a sibling with autism, your risk goes up somewhere between 4 and 14 percent, depending on the study you look at. The new data with twins says that fraternal twins, for a diagnosis of autism spectrum disorder, would be in about the 31 percent concordance rate, and that is pretty high. So that is 30-fold higher than the general population. Identical twins with 100 percent DNA shared will be at 77 percent for autism spectrum disorder, a little bit lower for peer autism.

So what this study ended up saying, and I think where the confusion has come from, is that on a basis of some very complicated mathematical modeling, that that represented about 58 percent of the risk being environmental and about 38 percent being genetic, meaning more of this was environmental than genetic.

Frankly I don't think that is helpful. I think it may be more useful to try to go after the complexity of this by understanding how environments and genetics interact. It is important to recognize that autism is really sort of an umbrella term and it is representing many different syndromes. Some of those syndromes are absolutely genetic: Fragile X, Rett syndrome, Tuberous Sclerosis, very, very high rates of autism in each of those. They all involve a genetic lesion. So in those cases you are talking about autism in the context of a genetic disease.

There may be some, and we don't really know the number, in which the disorder is really generated by environmental factors yet to be determined. But there is a lot of research going on to try to track down what those could be. Much of the data that we have so far, and we are still I think early days on this, has been pointing to factors that impact second trimester, so prenatal or early post-natal factors in some cases. And there is a range of them that are coming particularly out of the UC Davis effort that is funded by, at this point, by NIH and by EPA and CDC where there is a number of things going on.

In this case one of the things they are looking at, well, they have got not only the antidepressant study that you have already mentioned, but there are questions about environmental exposures to certain kinds of chemicals and fertilizers. There are questions about medications, particularly valproic acid, which has been raised as a likely insult. There are other issues around whether certain kinds of illness prenatally might predispose and be a risk factor.

The bottom line is we still don't know. And we don't know of any factor that gives us more than a small amount of the risk that explains much of this increase.

Mr. PALLONE. Thank you, Mr. Chairman. Thank you.

Mr. PITTS. Thank you. And the chair now yields to the gentleman from Ohio, Mr. Latta, for 5 minutes for questions.

Mr. LATTA. Well, thank you, Mr. Chairman. I appreciate the opportunity. And to our guests, thanks very much for being here.

Both of these are subjects I know that all of us face when we go home with a lot of questions.

And Dr. Heinrich, just recently I was over in Cleveland at the Rainbow Babies Hospital, and it is an incredible facility they have over there. And you know, just to give you a couple of statistics, you know, as we were talking about prior to the enactment of CHGME in 1999, in 2000 it showed that Rainbow trained 69 residents and 26 fellows; today the hospital is training 112 residents and 68 fellows. I guess the first question is if the CHGME is not extended, who will do this training?

Ms. HEINRICH. I don't think that there is any one of our programs that could make up the gap if the funding is not continued for the CHGME program. The children's hospitals are eligible for our ongoing competitive programs. For example, in our physician expansion program there were several children's hospitals that together I think were given about \$13 million. The pediatric hospital residency programs can also apply to our ongoing primary care residency programs, for example, so they are eligible for other funding opportunities.

Mr. LATTA. Thank you. In your testimony on page 4, you say that approximately one-third of the CHGME payment goes for direct graduate medical expenses and two-thirds are for indirect graduate medical expenses. Can you tell me what those indirect medical expenses are?

Ms. HEINRICH. The indirect expenses may be expenses that the hospital identifies as associated with their training activity, whereas the direct expense is for support of the resident and for very specific training such as curriculum development or faculty.

Mr. LATTA. Thank you.

And Dr. Insel, if I could ask you a couple of questions here in my remaining time. And I know that when I was in Ohio legislature quite a few years ago, I had quite a few families and groups I met with during that time. And one of the things that—could you tell me, when you were talking about the five general provisions, you used the word “surveillance.” How would you define surveillance?

Mr. INSEL. This is looking at the prevalence; that is, the number of—in this case it is 8-year-olds, there is a new study of 4-year-olds as well, who have a diagnosis of autism spectrum disorder.

Mr. LATTA. OK. And also, it shows in the last two decades ASD was considered a rare disorder, and now you are saying that 1 in 110 children are being diagnosed with. What were those kids being diagnosed with before?

Mr. INSEL. That is a great question. We don't know how many of these children were diagnosed with some other disorder like childhood schizophrenia, sometimes mental retardation. One of the things that has changed over time is that you can now give a diagnosis of autism spectrum disorder and have one of these other diagnoses. Prior to 1991 that was not an option. But it still is not clear that all of these children had something else.

One of the questions that I think we need to really grapple with is whether this is a real increase. And I think most people who have been in this field, as I have for more than two decades, would say that it is not simply changing diagnosis, it is not simply great-

er awareness, it is not simply ascertainment that is better, but that there is a true increase—as there is in asthma, Type I diabetes, and food allergies—there are more people affected with autism today than there were two decades ago.

Mr. LATTA. With my remaining minute to go, if I could just get two more questions in real quick. One is, you know, if a child is diagnosed before the age of two, what drugs are out there today that are working for them?

Mr. INSEL. For medications for what we now think of as a neurodevelopmental disorder, we are sitting pretty empty-handed. We have medications that help on some of the secondary symptoms like helping with some of the temper tantrums, sometimes with some of the more compulsive behavioral pieces of this. But the reality is that the core symptoms—that is, the social deficits, problems in communication, some of this narrow attention—we don't really do very well with any medications. The best treatments have been behavioral. And those treatments in fact appear to be more effective when started early in life, 18 to 24 months, rather than later after age 4.

Mr. LATTA. I see my time is up, and I yield back, Mr. Chairman. Thanks very much.

Mr. PITTS. The chair thanks the gentleman, and yields to the gentleman from Michigan, the Ranking Member Emeritus, Mr. Dingell, for 5 minutes for questions.

Mr. DINGELL. Mr. Chairman, I thank you.

These questions will be directed to Dr. Heinrich. Doctor, the questions here are going to be simplified to a yes or no answer. The Children's Hospital GME program was intended, as I recall it, to correct any unintentional disparity between the Federal Government's support for Graduate Medical Education that left children's hospitals without support, especially given the freestanding children's hospitals generally do not provide care to patients eligible to receive Medicare.

Now, the question, do you feel that the Children's Hospital GME program was successful in addressing the disparity between freestanding children's hospitals in other teaching hospitals, yes or no?

Ms. HEINRICH. I believe it is yes.

Mr. DINGELL. Thank you. Now, in proposing to eliminate the Children's Hospital GME program, the President's budget justification called for a need to devote additional resources to train in primary care. The question: Are health services related to pediatrics considered to be primary care, yes or no?

Ms. HEINRICH. Yes.

Mr. DINGELL. Now, Doctor, are health services related to family medicine considered to be primary care, yes or no?

Ms. HEINRICH. If services to, I am sorry, family?

Mr. DINGELL. Well, let me repeat it. Are health services related to family medicine considered to be primary care?

Ms. HEINRICH. Family medicine, yes.

Mr. DINGELL. Now, Doctor, are health services related to internal medicine considered to be primary care, yes or no?

Ms. HEINRICH. Internal medicine before people subspecialize, yes.

Mr. DINGELL. Yes, thank you. Now, Doctor, my understanding is that 60 percent of the pediatricians trained by the Children's Hos-

pital GME program are in general pediatrics, and hospitals in the program also provide pediatric training for residents in internal medicine and family medicine. Would you agree, then, that the Children's Hospital GME program helps to expand the primary care workforce, yes or no?

Ms. HEINRICH. Our numbers aren't as high as yours, but yes, part of what they—a number of the people that they train are in primary care.

Mr. DINGELL. Thank you, Doctor. Now, isn't this, then, in line with the President's goal of training additional physicians in primary care, yes or no?

Ms. HEINRICH. Part of the program is in line with the goal of increasing the number of providers in primary care, but we would say that it is important to focus our energy and our resources on the competitive programs.

Mr. DINGELL. So the answer is yes?

Ms. HEINRICH. Partially, yes.

Mr. DINGELL. Now, Doctor, in fiscal year 2000, the number of residents and fellows receiving Federal Children's Hospital Graduate Medical Education funding was a little over 4,200. Your testimony points out that in fiscal year 2010 the program supported approximately 5,800. The HRSA online performance index for the fiscal year 2012 budget submission notes that there has been continuous yearly growth between 3 and 6 percent in the number of resident full-time training equivalents at Children's Hospital since the inception of the program.

Question: Would you agree that this increase in the number of trainees reflects the continuing need to train pediatric physicians, yes or no?

Ms. HEINRICH. Yes, we do feel that there is a need to continue to train pediatric residents.

Mr. DINGELL. And, Doctor, I want you to understand these are friendly questions, these are not hostile, we are not trying to push you into any sand traps or anything here.

Now, in the 2010 application for the Children's Hospital GME funds, children's hospitals reported that half of their growth revenue for inpatient care and almost half of the growth revenue for outpatient care was for Medicaid and CHIP. Given that children's hospitals serve a large number of Medicaid and CHIP patients, as well as the uninsured, now the question, wouldn't you agree then, that these hospitals serve as an important safety net for families in need?

Ms. HEINRICH. I would have to go back and check on the numbers that you have provided.

Mr. DINGELL. I don't think the numbers are important, though, but they are substantial. And so can't we say on the basis, though, of almost any large numbers, that these hospitals are in fact an important safety net for families in need?

Ms. HEINRICH. I think that they are part of the safety net.

Mr. DINGELL. I guess I am over time. Thank you, Mr. Chairman, for your courtesy.

Mr. PITTS. The chair thanks the gentleman, and now yields 5 minutes to Dr. Burgess for questions.

Mr. BURGESS. Thank you, Mr. Chairman.

Dr. Heinrich, help me if you can, understand what is going on with Dell Children's Medical Center in Austin, Texas. It established a new teaching program in 2007, at a time Federal regulations said that new programs could receive children's graduate education funding if they were accredited as a new program by an accrediting body such as the Accreditation Council for Graduate Medical Education.

Then two years later in 2009, HRSA had a change of heart, and although Dell had been receiving funding for 2 years as an accredited teaching program, HRSA notified Dell that because of an interpretation by the Centers for Medicare and Medicaid Services to protect Medicare funds, Dell would no longer be receiving that funding.

Now, my understanding is that HRSA made that decision because CMS clarified its rules regarding which programs could qualify as new. The regulations issued at the time indicated that this change by CMS was undertaken to protect Medicare entitlement funds; is that correct?

Ms. HEINRICH. It certainly was associated with the CMS regulations on the determination of a new program.

Mr. BURGESS. Well, and the protection of entitlement funds, which would be under the jurisdiction of the Center for Medicare and Medicaid Services. So the rules are in place to protect Medicare funds, but considerations are very different for a Children's Graduate Medical Education program because they are funded with discretionary funds and grants. We appropriate those funds as part of the annual appropriations process.

So why the discrepancy there? Why are discretionary funds appropriated by the Congress being withheld as if they were mandatory funds being administered by CMS?

Ms. HEINRICH. I can't respond specifically to the different funding source and what difference that makes.

Mr. BURGESS. Well, look, all through the continuing resolution debate, we were told we couldn't touch entitlement funding because we were only dealing with discretionary money in the continuing resolution. OK, now the shoe is on the other foot and we have got appropriations discretionary funding going to Children's Graduate Medical Education, Dell Children's Hospital, Austin, Texas. And you are saying that because we are protecting mandatory funding, you can't have that money anymore.

I guess what I would ask is, will you work with me and my office to see if we can resolve this if there is a legislative fix that is needed so that people understand more clearly their individual roles in this? I think it is a—it is bound to just be an oversight, but it is one of those things that we have to fix because the money is not going where it was intended.

Ms. HEINRICH. We would be very happy to work with you and your office in looking into this.

Mr. BURGESS. Well, let me ask you another question. The HRSA Online Performance Index for your fiscal year 2012 budget submission, it states "the program"—speaking of Children's Graduate Medical Education—"the program also improves access to health care by expanding the capacity of the health care safety net at free-

standing children's hospitals for underserved children and families."

So that is correct, right?

Ms. HEINRICH. Yes.

Mr. BURGESS. Well, why was the administration's choice then to zero out the budget for Children's Hospital Graduate Medical Education in 2012? It apparently worked, but you are zeroing out the funding. Can you help us understand why that would be?

Ms. HEINRICH. In these challenging budget requirements, it is very difficult; and we have to make very difficult choices.

Mr. BURGESS. I get that, because we are knee-deep in that—neck-keep in that right now.

Ms. HEINRICH. Yes.

Mr. BURGESS. But, again, according to your own views and estimates on the Web, this program is working; and yet the President chose to zero it out. It just doesn't seem to make sense.

Ms. HEINRICH. It is a very hard choice to decide which of the programs when you have to make cuts must be cut.

Mr. BURGESS. Dr. Insel, but I run out of time, let me just ask you a question. You gave us some rather dramatic figures of—was it, in male children, one out of every 80?

Mr. INSEL. One in 70.

Mr. BURGESS. One in 70. That was the 8-year-old cohort. You have been at the NIH since 2002, so you have seen that 8-year-old cohort double in age. Do any of these children age out of the process? What is happening now with those 16-year-olds? Is it one in 70 16-year-olds?

Mr. INSEL. Generally, children with autism become teenagers with autism, become adults with autism. They may adapt. They may be better to function better. Many of these children are able to go through a regular school system but only with a great number of supports and often a very extensive and intensive set of behavior therapies. The average estimate for cost over a lifetime is \$3.2 million per person on the spectrum.

Mr. BURGESS. Thank you, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman and yields to the gentleman from Kentucky, Mr. Guthrie, for 5 minutes for questioning.

Mr. GUTHRIE. Thank you, Mr. Chairman, and thank you, Dr. Heinrich, for coming. I am going to focus most of my questions on Dr. Insel.

But I have a lot of people that contact me about autism. I am from Bowling Green, Kentucky. The Kelly Autism Center is a new part of Western Kentucky University that an entrepreneur's family started when their grandson was diagnosed with autism. So it touches all families, all places.

You kind of highlighted on some focus, so what I am going to do is kind of cede my time to you to kind of get through, if you would—you focused on second trimester with some things that you are focusing on. What are you seeing? What is on the horizon? I know you said you put a plan together. I know there are a lot of unknowns.

You have 4 minutes. I know you ran out of time on your testimony. Can you give just an overview of where we are and where we think we are going?

Mr. INSEL. Sure. Very quickly, what we often do in science is go where we have the most traction; and, right now, that is in genetics. The cost of doing a human genome has gone from \$2 billion to \$2,000 in the time that I have been at NIH, which is less than 10 years. So that gives you some mileage. And doing that has been informative, even in the last couple of months where we have been able to use the power of genomics to identify mutations that we didn't know were present that seemed to be associated with high risk and, in some cases, may be causative for autism.

But, clearly, that is going to hit a wall. I think what we are going to discover is that that will explain part of the population; and I don't think it is going to explain the increase, because your genome doesn't change over two decades.

So the interest now is in increasingly looking at what could be the environmental factors that are hitting those people who are genetically susceptible; and, as I was saying before, we have a very short list at this point because this is in some ways a relatively new area of investigation. And, to be honest about it, we don't have the traction in finding environmental factors that we do have in finding genetic sequence changes. So this is a long, expensive, and difficult process that mostly deals with large population studies and goes after correlations. So it is not quite the same as what we have been doing in genetics.

That said, there are a number of projects under way, some of which are looking at younger siblings where we know there is a great risk, picking them up as soon you have a positive pregnancy test and following them. Some are looking at large birth cohorts, both in Norway, Denmark, and now in the United States. Some are looking in great detail at environmental factors across both pregnancy and the first 3 years of life.

All of those, when done longitudinally, may begin to flesh out some signals, but right now the signals we have are relatively weak. They may show, like with the antidepressants, perhaps a two-, maybe even a threefold increase in risk, but nothing like the 70-fold increase in risk you have for having an identical twin.

Mr. GUTHRIE. OK. And that is where we are, kind of the state of the art where we are. Where do you think we will be in the next—I know it is maybe just guessing.

Mr. INSEL. I think part of the reason why I said there is some confusion about genetics versus environment is I think where we may end up is learning to use the power of genomics to actually finding environmental factors. So one of the things we know about from cancer research, for instance, is that environmental factors through somatic mutations on particular cells lead to changes in cell division and increased risk for tumor formation.

The same thing could be happening in the brain. We don't know that. The same thing could be happening in the germ cells that create the fetus. All those are opportunities to begin to track down changes in the genome, either because they are mutations or because they are modifiers of how the genome is read. And that is what the environment does. The environment can do that.

So we may be able to find the footprints of environmental exposures by looking at the genome long after they take place. We are not there yet, but we now are getting the tools—and by “now” I

mean in the last year or two—we have the tools to begin to do this with great precision and great throughput. And at that point I think we will be able to make a little more progress than we have to look for environmental causes.

Mr. GUTHRIE. Thank you.

I will use my last 30 seconds, just a couple of seconds, just to compliment what is happening in Bowling Green with the Kelly Autism Program. I don't know if you are familiar with it or not, but Suzanne Vitale, who is the grandmother of Philip Proctor, I guess he is about 11 now, maybe 12, and performs in plays and things like that. So if you put intensive therapy into someone, it can really help. They have the resources to do so. We just need to get the resources here as we want other kids to have the same opportunities.

Mr. INSEL. Well, thank you. There is no group of people that I have met that are more inspiring than the families of people with autism. These are really dedicated parents who make things happen.

Mr. GUTHRIE. Thank you.

I am out of time. I yield back.

Mr. PITTS. The chair thanks the gentleman and recognizes the gentleman from Georgia, Dr. Gingrey, for 5 minutes of questioning.

Mr. GINGREY. Mr. Chairman, thank you.

I will go to Dr. Heinrich first.

Dr. Heinrich, these questions I think have already been put to you maybe a little bit by Chairman Emeritus Dingell, but I would like to get you to respond once again. In proposing to eliminate the Children's Health Graduate Medical Education, the President's budget justification called for a need to devote additional resources to train in primary care. Yet—and I think you may have said this—60 percent of the pediatricians trained by CHGME hospitals are in general pediatrics, primary care; and, additionally, the Health Graduate Medical Education hospitals provide pediatric training for residents in internal medicine and family medicine. And you had stated to Mr. Dingell that both of those were primary care, particularly internal medicine, before they go on to subspecialize. How is it that this administration does not recognize that Children's Health Graduate Medical Education hospitals provide essential support for the future primary care workforce for our Nation's children?

Ms. HEINRICH. We are not saying that this isn't a successful program. Our latest figures are that about 46 percent of the resources are going into general pediatrics, maybe 27 percent to the pediatric subspecialists, and then another 27–28 percent that go to the other residents who rotate through the children's hospitals. We are simply saying that in this environment you have to make hard choices; and, in this instance, that is what we have done for the 2012 budget request. We are also saying that pediatricians can be trained in other facilities and can be trained through other types of programs.

Mr. GINGREY. Thank you.

Dr. Insel, the research on autism conducted at the Autism Centers of Excellence have been described by some as being redundant and too focused maybe on gene and diagnosis research and not on, for example, things like autoimmune problems. In addition, there

is concern that administrative costs are too high and they take away much-needed funds from research. Comment on these criticisms for me, if you will. And I will have a follow-up question: Do you believe that autism research efforts are well coordinated?

Mr. INSEL. Well, there are 11 Autism Centers of Excellence. They represent about altogether less than \$25 million of the investment from NIH, which is now about \$218 million for 2010. So they are just a little bit more than perhaps 10 percent of our investment.

They are places where there is a wide range of research. Some of it does in fact involve genetics. But one of the most recent networks funded is all about environmental factors, the early—and early in this case stands for early autism risk longitudinal investigation study, which is pulled together by Drexel University, Dr. Newschaffer, looking at actually the long-term exposure history for people who are at risk for autism. So I wouldn't think it would be accurate to say that they are only about the genetics of autism. That is one of the things that happens. There is also treatment development, biomarkers, a whole range of things that are going on in those centers.

What about the coordination? I think that one of the successes of the IACC has been to increase coordination not only within the Federal agencies, where you see CDC and NIH and HRSA working much better on many of these questions, but perhaps in this area most importantly between the Federal agencies and some of the private foundations.

Autism is a little unusual in the world that I live in, because this is a place where there is quite a bit of private money now coming in to support research in a very exciting way. And that is—

Mr. GINGREY. Let me interrupt you for a second, because I am about to run out of time, and I did want to ask you one last question.

In your testimony, you talked about identical twins and the prevalence of autism in regard to—my question really is, why isn't it 100 percent? If you have got—it is either DNA or genetic-related or environmental, and you say, who knows, 60–40, 50–50, 40–60. But those identical twins obviously have the exact same DNA and they have been exposed, as has their mom, to the exact same environment, certainly through 1-and-a-half to 2 years of age. So why isn't it 100 percent?

Mr. INSEL. Right. So it is important to remember that autism is not cystic fibrosis, Huntington's Disease, or a number of other single-gene, truly genetic disorders. In fact, it is not a single disorder. When we use the term autism, it is like talking about epilepsy, or maybe talking about fever. There are many, many different syndromes that end up in this umbrella term. Some of them, as I mentioned before, may truly be 100 percent genetic; and in those twins, if one has fragile X, the other will have fragile X, and they may both have autism.

But that doesn't cover more than perhaps 15 percent of the population as we know it right now. And for the rest, many disorders that are in this umbrella, under this umbrella, there may be many other sorts of ways to think about how to get there, and some of them could be environmental.

Mr. GINGREY. Thank you, and I yield back.

Thank you, Mr. Chairman.

Mr. PITTS. The chair recognizes the gentleman from Louisiana, Dr. Cassidy, for 5 minutes nor questions.

Mr. CASSIDY. Again, I only have 5 minutes, if I cut you off.

I am trying to get my head around—so, previously, CHGME for pediatrics got roughly how much money and then how much in this latest budget?

Ms. HEINRICH. OK. For the CR for 2011, we are funding it at \$268 million; and in fiscal year '10 it was \$317 million.

Mr. CASSIDY. And the President's budget zeroed it out?

Ms. HEINRICH. For 2012.

Mr. CASSIDY. Wow. Now, I am an internist. I am actually still on the faculty with an internal medicine program. And although there is collaboration between internal medicine, I find really pediatrics has their own gig going and internal medicine may have their own, and that is important. So if HRSA is going to be attempting to be all things to all specialties, in practice I just don't see that working as well. What do you imagine HRSA will dedicate towards pediatric training as it is dividing up this pool in different primary training specialties?

Ms. HEINRICH. Well, as you know, most of the training for physicians at the residency level are funded by Medicare GME, and we have a relatively small portion. The focus of this administration is to expand the primary care—

Mr. CASSIDY. But how much will this HRSA-type funding mechanism result in going to pediatric programs? You have been getting roughly \$270 million. How much will result under the Obama budget?

Ms. HEINRICH. Within the competitive programs that we have for the primary care providers, it would really depend. It will depend on how—

Mr. CASSIDY. But you must have a ballpark.

Ms. HEINRICH. I don't, because—

Mr. CASSIDY. In that case, if I was a pediatric program, I would see a train coming down a tunnel. Because I would say, oh, my gosh, they have no clue how much they are going to be allocating towards pediatric programs.

Is there no sense at all of how much—because autism is a pediatric disease, and our ability to train primary care pediatrics to do the 5-minute exam will in part depend upon the effectiveness of HRSA pulling this off. So HRSA has no guidelines or projections how much will be going to pediatric hospitals?

Ms. HEINRICH. The pediatric hospitals would be part of a competition that we would have, say, for primary care providers.

Mr. CASSIDY. I see that, but I guess we keep talking past each other. My specific question is, and it sounds like you don't, do you have a sense of how much money will be going to these programs to replace the \$270 million being lost?

Ms. HEINRICH. You are right. We do not know that.

Mr. CASSIDY. That is frightening. There just seems there should be some sort of proactiveness involved.

Dr. Insel, in the spectrum of ASD, I gather there are some people now in the ASD kind of group who formally may not have been recognized and may have just kind of gone through life always

thought to be a little odd but now they are actually diagnosed. Is that a fair statement?

Mr. INSEL. It is.

Mr. CASSIDY. Now, you mentioned—very frightening—the \$3 million cost to society for untreated—for a person who is a member of the ASD group, if you will, diagnostic group, that \$3.2 million, I assume that is for the kind of full-blown, not for the person who is marginal who previously would not have been recognized but now is included in a diagnostic spectrum. Is that fair?

Mr. INSEL. Correct.

Mr. CASSIDY. So what percent of the entire group so diagnosed with ASD would be those that would consume a large amount of future societal resources? Be it prison, be it neuralgic service, you name it.

Mr. INSEL. I can't give you a precise number for that.

Mr. CASSIDY. Can you give me a ballpark?

Mr. INSEL. I would say it is somewhere between 50 and 60 percent of people who are on the spectrum are going to be in that group of people who would have been, by the way, identified 20 years ago because they don't have a subtle problem.

Mr. CASSIDY. Right. They are the ones that are going to consume more.

I don't mean to be rude. I am almost out of time. What is going to be the cost of society and what is the potential of early intervention to diminish that cost?

Mr. INSEL. We have a good sense of the latter part. We know that early intervention for about half of these children—"early" meaning before 24 months—can lead to not only great improvement in IQ and adaptive behavior but potentially even to loss of diagnosis. So that is fairly impressive.

The cost to society which we have tried to model out in various ways, I would have to submit that for the record. But I can tell you that the \$3.2 million, on average, you can multiply, just to give you a ballpark, times what we think are the 700,000 people who are on this spectrum, and it is fair to say that somewhere around 500,000 are going to be on the severe end of the spectrum or will be in that range that is going to require additional support.

Mr. CASSIDY. I am over time. I could take more.

If you could just send that as a response, the kind of a complete spreadsheet of this is the percent that will require more services and this is the mean. I say that not to impose upon you, but that will help guide public policy.

Mr. INSEL. I am happy to help.

Mr. CASSIDY. I yield back. Thank you both.

Mr. PITTS. The chair thanks the gentleman.

Without objection, the chair recognizes Dr. Christensen, who is not a member of the subcommittee, but is here and would like to ask questions for 5 minutes.

Mrs. CHRISTENSEN. Thank you, Mr. Chairman, and thank you, Ranking Member, as well for allowing me to sit in on this very informative hearing on two bills that really, as you can hear, enjoy bipartisan support.

I guess I would ask Dr. Insel first, but I am really amazed and really pleased to have been able to read in your testimony all of

the advances that are taking place in autism spectrum disorder. I am seeing a lot more attention paid to it in my district as well. So I want to commend the IACC for all of the work that has been done in these 10 or so years. I can't see how we could have had the same kind of coordination without the committee. So I want to thank you and the committee members for your service.

My question is related to some of the health disparities we deal with, Dr. Insel. Given the lesser access to quality health care that is experienced by racial and ethnic minorities and the often-reported under-diagnosis of some disabilities and mental illness in these groups, are you seeing disparities in the diagnosis and treatment of ASD in people of color? And, if so, does the IACC have a plan to address it?

And just an additional part to that question, are the territories included in your outreach to the public and providers?

Mr. INSEL. Well, thank you for those questions.

Yes, the disparity is there. There is nothing unique about autism in terms of health equity. We have many of the same problems you see in the rest of health care.

The difference here, though, may be a little more profound in the sense that where we see the greatest disparity is the age of diagnosis. Children are diagnosed, but not at age 4 but at age 6. And remember what I said before, that the early interventions appear to have the most profound improvements, the greatest impact on prognosis. So you have lost a real opportunity there to have that kind of an impact. So this is enormously important.

The strategic plan, especially the one that is out in 2011, it mentions specifically the importance of having a diverse portfolio in terms of looking at many different communities and making sure that issues around health disparities are addressed. That is a major piece of it.

I should just finish by saying that I don't believe the territories itself have been an area of outreach, but I can again find out more about that and submit that for the record.

Mrs. CHRISTENSEN. Thank you.

My understanding is in children with disabilities in the U.S. Virgin Islands specifically, it is somewhere about 4 to 5 percent of those children are diagnosed with ASD.

Dr. Heinrich, what percent of pediatric residents are supported by this CHGME? I know we have talked about what percentage of the pediatric residents are in primary care. But is it about half?

Ms. HEINRICH. It probably is about half, but I could get back to you with the specific number, if you wish.

Mrs. CHRISTENSEN. OK. And are there any plans in place, given the passage of the Patient Protection and Affordable Care Act and the increase in the number of individuals or families that will be covered, for what kind of an increase in pediatric primary care you might need? I realize we have Medicaid and SCHIP. But have there been any projections?

Ms. HEINRICH. We don't have a projection specifically for pediatrics, but we have expanded the primary care workforce through the Affordable Care Act in 2010 and continue some of that in 2011. So, for example, we have funded additional primary care residency training programs, and there were about six children's hospitals

that are participating in that program. They did very well. We are also expanding the nurse practitioner primary care programs and the PA primary care programs, for example.

Mrs. CHRISTENSEN. Let me see if I can get another question in.

My original plan was to go into adolescent medicine, although I decided to do it through family medicine, but you still probably paid for part of my pediatric training. Do you have input into the design of the training programs in the pediatric residencies that you support and do you see any specific attention being paid to that adolescent population that has unique needs that are not necessarily what we consider pediatric?

Ms. HEINRICH. We don't design the curriculum or the training programs. Those are really determined by the accrediting bodies, if you will. Of course—

Mrs. CHRISTENSEN. Is there consideration for whether you fund them or not?

Ms. HEINRICH. Well, the law requires that any entity that qualifies can participate in the program. But in the law it does say that there will be special attention to underserved populations and quality, for example, so that is stipulated in the law.

Mr. PITTS. The chair thanks the gentlelady.

That completes the first rounds of questions. We will go to one follow-up on each side.

The chair recognizes Dr. Burgess for 5 minutes for follow-up.

Mr. BURGESS. Thank you, Mr. Chairman.

Dr. Insel, I apologize for being out of the room when Dr. Gingrey's questions were being asked, but let me just be sure I understand correctly. I think the concern that was being addressed there was that the general and accounting side of the ledger is consuming more of the dollars that then can't go to the R&D side of the ledger. Is that basically the tension that is there?

Mr. INSEL. I am afraid I don't follow the question.

Mr. BURGESS. Are we spending more for the centers than we are getting in excellence? Are we spending more for the administrative side than we are getting on the research side?

Mr. INSEL. Well, the centers are all research centers. So the centers of excellence are part of—

Mr. BURGESS. Who is responsible for constructing the budget and the oversight of that budget? Is that NIMH or is that NIH?

Mr. INSEL. I think it is the National Institute of Child Health and Human Development.

Mr. BURGESS. Perhaps they could provide us, Mr. Chairman, with—what would be reasonable—the last 3 years of budgetary figures?

Mr. INSEL. I can give you—I mean, the range is between 22 and 26 million, depending on how you cut that pie over the last 3 years. Overall funding in 2010 for NIH was \$218 million. So, as I said, it is roughly about 10 percent of our overall investment in autism research.

Mr. BURGESS. On the breakdown of the autism research dollars themselves, I guess the discomfiture is there are those that say we are spending more for overhead than we are actually getting in research.

Mr. INSEL. So—I apologize. I didn't really understand where you were going.

So the centers are the research centers. The overhead, which is true across our entire portfolio, is quite a different matter. So it doesn't matter whether we are paying an individual grantee or paying a center. The overhead rates are going to depend on the institution that the money goes to, and that overhead generally averages out about 50 percent or a little bit more for most institutions.

Mr. BURGESS. That seems high, but maybe it has just been too many years that I have been involved on the research end. But if you could provide us with some of those budgetary figures, I think that would be helpful.

Mr. INSEL. Just so I understand, what you would like to see are what the overhead figures are within the autism realm—

Mr. BURGESS. You have 12 centers of excellence?

Mr. INSEL. Eleven.

Mr. BURGESS. Within those 11 centers of excellence.

Mr. INSEL. I would be happy to provide that.

Mr. BURGESS. Well, let's take then just a broader view of your world. You know, advances in brain science have been occurring at a significantly more rapid rate the past decade than any decade prior; and whether it be Alzheimer's, traumatic brain injury, autism, you guys are accumulating a vast body of knowledge. What do you see over the horizon? Are you learning things in your study of autism that are helpful in other areas of brain science, like those suffering with Alzheimer's and those suffering with traumatic brain injury?

Mr. INSEL. Very much so. In fact, one could ask why is NIMH leading the charge on autism when autism is usually considered either a neurological or pediatric disorder and not necessarily a classical or prototypical mental illness. And yet for us this has been the prototype that we have wanted to follow. We think about all mental illnesses increasingly as neuro-developmental. The difference is that the symptoms of schizophrenia start at age 18 rather than age 3 or 2 in autism. But many of the aspects of the biology, the biology mostly having to do with how neurons connect and how they develop. So we tend to now think about autism as a synaptic disease; and we are increasingly talking about schizophrenia, mood disorders, other disorders, as synaptic diseases as well. So I think we are going to learn from autism important insights that will play out all across the spectrum of neuro-development.

Mr. BURGESS. And with the last reauthorization at the National Institutes of Health, the provision was made for translational research which gave the director, in this case Dr. Collins, some discretionary authority that the director had not had before. Do you see this as being something that has been helpful as far as being able to work across the various silos and agencies within the institute?

Mr. INSEL. Absolutely. And I would say that Dr. Collins' focus on translational science here couldn't be more urgent for autism. I think you may have been out of the room when I pointed out that, even though this is considered a developmental brain disorder, the only treatments we have at this point are behavioral, that is the

treatments for the core symptoms that are effective. So we have an urgent need to create a pipeline for medications that might help. Perhaps they would be medications that would make behavior therapy more effective.

Mr. BURGESS. Correct. That behavior therapy seems to be labor intensive and expensive, if I caught the end of your comments to Dr. Cassidy correctly.

Mr. INSEL. Yes.

Mr. BURGESS. Thank you for your time, Mr. Chairman. I yield back.

Mr. PITTS. The chair thanks the gentleman and recognizes the ranking member, Mr. Pallone, for 5 minutes for follow up.

Mr. PALLONE. Thank you, Mr. Chairman.

I know you mentioned, as the chair of the IACC, you described many efforts and apparently many successes which have resulted from your committee's work. In the coming weeks, our committee is going to be taking up a proposal to grant the Secretary explicit authority to establish on her own coordination committees for specific diseases and conditions without additional authorizing language. As we consider this proposal, it would be helpful to get your insights on what worked and what didn't work, you know, what worked best or what didn't work in terms of the IACC's own activities. So I wanted to ask you, in your own words, why has the IACC apparently succeeded in actually doing what the Combating Autism Act intended, and then what elements or operations of the committee made it work so well?

Mr. INSEL. Well, I wouldn't want to suggest for a moment this has been easy. I mean, I think it has been successful, but there have been a lot of bumps in the road, and I think we have learned along the way.

I have to say this is an area where I believe many members of the autism community felt that the government wasn't responsive and that the Federal agencies were asleep at the wheel. And I think one of the things the IACC has done is to make those people in the community—and this is a very diverse community—but making that diverse group of participants, keeping them as really part of the process and making sure that not only did we listen to them but they had a chance to hear what we struggled with, and we could do a number of things together.

One of the things that has been perhaps most gratifying for us—and I am not sure how well this would work in other areas—is the opportunity to actually create specific public-private partnerships around key projects. A huge issue in autism is the physical health of children with autism. They have lots of problems besides the behavioral ones I described. Yet we didn't have good best practices for how to deal with sleep disturbances, how to deal with seizures, how to deal with some of the gastrointestinal problems that are really quite common in some children with autism.

So one of the things that came out of an effort from Autism Speaks, which is one of the foundations for autism, was to create a the national network called the Autism Treatment Network, ATN, 17 sites across the country. We could partner with them. HRSA has also partnered with Autism Speaks on the same network.

That has I think been a big part of the success, is creating those kinds of partnerships that might have been difficult to do without the IACC as a forum to get those needs and to also prioritize the needs all at one time.

Mr. PALLONE. I appreciate that.

I yield back, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman.

That concludes our questioning for the panel, excellent panel, very informational.

This will conclude today's hearing. I remind members that they have 10 business days to submit questions for the record, and I ask the witnesses to please agree to respond promptly to the questions.

The subcommittee is adjourned.

[Whereupon, at 3:32 p.m., the subcommittee was adjourned.]

[Material submitted for inclusion in the record follows:]

07.11.2011 – Congressman Leonard Lance- E&C Health Subcommittee
- CHGME and Combating Autism Reauthorization - Opening Statement

Thank you Mr. Chairman.

Children's Hospitals Graduate Medical Education program is one of the most important federal investments in strengthening children's health care in America.

Independent children's hospitals have an indispensable role in the children's health and the pediatric workforce, training 40 percent of all pediatric residents and 43 percent of pediatric specialty fellows, and providing pediatric training for many other residents.

In my congressional district the staff at Children's Specialized Hospital in Mountainside, New Jersey under the leadership of my friend Amy Mansue do an outstanding job caring for children and training a highly qualified, effective medical staff.

There is strong bipartisan and bicameral support for the Children's Hospitals Graduate Medical Education program. And nowhere is this more evident than on the House Energy and Commerce Committee where my fellow colleagues are working across party lines in support of the Children's Hospitals Graduate Medical Education Program.

Today's legislation under discussion to reauthorize the CHGME program will help pediatric training programs by maintaining and strengthening existing hospital graduate medical education programs.

While I recognize that Congress faces many difficult funding decisions this year I believe the Children's Hospital Graduate Medical Education

program is a critical investment in our country's medical future and to ensure that children will have continuing access to the care they need across provider settings.

I also would like to take a moment and applaud the committee for considering legislation concerning autism.

Autism is the fastest-growing developmental disability with nearly 1.5 million Americans living with an autism spectrum disorder.

Autism spectrum disorders cost nearly \$60 billion a year and it is estimated that in 10 years the annual cost could be as high as \$200 billion.

In 2007, New Jersey had the highest prevalence rate of the 14 states that were part of the federally sponsored Autism and Developmental Disabilities Monitoring Network.

The Combating Autism Act created vital programs to research autism and provide education, early detection and intervention programs.

I look forward to hearing from the witnesses on ways we can work together to improve these important programs.

**Statement of Rep. Henry A. Waxman
Ranking Member
Committee on Energy and Commerce
Subcommittee on Health Legislative Hearing
“Miscellaneous Public Health Legislation”
July 11, 2011**

Thank you, Mr. Chairman, for holding today’s hearing on two important pieces of public health legislation – H.R. 1822, the Children’s Hospital Graduate Medical Education Support Act and H.R. 2005, the Combating Autism Reauthorization Act.

I am pleased that we have come together on a bi-partisan basis to move forward with these bills and want to thank the Chair and members on both sides of the aisle for working in concert to make that happen.

This bi-partisan approach has been the foundation upon which each of the original programs addressed in these bills was established.

Created in 1999 in response to the significant decline in pediatricians across the country, the Children’s Hospital GME Program provides ongoing and consistent financial support for the training of physicians who want to specialize in pediatrics. Over the years, the program has been enormously successful in reversing this trend; indeed, today children’s hospitals supported by the program train 40% of all pediatricians and 43% of all pediatric specialists.

The focus on training of pediatric specialists is especially critical because experts report that we need more of them. They have recommended, for example, expansions of graduate medical education for pediatrics by as much as 75% for pediatric rheumatologists.

Like the Children’s Hospital GME Program, the Affordable Care Act’s new loan repayment program for pediatric subspecialists is designed to help meet these kinds of needs. I would hope that both of these programs receive the level of funding support they require.

Unfortunately, the President's budget for Fiscal Year 2012 eliminates completely funding for the Children's Hospital GME Program. I believe this position is ill advised and short sighted and should not stand. Nonetheless, it is important that we enact the Pitts-Pallone Children's Hospital GME reauthorization bill not only to ensure that the program remains in place, but also to send a strong message about the need to fully fund it.

That is the same bi-partisan message we send in taking up H.R. 2005, Congressman Doyle's and Chris Smith's bill to reauthorize the Combating Autism Act. Origins of this Act go back to 2000 with the rising concern about the increased prevalence of autism. That concern continues today with CDC now estimating that the autism spectrum affects one in every 110 American children, and one of every 70 boys.

The Combating Autism Act encompasses a number of different programs – research at NIH, surveillance and epidemiological research at CDC; regional centers of excellence on autism spectrum disorders and other developmental disabilities; and various public education efforts. All have made significant contributions in the nation's effort to better understand and address this very difficult diagnosis. All remain critically important to advance the cause. And all are reauthorized in H.R. 2005.

I look forward to working with my colleagues in moving forward with both of these important pieces of legislation. We begin that process today with this hearing.

I want to thank our witnesses for appearing before the Subcommittee and look forward as well to their testimony.

Statement from Representative John D. Dingell
House Committee on Energy and Commerce
Subcommittee on Health
"Legislative Hearing on Miscellaneous Public Health Legislation"
July 11, 2011

Mr. Chairman, thank you for holding today's hearing.

Since I was elected to the U.S. House of Representatives, I have always strived to ensure that our nation's children – the future of our country – have access to high-quality, effective medical care. The two pieces of legislation before us today have made enormous strides towards meeting this goal, which is why I am pleased to voice my support for H.R. 1852 and H.R. 2005.

I supported the creation of the Children's Hospital Graduate Medical Education (GME) program in 1999 not only because of the significant contribution it made to our national health care workforce, but more importantly it represented a historic investment in the health of our nation's children. This program has enjoyed broad bipartisan support over the years, and I am proud to join with my colleagues Health Subcommittee Chairman Pitts and Health Subcommittee Ranking Member Pallone as a cosponsor of H.R. 1852, the Children's Hospital GME Reauthorization Act of 2011.

The Children's Hospital GME program has proven to be extremely successful given that its recipient hospitals make up only one percent of all hospitals, but train 40 percent of all pediatricians and 43 percent of all pediatric specialists. In addition, its funding has enabled children's teaching hospitals to reverse a 13 percent decline in pediatric residencies that occurred prior to the program's enactment and enabled these teaching hospitals to expand their programs by 35 percent in response to local, state and national needs.

Earlier this year, the Administration proposed eliminating the program. I strongly oppose this proposal. Eliminating this program would have a drastic negative impact on access to primary care, and would yield a devastating blow for our children and their vital access to specialty care. While I appreciate the difficult decisions the Administration has to make, I do not believe cutting funding for a successful program that has largely met the goals laid out for it makes fiscal sense. I hope my colleagues will agree with me and join me in supporting the reauthorization of this critical program.

I also want to voice my strong support for the Combating Autism Reauthorization Act or H.R. 2005. Autism affects 1 in 110 children and 1 in every 70 boys nationwide. Through the Combating Autism Act, Congress and the federal government have focused our efforts to provide increased research and services to address this disorder. The costs of Autism Spectrum Disorder to affected families, people, and society are enormous. The cost to society is currently estimated to be \$35 - \$90 billion annually. Although research and services for Autism Spectrum Disorder have expanded in recent years, more must be done to help families facing this challenge.

I am honored to host two world class autism centers in my district: the Autism and Communications Disorder Center at the University of Michigan and the Autism Collaborative Center at Eastern Michigan University. While the University of Michigan Center is scheduled to close this fall, the Autism Collaborative at EMU will continue and will luckily fill that void. The EMU Autism Collaborative offers diagnostic assessments, services, and training at a greatly reduced price to families. These services are essential for these individuals and families who cannot afford them on their own.

Reauthorization of the Combating Autism Act will further encourage the federal government to work with educational institutions and private organizations to identify and develop early diagnostic tests, as well as encourage development of new effective treatments for people with autism and their families. If we are to continue the momentum of the research being done at NIH, CDC and HRSA, as well as to continue to improve the quality of life for individuals with autism and their families, then we must reauthorize this critical program. I urge my colleagues support for H.R. 2005.

As I have said before, children are 25 percent of the population in our country, but they are 100 percent of the future. I will continue to lend my support to programs that are dedicated to providing and improving the quality of health care our nation's children need and deserve, and I hope that this Committee will join me. Together we can continue to advance such measures together on a bipartisan basis.

FRED UPTON, MICHIGAN
CHAIRMAN

HENRY A. WAXMAN, CALIFORNIA
RANKING MEMBER

ONE HUNDRED TWELFTH CONGRESS
Congress of the United States
House of Representatives
COMMITTEE ON ENERGY AND COMMERCE
2125 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515-6115

Majority (202) 225-2927
Minority (202) 225-3641

July 27, 2011

Dr. Thomas R. Insel
Director
National Institute of Mental Health
National Institutes of Health
6001 Executive Boulevard, Room 8235
Bethesda, MD 20892

Dear Dr. Insel:

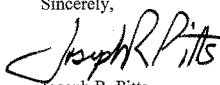
Thank you for appearing before the Subcommittee on Health on Monday, July 11, 2011, to testify at the hearing on public health legislation.

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for 10 business days to permit Members to submit additional questions to witnesses, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and then (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please e-mail your responses, in Word format, to the Legislative Clerk (katie.novaria@mail.house.gov) by the close of business on Wednesday, August 10, 2011.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,



Joseph R. Pitts
Chairman
Subcommittee on Health

cc: Congressman Frank Pallone, Ranking Member, Subcommittee on Health

Questions for the Record

Hearing: The Combating Autism Act (Miscellaneous Health Legislation)
 U.S. House of Representatives Energy and Commerce Subcommittee on Health, July 11, 2011

The Honorable Michael Burgess

- 1) **The research on autism conducted in the Autism Centers of Excellence has been described by some as “redundant” and too focused on gene and diagnosis research – and not on, for example, autoimmune problems. In addition, there is concern that administrative costs are too high and take funds away from research. Would you comment on these criticisms?**

The research that the NIH supports through the Autism Centers of Excellence (ACE) program spans a wide variety of medical and behavioral science disciplines as called for in the Combating Autism Act of 2006 (PL 109-416). In addition to studying the genetic risk factors that may contribute to autism spectrum disorder (ASD) and ways to improve methods for reliable and accurate diagnosis, the 11 ACE centers and networks also conduct research on how brain development and function is affected by ASD, the role of potential environmental risk factors for ASD, development of critically-needed social and behavioral treatments for children and adults on the autism spectrum, and identifying effective drug therapies to ameliorate behavioral and physical symptoms associated with ASD.

For example, in the effort to identify potential environmental causes of ASD, three primary objectives of the Early Autism Risk Longitudinal Investigation (EARLI) network at Drexel University are to: a) determine whether indicators of a mother’s immune function, measured during pregnancy, at delivery, and six months post-partum, are associated with risk for developing ASD, b) investigate whether exposure of mothers during pregnancy to persistent organic pollutants is associated with autism risk, and c) explore possible maternal and child epigenetic changes (modifications to molecules that bind DNA and alter gene expression) as predictors of ASD risk.

In the area of treatment, ACE projects are developing and testing interventions targeted to infants and toddlers. For example, an ACE research project at the University of California, Davis MIND Institute is conducting a randomized control trial of an early intensive behavioral intervention known as the Early Start Denver Model (ESDM), building on the results of an earlier successful trial. The new study will involve over 100 toddlers from three different sites and will evaluate the efficacy of the intervention for improving child outcomes after 12 and 24 months of treatment.

Autism is a complex and multidimensional neurodevelopmental disorder that affects all aspects of an individual’s life. In recognition of this, the ACE programs are tackling this disorder using a wide array of approaches from a number of different medical disciplines. Each center fosters sharing of knowledge and information among its researchers so that different approaches can inform one another, resulting in synergy and development of multifaceted solutions to this complex disorder. For example, the ACE center at the University of Illinois at Chicago focuses

on the study of “insistence on sameness” (a core behavior in autism) from genetic, neurobiological, cognitive neuroscience, and pharmacological approaches. UCLA’s center focuses on the core communication deficits in ASD by studying the relationship between the variability of language and genetic factors and conducting a communication intervention. And the UNC Chapel Hill ACE program, which focuses on longitudinal studies of brain enlargement in young infants, also received co-funding from Autism Speaks and the Simons foundation to collect DNA and data on environmental exposures. The next planned phase of the ACE research initiative will be guided by the latest version of the IACC Strategic Plan for ASD Research, which itself reflects the multifaceted approaches needed to study and treat autism spectrum disorders.

With respect to the questions regarding administrative costs of the ACEs, the indirect cost rate for each grantee institution is set through a negotiation between the Department of Health and Human Services and the grantee institution, and once negotiated, the same rate applies to all federal grants at that institution. Thus, the indirect cost for each ACE award is precisely the same as the rate negotiated for all other federal research grants at that grantee institution. These rates vary across institutions and cover items such as facilities operation and maintenance costs, depreciation and administrative costs that are required in order for an institution to operate and support the conduct of research.

2) Can you provide budget information on the Autism Centers of Excellence, especially related to overhead and indirect costs?

Please see attached spreadsheet with direct, indirect and total costs for each NIH Autism Center of Excellence from 2008-2010.

The Honorable Bill Cassidy

1) Please provide me with the following data requests for all of the disorders included in the Autism Spectrum Disorder:

a. The total number of individuals living with each disorder

Providing a precise accounting of the total number of individuals living with ASD is not possible at this time for several reasons. First, CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network monitors the prevalence of ASDs among eight-year-old children in various geographic regions across the United States. Studies have focused on eight-year-olds as this has been determined to be the age at which the most children have been identified and represents the peak prevalence estimate. Providing an estimate of *all* individuals living with ASDs would require CDC to monitor the prevalence in all age groups including adults. The ADDM Network, to date, has monitored the conditions only in children. There are currently no U.S. prevalence estimates for adult populations.

Second, the ADDM Network reports prevalence estimates for all ASDs collectively, not by subtype. Roughly 2/3 to 3/4 of children identified with ASDs by the ADDM Network have a specific subtype diagnosed, therefore prevalence estimates based on subtypes would be understated. However, ADDM data suggest that approximately 10% of children with ASDs have Asperger's syndrome.

To address this question using ADDM data, we must extrapolate from the current estimate and assume unvarying prevalence in the current population of individuals ages 0 to 21. This yields an estimated 730,000 individuals between the ages of 0 to 21 with ASDs. This extrapolated estimate is based on the average ASD prevalence from all sites in the ADDM Network 2006 surveillance year, reporting 1 in 110 8-year-old children with an ASD (CDC, 2009). The ADDM Network identified a significant increase in ASD prevalence from 2002 to 2006 (57%) and will be publishing its next prevalence report for 2008 within the next 6 months. When these new data are published CDC will reassess the relevancy of this extrapolated estimate.

b. The cost of a treatment intervention for each disorder

Children and adults with ASD receive a variety of interventions based on the severity of the disorder in each individual and factors such as availability and access to interventions and individual or parent/caregiver preference. These interventions can include Applied Behavioral Analysis (ABA) therapy, other behavioral interventions, speech and language therapy, occupational therapy, educational interventions, medications and alternative and complementary interventions. According to a study by Washington University social work researcher, Dr. Paul Shattuck, a full-time ABA intervention, which may be used by families of children with severe ASD, can cost families an estimated \$41,295 per year (Shattuck et al., 2009). This is a simplified estimate only taking into account one category of therapy. Actual costs for any given family can vary widely, however, depending on the interventions used.

According to Harvard School of Public Health professor, Dr. Michael Ganz, the lifetime per capita incremental societal cost of autism is \$3.2 million. This estimate includes both direct (medical and nonmedical) and indirect costs. Direct medical costs typically include physician and other professional services, hospital and emergency department services, drugs, equipment and other supplies, and the cost of medically related travel and time. Special education, transportation, child care, respite care, out-of-home placement, home and vehicle modifications, and supported employment services are generally included as direct nonmedical costs. Indirect costs measure the value of lost or impaired work time (income), benefits, and household services of individuals with autism and their caregivers because of missed time at work, reduced work hours, switching to a lower-paying but more flexible job, or leaving the workforce. For autism, the indirect costs of lost productivity and adult care (not direct medical costs) were found to be the largest

cost components. Expenses vary across the lifespan depending on the severity of ASD and the services needed, with direct medical costs highest between ages 3-7 and indirect costs peaking at ages 23-27, when there is a high amount of lost productivity for people with autism (Ganz 2007).

c. The number and percentage of individuals that currently benefit from a treatment intervention

Your answer should include a definition of benefit. Variations in benefit ranging from total resolution to marginal improvement and all categories in between should be distinguished in your answer.

No peer reviewed data are available on the number of individuals with ASD nationwide receiving various interventions and the effectiveness of each intervention and/or combination of interventions in the population. As described above, any given individual with autism may be receiving one or more interventions such as Applied Behavioral Analysis (ABA) therapy, other behavioral interventions, speech and language therapy, occupational therapy, educational interventions, medications and alternative and complementary interventions. Interventions received may depend on availability, access, and individual/parental caregiver preference. Clinical trials are being conducted on specific interventions, and their results are measured according to standards used in the field, but the research does not generally measure or gauge individual outcomes on the basis of a range from "marginal improvement to total resolution." Efficacy (benefit) is usually measured based on improvement in specific skills or behaviors as measured by standardized assessment tools or by measures designed for the specific study conducted.

The following recent research results reflect current knowledge about efficacy of behavioral interventions. For each, a brief description of the results is provided, along with references to the original research articles, where detailed information about the measures of efficacy and the tools used for assessment can be found.

- A recent study by NIH Autism Center of Excellence researcher, Dr. Sally Rogers, has shown significant positive effects in toddlers of an intervention called the Early Start Denver Model (ESDM), which is a relationship-based approach that draws on elements of Applied Behavior Analysis (ABA), a style of therapy that emphasizes breaking activities into small, measurable units that are then reinforced with reward. In this randomized, controlled intervention trial of 48 children diagnosed with ASD between 18 and 30 months of age, the cognitive ability of the ESDM group on average improved 17.6 standard score points (1 standard deviation = 15 points) compared with 7.0 points in the comparison group relative to baseline scores after 2 years of intervention. The children in the ESDM group also showed continued growth in adaptive behaviors (e.g., brushing teeth, getting dressed, eating with utensils, etc.), while the children in the control group

fell further behind their typically developing peers. Notably, 7 of the 24 children in the Early Start Denver Model group had significant enough improvements to change from a diagnosis of autistic disorder to PDD-NOS, a milder form of ASD. Only one of the children in the control group had a change in diagnosis (Dawson et al., 2010). The significant cognitive gains and change in diagnosis from a more severe form of ASD to a milder form are the measureable benefits of this intervention.

- NIH-supported researcher, Dr. Rebecca Landa of the Kennedy Krieger Institute, conducted a randomized clinical trial in toddlers with ASD that introduced a curriculum focused on social engagement and joint attention skills as an addition to an ongoing comprehensive behavioral intervention. Joint attention refers to the development of specific skills that involve sharing attention with others through pointing, showing, and coordinating looks between objects and people; this skill is impaired in children with ASD. Fifty children participated and were randomized to treatment (joint attention intervention plus standard treatment) and control (standard treatment only) groups. Children in both groups made improvements in social, cognitive and language skills during the six-month intervention period. Children who received the social intervention made greater and more rapid gains than those in the control group. The researchers also noted that children in the social intervention group used their newly acquired abilities with different people, locations, and type of activity. This is noteworthy because children with ASD have particular difficulty doing so. They tend to use new skills mostly within familiar routines and situations. The additional curriculum (which incurred no additional treatment cost to provide) more than doubled (17% to 42%) the amount of imitated acts paired with eye contact in the experimental group (Landa et al., 2011).
- A randomized, controlled trial of an intervention to improve joint attention in toddlers, conducted by NIH-supported researcher Dr. Connie Kasari, has also been successful, suggesting that short-term interventions administered by parents who have received training in the intervention's methods can have important effects on core impairments in toddlers with autism (Kasari et al., 2010). For children with autism, both joint attention skills and sustained joint engagement are significantly impaired. Results of this study of 38 children with autism and 19 controls and their parents/caregivers showed statistically significant gains for the intervention group engaged in joint engagement (as opposed to object-focused play) than the control group as measured by counts of instances of joint attention during targeted mother-child play interactions during the study, according to the specifications of the study design.
- A national survey of parents and guardians of young adults with autism spectrum disorders (aged 19-23 years) was analyzed to compare rates of service use during

and after high school (Shattuck et al., 2011). Services examined included mental health services, medical evaluation and assessment, speech therapy, and case management. Seventy-five percent of parents surveyed indicated that their child received speech therapy during high school. However, this dropped to only 9% in the post-high school years. The rate of young adults receiving medical evaluation and assessment services dropped from 47% to 24%, those using mental health services decreased from 46% to 35%, and recipients of case management services declined from 64% to 42%. While this study provides some clues regarding the percentage of people with ASDs that benefit from treatment interventions and services (based on a sample of 410 individuals), it also points to the great need for transition services for young adults with ASD. In the survey, 39% of respondents reported that their child received no services following high school. The study also indicated that individuals with higher functional mental skills were more likely to receive no services and less likely to receive case management or medical services, indicating that less cost for their care would be incurred over their lifetime. In this survey, about 23% of participants were categorized as having high functioning mental skills.

The Honorable Mike Doyle

- 1) During the hearing, Dr. Insel testified that funding for all of the programs under the Combating Autism Act are authorized to continue with or without reauthorization except the IACC. I have heard since from key stakeholders that continuing many of the activities would be extremely difficult without the specific authorization from Congress to do so. Could you please clarify what you think the impacts of not reauthorizing the CAA would have on the programs and activities authorized under the law and provide information on the obstacles that the various participating federal agencies would experience in continuing to implement the activities currently authorized under the law?**

Reauthorization of the CAA would enable currently authorized programs to continue uninterrupted. As the Secretary remarked on April 25, 2011 in her statement for Autism Awareness Day, she and the President fully support reauthorizing the Combating Autism Act this year because there is still “important work to do – more research to carry out, more treatment to develop and refine, and more tools to give doctors and nurses so they can get even better at diagnosing autism early.”

To clarify previous testimony, at least one activity could not continue without reauthorization due to the sunset provisions in the CAA. Without reauthorization, the Interagency Autism Coordinating Committee (IACC) will sunset on September 30, 2011 and its role in coordinating agency efforts and providing a forum for public participation will cease. The CAA’s authorization of the IACC has provided a framework to coordinate federal efforts, promote public-private partnerships, and spur rapid progress in autism research over the past five years. Without the IACC, this progress may be slowed or hampered.

Also scheduled to sunset on September 30, 2011 are the Health Resources and Services Administration's (HRSA) autism education and early detection and intervention activities. Without reauthorization of the CAA, HRSA would have to terminate grants for training programs, intervention research, and State demonstration grants. HRSA might be able to fund these activities through a different authority, but this approach would require significant administrative work and burden, including on the part of existing grantees, that could cause interruption to current activities absent reauthorization. To fund these activities through a different mechanism could require some ongoing programs to be reduced.

The CAA has served to ensure that autism programs are prioritized and implemented in a coordinated manner across the federal agencies, with collaboration from private partners in many cases, and with the input and participation of the public. This coordination and collaboration has accelerated the pace of autism research over the past five years, resulting in gains in knowledge about the disorder and new possibilities for early diagnosis and treatment. The administration believes that reauthorization of the CAA is critical to maintaining continuity and would provide an important opportunity to continue building on the momentum of progress.

The FY 2012 President's Budget includes language that would allow HRSA's activities under the Act to continue into FY 2012 absent a reauthorization.

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Autism Centers of Excellence - Principal Investigators

RFA HD06-016

Grant #	First	Last	Institution	Project Title	FY08			FY09			FY10		
					Direct Costs	Indirect Costs	Total Cost	Direct Costs	Indirect Costs	Total Cost	Direct Costs	Indirect Costs	Total Cost
1-P50-HD055748-01	Nancy	Minshew	University of Pittsburgh	Biological and Information Processing Mechanisms Underlying Autism	\$1,503,328	\$527,779	\$1,788,188	\$1,847,482	\$589,522	\$2,293,139	\$1,510,011	\$497,067	\$1,868,838
1-P50-HD055751-01	Edwin	Cook	University of Illinois, Chicago	ACE: Translational Studies of Insistence on Sameness in Autism	\$1,269,689	\$615,792	\$1,885,481	\$1,272,171	\$615,709	\$1,887,880	\$1,303,274	\$609,416	\$1,912,690
1-P50-HD055782-01	Bryan	King	University of Washington	UW Autism Center of Excellence	\$1,577,134	\$770,705	\$2,205,452	\$1,465,799	\$739,653	\$2,205,452	\$1,451,140	\$728,692	\$2,179,832
1-P50-HD055784-01	Susan	Bookheimer	University of California, Los Angeles	Determinants of Social, Communicative, and Other Core Deficits in Autism	\$1,756,803	\$913,650	\$2,231,564	\$1,729,231	\$908,415	\$2,609,657	\$1,452,985	\$759,473	\$2,212,458
1-P50-MH081755-01	Eric	Courchesne	University of California, San Diego	Biomarkers of Autism at 12 Months: From Brain Overgrowth to Genes	\$1,321,626	\$595,387	\$1,917,013	\$1,420,980	\$560,706	\$1,981,686	\$1,459,331	\$543,930	\$1,963,695
1-P50-MH081756-01	Fred	Volkmar	Yale University	Mechanisms of Social Engagement in ASD	\$1,572,567	\$939,125	\$2,511,692	\$1,573,199	\$907,402	\$2,480,601	\$1,686,465	\$977,490	\$2,440,136

ACE Networks - Principal Investigators

RFA HD06-004

Grant #	First	Last	Institution	Project Title	FY08			FY09			FY10		
					Direct Costs	Indirect Costs	Total Cost	Direct Costs	Indirect Costs	Total Cost	Direct Costs	Indirect Costs	Total Cost
1-R01-ES016443-01	Craig	Newschaffer	Drexel University	Early Autism Risk Longitudinal Investigation (EARLI) Network	\$2,481,307	\$261,692	\$2,742,999	\$3,438,508	\$302,304	\$3,740,812	\$2,797,167	\$173,926	\$2,971,093
1-R01-HD055741-01	Joe	Piven	University of North Carolina, Chapel Hill	A Longitudinal MRI Study of Infants at Risk for Autism	\$2,934,736	\$414,320	\$3,349,056	\$2,936,587	\$380,877	\$3,317,464	\$2,903,037	\$380,196	\$3,283,233
1-R01-MH081754-01	Dan	Geschwind	University of California, Los Angeles	A Comprehensive Approach to Identification of Autism Susceptibility Genes	\$2,471,439	\$560,337	\$3,031,776	\$2,437,385	\$489,518	\$2,895,517	\$2,397,246	\$456,132	\$2,823,814
1-R01-MH081757-01	Sally	Rogers	University of California, Davis	A Multi-Site Randomized Study of Intensive Treatment for Toddlers with Autism	\$2,650,590	\$320,535	\$2,971,125	\$4,334,839	\$663,455	\$2,968,118	\$2,614,889	\$305,204	\$2,920,093
1-U01-NS061264-01	Diane	Chugani	Wayne State University	Early Pharmacotherapy Guided by Biomarkers in Autism	\$960,479	\$239,520	\$1,199,999	\$894,734	\$227,638	\$100,000	\$865,423	\$134,577	\$1,000,000