IMPROVING THE FEDERAL RESPONSE TO CHALLENGES IN MENTAL HEALTH CARE IN AMERICA

HEARING

OF THE

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

UNITED STATES SENATE

ONE HUNDRED FOURTEENTH CONGRESS

SECOND SESSION

ON

EXAMINING IMPROVING THE FEDERAL RESPONSE TO CHALLENGES IN MENTAL HEALTH CARE IN AMERICA

JANUARY 20, 2016

Printed for the use of the Committee on Health, Education, Labor, and Pensions

Available via the World Wide Web: http://www.gpo.gov/fdsys/
CONTENTS

STATEMENTS

WEDNESDAY, JANUARY 20, 2016

Page

COMMITTEE MEMBERS

Alexander, Hon. Lamar, Chairman, Committee on Health, Education, Labor, and Pensions, opening statement ........................................ 1
Murray, Hon. Patty, a U.S. Senator from the State of Washington .......... 3
Mikulski, Hon. Barbara, a U.S. Senator from the State of Maryland .......... 5
Collins, Hon. Susan, a U.S. Senator from the State of Maine ................. 30
Murphy, Hon. Christopher S., a U.S. Senator from the State of Connecticut 32
Cassidy, Hon. Bill, M.D., a U.S. Senator from the State of Louisiana ........ 34
Warren, Hon. Elizabeth, a U.S. Senator from the State of Massachusetts .... 36
Franken, Hon. Al, a U.S. Senator from the State of Minnesota ............... 37
Whitehouse, Hon. Sheldon, a U.S. Senator from the State of Rhode Island ... 38

WITNESSES

Hepburn, Brian M., M.D., Executive Director, National Association of State Mental Health Program Directors, Alexandria, VA ....................... 7
Prepared statement ............................................................................. 8
Blake, Penny, RN, CCRN, CEN, Staff RN Emergency Department, Emergency Nurses Association, North Palm Beach, FL ......................... 11
Prepared statement ............................................................................. 13
Eaton, William W., Ph.D., Professor, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD .......... 16
Prepared statement ............................................................................. 17
Rahim, Hakeem, Ed.M., MA, CEO, Live Breathe LLC, Let’s Talk Mental Illness, National Alliance on Mental Illness, Hempstead, NY ............... 23
Prepared statement ............................................................................. 24

ADDITIONAL MATERIAL

Statements, articles, publications, letters, etc.:
Senator Casey ......................................................................................... 42
Senator Baldwin ................................................................................... 42
Response by Brian Hepburn, M.D. to questions of:
Senator Isakson .................................................................................. 43
Senator Murray ................................................................................... 43
Senator Casey ....................................................................................... 44
Senator Whitehouse ........................................................................... 45
Senator Baldwin .................................................................................. 46
Response by Penny Blake, RN, CCRN, CEN to questions of:
Senator Alexander ............................................................................. 47
Senator Casey ....................................................................................... 48
Senator Whitehouse ........................................................................... 49
Senator Baldwin .................................................................................. 50
Response by William W. Eaton, Ph.D. to question of Senator Whitehouse . 50

(III)
OPENING STATEMENT OF SENATOR ALEXANDER

Before we begin today’s hearing, I want to briefly mention for the information of committee our progress on two or three items on our agenda. Yesterday, I announced that we plan to hold our first markup on February 9th to consider the first set of bipartisan bills aimed at spurring biomedical innovation for American patients. Senators and staff have been working throughout 2015 on this, on a number of bipartisan pieces of legislation.

The House has completed its work on the 21st Century Cures Act. The president has reiterated his support for a precision medicine initiative and in the State of the Union address for a cancer moonshot. So it’s urgent that the Senate finish its work and turn into law these ideas that will help virtually every American.

We’ve also been working for months together on legislation to help achieve interoperability of electronic health care records for doctors, hospitals, and their patients. We have a lot of agreement on what to do about that, and the committee will be releasing today a bipartisan staff draft of that legislation for public comment.

This February markup will be the first of three committee meetings that have been planned to debate and amend bills as the committee moves forward on the goal of modernizing the FDA and the NIH to get safe, cutting-edge drugs and devices to patients more quickly. The bills that will be considered in February have bipar-
tisan co-sponsorship by committee members. The same with those that will be considered in April.

In addition, this year, the committee intends to be busy on oversight of the Every Student Succeeds Act. A law that is not implemented properly isn’t worth the paper it’s written on. So we’ll be spending time on making sure the Department of Education implements that the way the Congress wrote it and the way the President signed it.

Of course, we’ve done a lot of work on reauthorizing Higher Education, which expired at the end of last year. We have a number of bipartisan proposals that will make it easier and simpler for students to attend college and for administrators to manage our 6,000 colleges and universities.

We have a lot that we ought to be able to do this year. One of the most important of those items has to do with the mental health crisis that we’re discussing today. I hope—and Senator Murray and I agree on this—that we can move promptly to offer bipartisan recommendations on how to address the mental health crisis. We’ve already done a lot of work on it. We passed in September the Mental Health Awareness and Improvement Act that Senator Murray and I introduced. The Senate passed that in December.

Senator Cassidy and Senator Murphy have introduced legislation, and Senator Murray and I are working with them. We hope to move promptly to bring a combination of those recommendations to the full committee.

Not everything the Senate may want to do is in our jurisdiction. So we’re working with Senator Blunt, who, with Senator Murray, runs the Health Appropriations Subcommittee, on ideas that Senator Blunt has proposed, and we’re working with Senator Cornyn on issues that the Judiciary Committee is considering and with the Finance Committee, which will probably have to be involved as well.

What we want to do is to move promptly in this committee to take the things that are within our jurisdiction and have them ready for the floor and work in parallel with the other committees so the leader can bring them to the floor if he chooses to do that.

The reason there is such interest in the mental health crisis today is that about one in five adults had a mental health condition in the past year, according to the Mental Health Services Administration. That’s nearly 10 million adults with illnesses such as schizophrenia, bipolar disorder, or depression that interferes with a major life activity.

And 60 percent of adults with mental illness did not receive mental health services in 2014. Only about half of adolescents with a mental health condition received treatment for their condition. Mental health conditions that remain untreated can lead to dropping out of school, substance abuse, incarceration, unemployment, homelessness, and suicide.

Suicide is the 10th leading cause of death in the United States, and 90 percent of those who die by suicide have an underlying mental illness. I hear that from many Tennesseans. Between 2010 and 2012, nearly 21 percent—that’s one out of five adults in Tennessee—reported having a mental illness. Four percent had a serious mental illness. The most recent data shows that our rate of sui-
cide reached its highest level in 5 years a couple of years ago. It was the second leading cause of death.

At our October hearing on mental health, the committee heard from administration witnesses about what the Federal Government is already doing to address mental illness. Today, we look forward to hearing from doctors, nurses, advocates, and administrators who work every day with Americans who struggle with a mental health condition about how the Federal Government can help patients, health care providers, communities, and States to better address these issues. We want people to be able to take advantage of the most innovative research. We heard some about that at our recent hearing, about the RAISE study.

I'm interested to hear how the government can support State efforts to implement evidence-based treatment programs. This will require modernizing our leading Federal agency for mental health. It will require involvement from patients, families, communities, health care providers, health departments, law enforcement, State partners, and many others who are involved. I look forward to hearing from our witnesses about the challenges we face and the solutions that they offer.

Senator Murray.

OPENING STATEMENT OF SENATOR MURRAY

Senator Murray. Thank you very much, Chairman Alexander.

Thank you to all of our colleagues who are here today. I am really glad that we have this opportunity today to continue our discussion about ways to improve our mental health care system.

We have a really incredible group of witnesses today joining us to share your expertise and experiences. Thank you all for coming.

As I'm sure all of us do, I hear far too often from families in Washington State about loved ones, friends, and neighbors who are struggling with mental illness and aren't getting the support they need. It is heartbreaking, especially because when someone does get treatment and support, it can truly make a difference.

I recently heard from a woman in Seattle, who I will call Amanda. She was experiencing mental illness so severe that she lived in a dumpster for fear of being abducted by aliens. Case managers were able to get her the appropriate medication she needed. They also connected her with primary care, housing, and supplemental security income benefits. Today, Amanda is enrolled in school and pursuing her degree with hopes of full-time employment. That is quite a change for her.

My constituent, Jack's, story is similarly powerful. Jack is a veteran from King County. He enrolled in outpatient support services after he was hospitalized several times for attempted suicide. He had serious addiction problems and was becoming alienated from his family. But after being connected with support, he was able to find recovery, even while he was being treated for cancer. He now lives independently and is reconnecting with his teenage son.

Amanda's and Jack's stories show that comprehensive, high-quality mental health care can truly give someone their life back. But, unfortunately, a lot of stories don't end that way. In fact, only 63 percent of people with serious mental health illness received treatment in the past year.
I'm going to focus on a few challenges in particular today, ones which I believe our witnesses will have a lot to say about as well. The first is inadequate access to treatment. Far too many communities lack access to mental health professionals. In fact, half of all U.S. counties don't have a single psychiatrist, psychologist, or social worker. That means for many patients and families, it is unclear where to turn for help. So we need to make sure communities have access to trained professionals who can intervene, treat, and support those struggling with mental illness.

And, in addition to strengthening our mental health workforce, we need to make sure that when someone presents in crisis, or simply chooses to seek help, there are providers who can take them in and meet their needs. No patient should be turned away, asked to wait in an emergency room for days, or be left out on the street because there isn't an available bed.

Ms. Blake, I'm sure this is a problem you have seen all too often in the ER. I think we can and must do better on this, and I'm looking forward to hearing all of your thoughts.

Another issue I am really eager to talk about today is the need to truly integrate mental and physical health care. The two stories I shared a minute ago have something especially important in common. Amanda didn't just need psychiatric help. She needed primary care. Jack needed help with addiction and depression, but during the course of his recovery, he also needed treatment for cancer.

The siloes that exist between mental health care and physical health care don't match patients' realities, and that needs to change. The legislation that Senators Murphy and Cassidy have worked on together would take some very important steps to better integrate mental and physical health care.

I am also interested in some innovative steps being taken at the State level. For example, in my State, the University of Washington has a residency program that allows students focused on psychiatry to get experience working in physical health settings.

Dr. Hepburn, I know you are focused on this challenge in your work, and I'm grateful that we'll have your insights today.

And, finally, I want to reiterate something I mentioned at our last hearing. If we are going to confront the challenges I've laid out today and many others within our mental health system, we have to break down the barriers that stigma creates for those suffering from mental illness. That means prioritizing research like Dr. Eaton's, which helps enhance our understanding of and ability to effectively treat mental illnesses. And it means raising awareness so that those struggling don't feel they have to struggle alone.

Today, nearly one in five people in our country experience mental illness in a given year. Far too many of them don't receive treatment when they need it, and part of the reason is that stigma gets in their way.

Mr. Rahim, you've worked for over a decade to raise awareness and promote understanding of mental health in communities across the country. And you've been an inspiration to many people who otherwise might not have had the courage to seek help. So I want to thank you for your work, and I'm eager to hear what you think Congress should do to lend our voices to efforts like yours.
Again, thank you to all of our witnesses who are here today. We have a lot of urgent work ahead of us to make sure that our families and communities have access to the comprehensive, high-quality mental health care they need.

I look forward, Mr. Chairman, to working on a bipartisan effort to strengthen our mental health system and give patients and families the opportunity to lead healthy, fulfilling lives.

Thank you.

The CHAIRMAN. Thank you, Senator Murray.

We welcome our four witnesses, and I thank you for arranging to be here. You all have busy schedules, other things to be doing. We're grateful to you for that.

I'm going to ask Senator Mikulski to introduce one of you since she has a conflict which will require her to leave soon.

STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. Thank you very much, Senator Alexander, and I want to thank you for your continuing progress on holding hearings on the issue of mental health. I know this is the third hearing on the topic, and I want to really salute you and Senator Murray for moving in this direction.

The Subcommittee on Commerce, Justice, Science, and Related Agencies of the Committee on Appropriations is holding a hearing on President Obama's proposals on gun control, and as the vice-chair, I must be at my duty station and will have to excuse myself. I really wanted to be at this hearing because of the fact that I'm a professionally trained social worker. We've been working on these issues all of my professional life. This is what I live for. This is why I came to the Senate, to listen to good people with great ideas on how we can help our people.

We have two distinguished Marylanders here. One, of course, is Dr. Hepburn, who headed up the State of Maryland's Agency on Health and Mental Health. He is a University of Maryland trained clinician who then went on to try to breathe mental health into a bureaucracy and then bring care to our people in a State that mandates an affordable budget. So we're going to have some great ideas.

Then we have Dr. Eaton here. Dr. William Eaton is a professor of the Department of Mental Health at the famous Johns Hopkins Bloomberg School of Public Health. Dr. Eaton is a professor there, and he chairs the Department of Mental Health. It is the only department-level unit in a school of public health in the world. Usually public health thinks about vaccinations. What Dr. Eaton thinks about is how we can build resilient personalities and do the preventive work.

He will talk to you today about his work, his research, his recommendations. Understanding, I believe, the thrust will be that everybody who has a mental health problem needs individual treatment, but they live in a social world, and we need to look at the social indicators, look at the social epidemiology, and how we can strengthen the anchor institutions of the family and the school.

You're going to learn a lot from him. I've already learned a lot from him, as I do from listening to the folks at Johns Hopkins
School of Public Health. I really look forward to where we’re going on this issue of mental health, in a nutshell.

When I got out of graduate school, Senator Alexander—I actually went to graduate school on a National Institutes of Health grant—they were training community mental health social workers. President Kennedy led the battle to establish community mental health centers, to get rid of the old snake pit type mental health hospitals.

All the practitioners at the table remember that, and, Mr. Rahim, I’m sure you’ve heard stories of that, and we welcome you here with your personal courage.

But maybe it’s not that we need new institutions. Maybe we have to look at what we thought we were going to do, and we never did it. We never followed through on community mental health centers. Maybe that’s the way to go.

We never followed through in the aggressive way to enforce the Wellstone-Domenici Mental Health Parity Act. Maybe that’s the way we need to go. And speaking as a social worker, along with the nurses, we know that mental health requires a team approach, and it is both, of course, the psychiatrists, which we need, but it’s those of us who are trained in these matters.

I know my colleagues would never think I had a therapeutic personality, but I look forward to working with you in the best way possible to advance the ideas that will come forth and how we can really meet this crisis that’s growing and expanding.

Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Mikulski.

We will now hear from our witnesses, and let me present them. Again, Dr. Hepburn has been mentioned. He’s the Executive Director of the National Association of State Mental Health Program Directors, which represents mental health service delivery systems in all 50 States. He’s been a clinical associate professor of psychiatry at the University of Maryland Medical System for nearly 20 years, and he has cared for patients for more than 20 years.

The second witness is Ms. Penny Blake, a registered nurse working in an emergency department in central Florida. She’s been a nurse for 40 years and has worked in an emergency department for 15 years. She chairs the National Advocacy Advisory Council for Emergency Nurses.

Dr. Eaton, who Senator Mikulski mentioned, is a professor at the Bloomberg School of Public Health, an expert in his field who has written hundreds of articles. Much of his work has focused on the co-occurrence of mental health disorders and other chronic health issues, like diabetes and heart disease.

Mr. Hakeem Rahim is the CEO of Live Breathe, an organization focused on mental health advocacy and reducing the stigma associated with mental health. He brings his own invaluable perspective of his own journey of mental illness, which began during his freshman year in college.

We look forward to hearing from the four of you. If you’ll each try to summarize your remarks in about 5 minutes, that will leave more time for the senators to have a conversation with you about your testimony.

Why don’t we start with Dr. Hepburn.
Dr. Hepburn. Thank you very much, Chairman Alexander, Ranking Member Murray, and Senator Mikulski. It’s hard to think of Maryland without Senator Mikulski. Thank you.

Thank you for the opportunity today to address this committee on State services regarding mental illness. Thanks go to this committee and its members and other members of the Senate and the House who are working to find ways to support, strengthen, and augment the country’s mental health system.

I want to especially thank, in addition to the chair and ranking member, Senators Cassidy and Murphy and also Senator Franken. I also want to congratulate Senator Franken on his second grandchild. That’s where it all starts, being a good grandparent.

We appreciate the full Congress passing Senator Cardin’s legislation on IMD Demonstration. Also, we appreciate the support from Congress on the First Episode Psychosis Program.

The organization which I represent, the National Association of State Mental Health Program Directors, represents the State executives of the Mental Health Authorities, representing agencies that have $41 billion in public mental health services and deliver services to 7.3 million people. The mission of NASMHPD is to work with the States and partners in order to promote wellness, recovery, and resiliency.

NASMHPD members work to promote prevention and early intervention, integration of behavioral health and physical health, trauma informed approaches, minimized consumer contact with police, develop the workforce, promote supported employment, supportive housing, and decrease homelessness, support the use of data and health information technology.

The State Mental Health Authorities vary widely in terms of how they’re organized. However, they share some common functions: planning and coordinating a comprehensive array of mental health services, submitting an annual application to the Block Grant, educating the public, operating and funding inpatient services. This could be with State hospitals, or it could be buying inpatient services in the private sector.

The State Mental Health Authorities work closely with SAMHSA, which has been an excellent partner for us. The acting administrator, Kana Enomoto, is a respected leader in the field. We appreciate having her as a leader and a partner.

SAMHSA has provided strong leadership in promoting the best practices for individuals with severe mental illness. The best example of that is the First Episode Psychosis Program. The First Episode Psychosis Program started with research. The research showed that it was a best practice. NIMH then worked with SAMHSA to promote the First Episode Psychosis Program. Its implementation is now across the country. It’s really an excellent way of showing how the Federal Government can work with the States and work with providers in order to promote a best practice.

It’s important to note that the role of the State Mental Health Authorities has changed over the last 30 years. Thirty years ago, the States were primarily involved in State hospitals. Seventy-five
percent of the budget went to State hospitals. Now, 75 percent of the budget goes to the community.

Thirty years ago, the private sector was not really addressing issues that are in the public sector. Now, it’s hard to separate public sector and private sector. When it comes to admissions to State hospitals, now, almost all the admissions are court related. Almost all the civil admissions were previously uninsured individuals going to State hospitals. Now, those uninsured individuals get the same care as insured individuals, and they go to the private sector.

I want to say something about the funding for the State Mental Health Authorities. Basically, the funding for most States is primarily from the States themselves, so that the State budget and Medicaid make up almost all that’s spent in the budget by the State Mental Health Authority. The Block Grant accounts for less than 1 percent of the funding for mental health within the States.

What are some additional actions that Congress and the Administration could take to support the State Mental Health Authorities? One is, as I indicated, the First Episode Psychosis Program, an excellent program. The fact that you’ve agreed to move it from 5 percent to 10 percent is excellent. What we would ask is for a change in the methodology. The smaller States are not able to move ahead with the First Episode Psychosis Program the way the larger States are because of the Block Grant methodology.

A second is to modify the Medicaid Institution of Mental Disease exclusion so that IMDs can get paid for taking care of individuals with Medicaid who are adults, at least, to start with the private sector. In Maryland, we participated with a demonstration that showed that the average length of stay in the private psychiatric hospitals were 10 days. Cost per episode was about the same as for the acute and general hospital psychiatric units.

We would ask to reauthorize the Medicaid Money Follows the Person. This has been a very important program in terms of helping to keep people——

The Chairman. Dr. Hepburn, could you wind down your testimony, please?

Dr. Hepburn. Yes, I’m sorry—to keep people out of institutions, promoting zero suicide, promoting technology, promoting smoking cessation, and supporting mental health and addiction parity. And with that, I will stop.

Thank you very much.

[The prepared statement of Dr. Hepburn follows:]

PREPARED STATEMENT OF BRIAN HEPBURN, M.D.

Chairman Alexander, Ranking Member Murray, and members of the Senate HELP Committee, thank you for the opportunity today to address the Senate HELP Committee on State services for individuals with mental illness. And our thanks go to this committee and its members, and other Members of Congress in the Senate and the House, who are working to find ways to support, strengthen, and augment the country’s mental health care delivery system through legislation. Thanks especially to the Chair and Ranking Member for their own Mental Health Awareness and Improvement Act, Senators Cassidy and Murphy for their Mental Health Reform Act, and Senators Franken and Cornyn for their Comprehensive Justice and Mental Health Act. We are also appreciative of the full Congress passing Senator Cardin’s Improving Access to Emergency Psychiatric Care Act and approving the additional moneys provided in the fiscal year 2016 budget for the Mental Health Block Grant.

The organization which I represent, the National Association of State Mental Health Program Directors (NASMHPD), represents the State executives of the State
Mental Health Agencies (SMHAs) responsible for the $41 billion public mental health service delivery systems serving 7.3 million people annually in 50 States, four territories, and the District of Columbia.

Prior to becoming NASMHPD's Executive Director in July 2015, I served 13 years as Maryland's Mental Health Program Director. I have also been a practicing psychiatrist.

The NASMHPD mission is to work with States, Federal partners, and stakeholders to promote wellness, recovery, and resiliency for individuals with mental health conditions or co-occurring mental health and substance related disorders across all ages and cultural groups, including youth, older persons, veterans and their families, and people under court jurisdiction.

In collaboration with States, Federal partners, and stakeholders, NASMHPD works to promote:

1. Prevention and Early Intervention.
2. Integration of behavioral health care (both mental health and substance abuse disorder treatment) with physical health care.
3. Trauma-Informed approaches to care across sectors, with civilians, veterans, and those in the correctional system.
4. Models and interventions that minimize contact with police, the courts, and correctional facilities.
5. The development and sustainability of an effective Behavioral Health Workforce.
6. The availability of supportive employment and supportive housing, and a reduction in homelessness for individuals with mental illness and or addictions.

The use of data and Health Information Technology to improve the quality of mental health services.

The SMHAs vary widely in how they are organized within each State government, how they pay for and organize their mental health service delivery systems, and their fiscal and staffing resources. However, all SMHAs share some common functions:

- Planning and coordinating a comprehensive array of mental health services with other State government Medicaid, correctional, educational, judicial, housing, and employment agencies, as well as local health and substance use disorder agencies, to meet the mental health treatment needs of individuals in their State;
- Submitting an annual comprehensive community Mental Health Block Grant (MHBG) plan to the Substance Abuse and Mental Health Services Administration (SAMHSA), and monitoring, collecting data, evaluating, and reporting to SAMHSA on the performance and outcomes of systems funded by the MHBG;
- Educating the public about mental illness and supporting public health prevention activities for mental health; and
- Operating inpatient services units that provide critical intensive treatment for individuals with high levels of need or who are at risk of harm to themselves or others—including individuals involuntarily committed by the courts—in public psychiatric hospitals or psychiatric units in general hospitals and/or, increasingly, funding inpatient psychiatric services in private psychiatric hospitals or psychiatric units of private general hospitals.

In all of these functions, the SMHAs work closely with SAMHSA, which provides needed technical assistance and identifies and funds peer-reviewed, evidence-based practices to meet consumer needs. SAMHSA has been an excellent partner. Acting Administrator Kana Enomoto is a respected leader in the field, with a strong clinical background. We appreciate the opportunity to have her as a leader and partner.

SAMHSA has provided strong leadership in promoting best practices for the severely mentally ill. The practices championed by SAMHSA and adopted by the States have included crisis services and crisis intervention teams and training and peer support services, as well as practices aimed at preventing suicide—such as the Zero Suicide initiative—and reducing homelessness, helping veterans find mental health and other supportive services, and addressing child and adolescent mental health through early intervention. In each of these programs and practices, SAMHSA and the States focus on promoting a recovery-oriented and person-centered system of care that empowers consumers in their decisionmaking and enables them to receive services in the least restrictive and most integrated setting.

The role of SMHAs has changed over the past 30 years. They have moved from primarily running State hospitals and directly providing services to increasingly focusing on community services. Thirty years ago, the funding for State hospitals was two-thirds of State mental health budgets and community funding was one-third. That has now flipped, so that funding for community services is two-thirds and the State hospitals are one-third of State mental health budgets. The majority of admis-
sions to State hospitals 30 years ago were civil admissions of uninsured individuals. Now, most States have moved the civil admissions to private hospitals and the State hospitals are increasingly used for court-related admissions. In addition, most States are now contracting with the private sector to provide the direct services in the community.

It is also worth noting that 60 percent ($24.8 billion) of SMHA funding comes from State government revenues. The Federal Medicaid program is the second largest payer of SMHA mental health services (29 percent of SMHA funds, or $11.9 billion), followed by Medicare (1.7 percent). The MHBG constitutes just 1 percent of SMHA funding. MHBG funding—totaling $450.4 million in fiscal year 2015, varies widely by State under a consumer-based formula; in fiscal year 2015, State MHBG moneys ranged from California’s $63.1 million to Wyoming’s $535,764.

Among the effective, evidence-based practices identified and promoted by SAMSHA through its National Registry of Evidence-Based Programs and Practices (NREPP) are those intended to address First Episodes of Psychosis (FEP). Recognizing the demonstrated effectiveness of FEP pilots funded by the National Institute for Mental Health (NIMH) since 2008 in reducing incidences of untreated mental illness, Congress for the first time in fiscal year 2014 designated 5 percent of all MHBG moneys—and increased grant funding accordingly—for programs that address first episodes of serious mental illness, including projects based on NIMH’s RAISE (“Recovery After an Initial Schizophrenic Episode”) FEP model operating in States such as Connecticut, New York, and Maryland. For this fiscal year 2016, Congress has increased the block grant set-aside for FEP initiatives to 10 percent, again increasing block grant funding to cover the expanded set-aside.

States have also become increasingly involved in working with consumer advocates, peer support workers with lived experience, providers, and State insurance divisions to see that insurers comply with the Federal mental health and addiction parity mandates enacted in 2008 and 2010. Full compliance is still a work in progress, but NASMHPD is convinced that continuing education and monitoring of insurers by providers, consumers, and State agencies should eventually ensure that mental health and substance use benefits are subject to no restrictions—quantitative or non-quantitative—greater than those imposed on surgical and medical benefits.

As increased MHBG funding continues to be made available to the States by Congress, the States should be able to effectively grow their FEP services and the other community-based services for which payers and payment are scarce, such as crisis services, wraparound services, supported housing and supported employment, and ACA enrollment outreach. NASMHPD’s members are grateful for the assistance provided so far, and we look forward to continuing to work with SAMHSA and Congress in developing a continuum of evidence-based mental health care and services for each community.

What are some additional actions that Congress and the Administration could take to support the State Mental Health Authorities?

- Continue to support the set aside for First Episode Psychosis programs, but consider changing the allocation methodology so that States with smaller consumer populations and thus smaller block grants, like Rhode Island, Alaska, Maine, Vermont, Wyoming, North Dakota, and Delaware, may receive an amount sufficient to fully implement a working FEP program.
- Modify the Medicaid Institution for Mental Disease (IMD) exclusion so that IMDs are able to receive Medicaid funding for adults.
- Reauthorize the Medicaid Money Follows the Person program, due to expire September 30, which States such as Texas are using to help fund behavioral health services for individuals in home- and community-based settings.
- Support the Zero Suicide goal. The National Suicide Prevention Lifeline, with funding from SAMHSA under the Garrett Lee Smith Act, has developed an excellent hotline system across the country, linking callers with needed crisis services.
- Encourage the use of technology for mental health through reimbursement by Medicaid. As stigma has decreased and more persons are seeking mental health services, there is a workforce and access problem. Technology such as telehealth may be able to help with both. Internet services help to reach underserved rural, urban, and frontier areas.
- Support targeted efforts for smoking cessation in persons with mental illness. Persons with mental illness die at a much earlier age than the general population. This is primarily due to smoking.
- And, finally, support parity by strengthening monitoring and enforcement mechanisms.

Thank you for your attention to and consideration of this testimony.
Ms. Blake. Chairman Alexander, Ranking Member Murray, and members of the committee, thank you for inviting me to testify at this important hearing.

I'm an emergency nurse working full time in the emergency department at Good Samaritan Hospital in West Palm Beach. It’s an acute care community hospital. In addition to the work in the emergency department, I’m the chairperson of the Advocacy Advisory Council for the Emergency Nurses Association, which is the largest professional health care organization dedicated to improving emergency care.

As a registered nurse for almost 40 years, my career has been devoted to providing the best possible care to every person who comes into our hospital's emergency department. Increasingly, this involves treating patients who are suffering from mental illnesses.

The emergency department at my hospital has a capacity of 32 actual beds which can be expanded if necessary. It serves a very diverse community that includes extreme poverty and some of the wealthiest neighborhoods in the entire country.

Since the Federal law prohibits hospitals from turning away anyone seeking emergency care, I see practically every kind of urgent medical condition. But on a typical shift, at least 10 percent of our cases involve psychiatric patients.

The reasons for the surge in mental health patients include an increase in drug abuse, veterans returning from Iraq and Afghanistan who suffer from PTSD, and the stresses that are created by a weak economy and joblessness. But in my view, the principal cause is the lack of adequate treatment options and resources in the community. Mental health patients often find they have nowhere to turn for treatment, so they go to the one place, the emergency room, that's guaranteed to be open at all times and willing to care for every patient.

In Florida, a physician or law enforcement officer can invoke a State law that allows for the involuntary hold for up to 72 hours for a person who is deemed to be a threat to themselves or others. After a 72-hour hold is put on the patient, the emergency department physician must clear the patient of any physical illness, and then the patient is placed in a 10 by 10 room until we can find a facility that can accept the patient for evaluation by a psychiatrist, because at my hospital, we do not have any psychiatrists on staff, and we do not have a psychiatric unit.

So all patients requiring inpatient care must be transferred to one of the four psychiatric facilities in Palm Beach County. I cannot think of a single time in the past year that any of our patients has been accepted immediately when that request has been made.

A mentally ill patient typically stays in our ED between 12 and 24 hours before they are transferred to a psychiatric care facility. However, 2, 3, or even 4 days boarding in the emergency department is not unusual. This is also the case in other hospitals in
Palm Beach County, and the problem is made worse by the lack of insurance coverage for people who suffer from mental illnesses.

Our experience is consistent with research conducted by the Emergency Nurses Association that found that the average boarding time in the emergency department is 18 hours for psychiatric patients versus only 4 hours for all other types of patients. Inadequate community health services and extended boarding times are detrimental both for emergency departments and the care received by mental health patients.

For hospital EDs, mental health patients are both resource and personnel intensive. Not only do these patients stay in the emergency department much longer than other patients, but they often require close supervision by multiple staff and personalized medical attention. By necessity, it diverts nurses, doctors, and technicians from the treatment of the other patients who come through our doors.

Whenever a patient is placed on a 72-hour hold, we have a certain protocol we must follow in order to ensure that patient’s safety. A security guard in our facility is placed at the door. For the patients who are experiencing a mental health crisis, the emergency department is far from the ideal place to receive care. EDs are chaotic, often loud areas in the hospital, and the nurses and physicians are stretched to their limits in caring for the other patients.

Our emergency physicians are understandably reluctant to prescribe psychoactive medications for these patients because it’s not their area of expertise. So if a patient needs medication, we usually just give some form of antianxiety agent. They don’t begin any kind of therapeutic interventions because there’s no one there with professional psychiatric training to help provide it.

Imagine that you are stressed, anxious, possibly suicidal and/or psychotic, perhaps having hallucinations, and you’re confined to a small space. All your belongings are taken away from you so you can’t hurt yourself. A guard is at your door, and there’s constant chaos, noise, and motion. And because of the shortage of inpatient beds or community-based treatment and psychiatric options, this situation continues for many hours or even days.

Mental health care patients would be better served in facilities that have specialized expertise. The most important thing that we feel is needed is that communities must have the health care infrastructure and funding to provide resources needed to keep this population healthy. They need to have parity for insurance and the same kind of coverage that people with physical illnesses have and a high-quality, community-based mental health system which would include acute and longer term care, access to community mental health clinics, inpatient and outpatient treatment, and the availability of 24-hour crisis psychiatric care and services that will allow the patient to be integrated more fully into society.

I want to thank you for allowing me the opportunity to represent and speak for my fellow emergency nurses. We passionately care about providing the best possible care to all of our patients, and we strive for them to have the best outcomes possible for their illnesses. That includes those who are the most vulnerable in our society, the person who is suffering from mental illness.
Thank you.

[The prepared statement of Ms. Blake follows:]

PREPARED STATEMENT OF PENNY BLAKE, RN, CCRN, CEN

SUMMARY

Chairman Alexander, Ranking Member Murray, members of the committee, thank you for inviting me to testify at this important hearing. My name is Penny Blake and I am an emergency nurse working in the emergency department at Good Samaritan Medical Center in West Palm Beach, FL. I have been a registered nurse for almost 40 years. My entire career has been devoted to providing the best possible care to every person who comes into my hospital’s ED. Increasingly, this involves treating patients who are suffering from severe mental illnesses and substance abuse.

Since Federal law prohibits hospitals from turning away anyone seeking emergency care, I see practically every kind of urgent medical condition imaginable. However, at least 10 percent of our cases involve psychiatric patients. This percentage has grown tremendously in the past several decades.

There are multiple reasons for the surge in mental health patients coming to hospital emergency departments. However, in my view, the principal cause is the lack of adequate treatment options and resources in the community. The shortfall in community mental health resources often leads to the boarding of psychiatric patients in the emergency department.

In Florida, a physician or law enforcement officer can invoke the Baker Act, a State law that allows for the involuntary hold for up to 72 hours for a person deemed to be a threat to themselves or others. The typical length of time that a mentally ill patient stays in our ED before being transferred to a Baker Act facility is between 12 and 24 hours. However, 2, 3, or even 4 days boarding is not unusual. This is consistent with research conducted by ENA that found the average boarding time for psychiatric patients is 18 hours versus only 4 hours for all patients in the ED.

Inadequate community mental health services and extended boarding times are detrimental both for emergency departments and the care received by mental health patients. For hospital EDs, mental health patients are both resource- and personnel-intensive. By necessity, this diverts nurses, doctors and technicians from the treatment of other patients.

For patients experiencing a mental health crisis, the emergency department is far from the ideal place to receive care. By their nature, EDs are chaotic, often loud areas of the hospital where nurses and physicians are regularly stretched to their limits taking care of everything from traumatic injuries to heart attacks. In addition, specialists in psychiatric care are not always available to see patients. Mental health patients would be better served in facilities that have the specialized expertise to handle the complex diagnosis and treatment of mental illness.

Our mental health patients and their families deserve better care than we currently give them. Most importantly, communities must have the health care infrastructure and funding to provide the resources needed to keep this population healthy. A high-quality, community-based mental health system would include acute and longer term care, access to community mental health clinics, inpatient and outpatient treatment, the availability of 24-hour crisis psychiatric care and services that would allow for integrating the patient more fully into society.

Thank you for allowing me the opportunity to represent and speak for my fellow emergency nurses. We passionately care about providing the best possible care to ALL of our patients, and strive for them to have the best outcomes possible for their illnesses. This includes those who are among the most vulnerable in our society—the person suffering from a mental illness.

I. INTRODUCTION

Chairman Alexander, Ranking Member Murray, members of the committee, thank you for inviting me to testify at this important hearing. My name is Penny Blake and I am an emergency nurse working full-time in the emergency department at Good Samaritan Medical Center, an acute care community hospital in West Palm Beach, FL.

In addition to my work in the emergency department, I am the Chairperson of the Advocacy Advisory Council for the Emergency Nurses Association (ENA), the largest professional health care organization dedicated to improving emergency
nursing care. ENA has 41,000 members throughout the United States and around the world. I am also the Government Affairs Chair for the Florida Emergency Nurses Association and past president of the Palm Beach County chapter of ENA.

II. THE CHALLENGES CONFRONTING EMERGENCY DEPARTMENTS IN CARING FOR THE MENTALLY ILL

I have been a registered nurse for almost 40 years. The majority of that time has been at the bedside in critical care and, for the past 18 years, in the emergency department. My entire career has been devoted to providing the best possible care to every person who comes into my hospital's emergency department. Increasingly, this involves treating patients who are suffering from severe mental illnesses and substance abuse.

The emergency department at Good Samaritan Medical Center has a capacity of 32 actual beds, which can be expanded by utilizing the halls and walls when necessary. It serves a very diverse community that includes extreme poverty and homelessness, as well as some of the wealthiest neighborhoods in the entire country.

Our patient mix varies depending on the time of day or the day of the week. Since Federal law prohibits hospitals from turning away anyone seeking emergency care, I see practically every kind of urgent medical condition imaginable. However, on a typical shift, at least 10 percent of our cases involve psychiatric patients. This percentage has grown tremendously in the past several decades.

There are multiple reasons for the surge in mental health patients coming to hospital emergency departments. These include an increase in drug abuse, the large number of veterans returning from Iraq and Afghanistan who suffer from PTSD, and the stresses created by a weak economy and joblessness.

However, in my view, the principal cause is the lack of adequate treatment options and resources in the community. Mental health patients often find they have nowhere to turn for treatment, so they go to the one place—emergency departments—guaranteed to be open at all times and willing to care for every patient.

In my hospital, the shortfall in community mental health resources often leads to the boarding of psychiatric patients in the emergency department.

In Florida, a physician or law enforcement officer can invoke the Baker Act, which is a State law that allows for the involuntary hold for up to 72 hours for a person who is deemed to be a threat to themselves or others.

At Good Samaritan, after a hold is put on a patient, the ED physician must clear the patient of any physical illness. The patient is then placed in a 10 x 10 room until we can find a facility that can accept the patient for evaluation by a psychiatrist to determine if continued inpatient treatment is warranted.

My hospital does not have psychiatrists on staff, nor do we have a psychiatric unit. Therefore, all patients requiring inpatient care must be transferred to one of the four psychiatric facilities in Palm Beach County. I cannot think of a single time in the past year that any of our patients has been accepted immediately when the request has been made.

The typical length of time that a mentally ill patient stays in our ED before they are transferred to a Baker Act facility is between 12 and 24 hours. However, 2, 3, or even 4 days boarding in the emergency department is not unusual. Based on conversations I have had with colleagues, this is also the case in other hospitals throughout the Palm Beach County area.

Last year, I visited the ED at a hospital in the southern part of the county. They had 14 patients lined up on stretchers in one of their hallway wings, all awaiting placement in inpatient psychiatric facilities. I was told that was a typical day for them. This problem is made worse by the lack of insurance coverage for people who suffer from mental illness.

My personal observations are consistent with research conducted by ENA that found the average boarding time in the emergency department for psychiatric patients is 18 hours versus only 4 hours for all patients in the ED.

Inadequate community mental health services and extended boarding times are detrimental both for emergency departments and the care received by mental health patients.

For hospital EDs, mental health patients are both resource- and personnel-intensive. Not only do these patients stay in the emergency department much longer than other patients, but they often require close supervision by multiple staff and, if available, personalized medical attention. By necessity, this diverts nurses, doctors and technicians from the treatment of other patients.

When a psychiatric patient who is in our emergency department is deemed to require invocation of the Baker Act, we have a certain protocol we must follow to ensure that patient’s safety. The patient is assigned to a closed room, their personal
belongings are removed, they are given a gown and slipper socks, and a security guard is placed outside their door, within sight of the patient. We do not have designated rooms for psychiatric patients, so we must attempt to modify the room they are in to prevent access to articles that might be used to harm themselves or others. The nurse who is assigned to that pod of rooms assumes the care for that patient, along with the other four or five patients who are also in that pod. None of the RN’s with whom I work has received any in-depth specialized education in the care of the mentally ill. We all may have had some courses during our nursing education, but for many of us, that was a long time ago.

For patients experiencing a mental health crisis, the emergency department is far from the ideal place to receive care. By their nature, EDs are chaotic, often loud areas of the hospital where nurses and physicians are regularly stretched to their limits taking care of everything from traumatic injuries to heart attacks.

In addition, specialists in psychiatric care are not always available to see patients in the emergency department. As I discussed earlier, this is the case in the hospital where I work.

Further, our emergency physicians are understandably reluctant to prescribe psychoactive medications for these patients, as it is not their area of expertise. This usually translates into the patient being medicated with some form of anti-anxiety agent, if needed, and then kept in the room on a stretcher, only being allowed accompanied trips to the bathroom. They receive a blanket, a pillow, a TV with remote control and meals. The assigned nurse assesses their vital signs and functions every 4 hours or more often as indicated. They do not begin therapeutic intervention as there is no one present with professional training to begin a therapeutic dialog.

Imagine being someone who is already stressed, anxious, possibly suicidal and/or psychotic, and perhaps having auditory or visual hallucinations. Then, you are confined to a small space, all your belongings are removed so you cannot hurt yourself, a guard is at your door, the lights are on outside the room all the time, and there is constant chaos, noise and motion. Further, imagine that because of the shortage of inpatient beds or community-based treatment options, this situation continues for many hours or even days.

Although we do everything possible to care for all patients in a professional and compassionate manner, mental health patients would be better served in facilities that have the specialized expertise to handle the complex diagnosis and treatment of mental illness.

In rare cases, the boarding of mental health patients and the subsequent overcrowding can also lead to violence in the ED. Although the vast majority of behavioral health patients are no more violent than other patients, there is no doubt that lack of treatment can exacerbate a stressful situation for these patients.

III. HOW TO IMPROVE PATIENT CARE

Our mental health patients and their families deserve better care than we currently give them. I did an informal poll of my colleagues across the country on what they believe are the most important needs for the behavioral health patients we see in our EDs. Their views exactly reflected mine.

These patients need access to the most appropriate facility for the problem they are having. In most cases, that facility should not be the local emergency department.

Individuals with psychiatric and substance abuse conditions should receive prioritization, resources, and treatment based upon clinical presentation that is equivalent to that provided for other illnesses and injuries.

Individuals with psychiatric and substance abuse conditions must be provided parity with regard to third-party reimbursement.

Emergency psychiatric services need to utilize a consistent practice model, including standardized procedures and protocols, for patient care regardless of facility, day of the week, or time of day.

Most importantly, communities must have the health care infrastructure and funding to provide the resources needed to keep this population healthy. These resources should include all related services. A high-quality, community-based mental health system would include acute and longer term care, access to community mental health clinics, inpatient and outpatient treatment, the availability of 24-hour crisis psychiatric care and services that would allow for integrating the patient more fully into society.

Any program should also promote collaboration and communication between emergency departments and their respective community agencies to effectively coordinate the care of patients with psychiatric and substance abuse conditions.
IV. CONCLUSION

Thank you for allowing me the opportunity to represent and speak for my fellow emergency nurses. We passionately care about providing the best possible care to ALL of our patients, and strive for them to have the best outcomes possible for their illnesses. This includes those who are among the most vulnerable in our society—the person suffering from a mental illness.

The CHAIRMAN. Thank you, Ms. Blake.

Dr. Eaton.

STATEMENT OF WILLIAM W. EATON, PH.D., PROFESSOR, DEPARTMENT OF MENTAL HEALTH, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH, BALTIMORE, MD

Mr. Eaton. Senator Alexander, Senator Murray and members of the committee, I think you are doing great work and I appreciate the opportunity to speak to you.

My orientation is from that of epidemiology, especially social epidemiology. The first point I wanted to make is, we all know somebody who has mental illness of one type or other or alcohol or drug abuse, and we feel strongly about this.

But there has been developed a new metric in the field of epidemiology called Disability Adjusted Life Years. That metric allows us to compare the disease burden of all the diseases, the mental and substance use disorders, as well as cancer, stroke, and all the physical diseases. When we do that comparison on a population basis using epidemiologic data, it clearly shows that mental and substance use disorders are the most important category of disease burden, and depression is the single most important disease itself in terms of disease burden.

The importance of mental disorders has been recognized many times in the past—the surgeon general’s report, the New Freedom Commission, and so forth. But now we have a metric which establishes scientifically that mental and substance use disorders are the most important form of disease category.

One of the reasons for this is that the mental disorders begin early in life, and they’re slow. You talk to somebody who has just had an onset of depressive disorder about it, and it turns out it will have started 10 years earlier. And the consequences of that depressive disorder will not show up sometimes for another 10 years.

The mental disorders, especially depressive disorder, actually predicts onset of stroke, dementia, heart attack, diabetes. It predicts it more powerfully than the common risk factors that we know. For example, a person with a history of depressive disorder has three or four times the risk of a heart attack. That’s a higher risk than somebody with high blood pressure or with a family history of heart disease.

The point is that the fact these mental disorders start early, they take a long time, and the consequences for physical illnesses are very strong. We need more research to figure out why these consequences are occurring, but also this argues, as has been stated, for the integration of primary health care with psychiatric care, because now the primary care doctor is interested in saving the life of his patient, the way he should be, and that means he should screen for depressive disorder and other disorders, probably, and learn how to do it. We should make that technology available.
I want to say that there are a range of prevention programs for mental and substance use disorders. There are many of them, and they have beneficial outcomes, proven years or even decades following the intervention. Most of these prevention programs are social interventions early in the life course prior to the onset of the disorder, so in the school system, for example, or even shortly after birth. Those preventive interventions are one of the unused resources, I guess I would say.

As a tiny aside, I would say there have been breakthroughs in genetics, especially the so-called methylation issue in genetics, which shows that the tendency for a gene to operate or not operate is affected by the environment. So in the future, we’ll be studying the way genes and environment work together, and when we study that, we’re likely to be oriented toward the social environment. The way the social environment works together with genetic material is the way that mental disorders have their occurrence.

The failure to help people with severe mental disorders is the most glaring problem in our mental health system. And it turns out that severe mental illnesses like schizophrenia and bipolar disorder—I think perhaps you know this, Senator Alexander, but they are associated with a shortened life span by even two decades.

Somebody with schizophrenia will die 20 years earlier. They’re not dying from schizophrenia. They’re dying because we’re not paying attention to the preventive activities that you and I receive, like Valsartan for blood pressure or lipid-lowering drugs. So that’s almost a criminal issue that these folks are dying so much earlier, and nobody chooses to be schizophrenic. It happens to them. It seems like we owe them that.

Finally, in building programs related to brain research, I want to mention that the National Institute of Mental Health has lost its focus on public mental health, and also it has abandoned what should be its natural interest in diagnostic categories. These new programs at the National Institute of Mental Health have basically confused a huge range of researchers and puzzled the international community. This also has vitiated the probability of developing research-based prevention programs for mental and substance use disorders.

From my point of view, the action is preventive interventions early in the life course, mostly social.

Thank you for your time.

[The prepared statement of Mr. Eaton follows:]

PREPARED STATEMENT OF WILLIAM W. EATON, PH.D.

SUMMARY

The Senate Hearing on Mental Health is appropriate because it is now established; using new and accepted measures of the burden of disease, that mental and substance use disorders produce a higher burden of disease in the United States than any other category of disease. For specific disorders, Major Depression is the single largest source of disease burden in the United States, as compared with all other diseases; and alcohol use disorders are the fifth largest source of disease burden.

Mental and substance use disorders occurring early in life predict later occurrence of important diseases such as diabetes, cardiovascular conditions, stroke, and dementia, and severe mental illnesses are associated with a dramatically shortened life span.
There are a range of successful population-based programs for preventing mental and substance use disorders. Most of these involve social interventions early in the life course.

Breakthroughs in genetics, including the study of methylation, when combined with measures of the environment including the vagaries of social life, will offer new opportunities to prevent mental and substance use disorders in the future.

The failure to help people with severe mental disorders of psychotic intensity, such as schizophrenia and bipolar disorder, is the most glaring problem in the mental health system.

The National Institute of Mental Health (NIMH) has lost its focus on public health and abandoned what should be its central focus on accepted diagnostic categories.

The mental health efforts of the Federal Government would benefit by careful consolidation of governmental units such as the NIMH, National Institute on Drug Abuse (NIDA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and perhaps some programs of the Substance Abuse and Mental Health Administration (SAMHSA).

This testimony is designed to give a brief and selective review of important aspects of public health as applied to the mental and substance use disorders. The presenter is William W. Eaton, professor and former chair of the Department of Mental Health, Bloomberg School of Public Health, Johns Hopkins University. The testimony represents the opinions of William Eaton and not the viewpoint of the Johns Hopkins University.

It is an opportune time for the U.S. Senate to be conducting hearings about mental and substance use because of the growing awareness of the importance of this topic. This growing awareness is in part due to the creation, about 20 years ago, of an algebra for estimating the overall burden of diseases, which allows comparison of the burden of diseases such as cancer, which are often fatal, to diseases such as depressive disorder, which is impairing and often long-lasting, but not as likely to be fatal. The new metric—Disability Adjusted Life Years, or DALYs—is accepted around the globe. Combining epidemiologic data on incidence, chronicity, and associated mortality for a given disorder, with clinical information about the disability associated with a disorder, it is possible to estimate the number of Disability Adjusted Life Years experienced by the total world population in a year—that is, entire burden of all occurrences of the specific disorder in the world, with this metric. As well, the total number of DALYs experienced as a result of all diseases in the world can be estimated. The broad category of mental and substance use disorders were responsible for 7.4 percent of the total disease burden experienced in the world in 2010—about the same percentage as the category of malignant neoplasms, and less than the 11.9 percent explained by the category of cardiovascular and circulatory diseases. In the United States and Canada in 2004, where the effect of fatal diseases of infancy and childhood is lessened than in the world as whole, the mental and substance use disorders were by far the largest contributor to the total burden of disease (about 24 percent of the total number of DALYs), compared to any other categories, such as cancer (12 percent of total DALYs) or cardiovascular conditions (14 percent). For more narrow disease conditions, Unipolar depressive disorders were responsible for 8.4 percent of the DALYs in the United States and Canada, the largest source compared to all other diseases (e.g., ischemic heart disease, responsible for 6.3 percent; cerebrovascular disease accounting for 3.9 percent). The fifth most important cause in the United States and Canada was alcohol use disorders (3.4 percent of all DALYs).

The importance of mental and substance use disorders has been emphasized for many years in prior reports such as the Surgeon General’s Report in 1999, the President’s New Freedom Commission in 2003, and the Institute of Medicine report in 2006 on Improving the Quality of Health Care for Mental and Substance-Use Conditions. Since the development of the Burden of Disease metric, the importance of mental and substance use disorders has been more firmly established.

The estimates of DALYs for mental and substance use disorders are higher than for other sometimes fatal disorders such as cancer because of the lifetime structure of these disorders: the mental and substance use disorders start much earlier in life, during childhood and adolescence in many cases, and a sizable proportion of the mental and substance use disorders endure for many years. But the estimate may actually be biased low, because of the effect the mental and substance use disorders have in raising risk for important medical conditions such as diabetes, heart disease, stroke, and dementia. For example, a person with a history of depressive disorder has about two or three times the risk for onset of diabetes, or having a heart
attack or stroke, as someone who has not had an episode of depressive disorder. This enhanced risk associated with depressive disorder is larger than many other well-known risk factors, such as a family history of the physical condition, or, for heart attack as an example the raised risk associated with high blood pressure or high cholesterol. For each of these medical conditions this enhanced risk resulting from depressive disorder has been replicated in more than five studies. There is also enhanced risk for onset of dementia in those with a history of depressive disorder, replicated more than five times. It has been estimated that persons with severe mental illness like schizophrenia and bipolar disorder have 20 years shorter life span than the general population, probably not caused by their mental illness, but rather because the treatment and prevention of other chronic medical conditions is ignored.

There are three important implications of these findings of mental to physical comorbidity.

• First, the estimates of disease burden for mental and substance use disorders may be biased low because they don’t account for mental disorders as early sources of physical disorders.

• Second, the possibility exists to lower the risk for the physical disorders by successful treatment of the mental disorders. Less than half of those with mental and substance use disorders get into treatment, in part due to the stigma of mental and substance use disorders, in part due to the cost involved, and in part due to the difficulty in finding good options for treatment. This logic reflects on the advantages of improving the system of care for mental and substance use disorders.

• Third, the health care system will benefit by integrating systems of primary health care with systems designed for treatment of mental and substance use disorders.

An aspect of mental and substance use disorders that is not well-appreciated is that there are many viable techniques for preventing their occurrence. The high prevalence of these disorders, their comorbidity, and the difficulty of treating them successfully argues for population-based prevention programs, which typically are aimed at entire populations (“universal interventions”) or populations thought to be at high risk for the disorders (“selective interventions”). Because the disorders start early in life, it is logical to take advantage of prevention programs oriented toward childhood, adolescence and young adulthood. These prevention programs typically involve social activities of some sort, as opposed to medical interventions that occur after onset of disorder. For example:

• The Nurse-Family Partnership Program begins by identifying high-risk births and providing assistance to the mothers in the period after birth.14

• The Good Behavior Game activates a social awareness in first graders with strong beneficial effects which last into adulthood.15

• The Teenscreen program facilitates schools to identify and get help for adolescents who may be at risk for suicide.16 17 18

• The Adolescent Depression Awareness Program, which is information about depressive disorder, designed in a format similar to information about other medical illnesses already available in the Health curriculum of many High Schools. These are examples of successful programs which have been widely adopted, but their application could be expanded, and the results would be a diminution of the later occurrence of mental and substance use disorders. In 1994 the report of the Institute of Medicine Committee on Prevention of Mental Disorders included that:

  “There could be no wiser investment in our country than a commitment to foster the prevention of mental disorders and the promotion of mental health through rigorous research with the highest of methodological standards.”21 This statement is still true.

There have been many advances in understanding the genetics of mental and substance use disorders in the last few decades, including breakthrough statistical techniques involving large samples of subjects (so-called Genome-Wide Association, or GWA, studies). Although most mental and substance use disorders have a moderate or strong tendency to be inherited, it is increasingly apparent that the inheritance will almost always be very complicated, involving many genes interacting in myriad ways. In the last decade it has become clear that the DNA can be permanently or temporarily activated, or deactivated, throughout the course of life (“methylation”). The sources of the methylation include exposure to toxins, obstetric events, physical illnesses, and the vagaries of social life. Therefore, it seems likely that the next decade will involve increasing research on the way in which genetic background and the biological and social environment interact to change the future...
risk for mental disorder. In turn, these developments are likely to inform the design of selective intervention programs.

The most glaring problem of this Nation with regard to mental and substance use disorders is the failure to help people with disorders of psychotic intensity (schizophrenia and bipolar disorder), even though the deinstitutionalization movement in the early 1960s was supposed to free them from the asylums which had been designed originally to protect them. People do not choose to have schizophrenia, and it places an enormous and unfair burden on them. Since schizophrenia persists in the population, generation after generation, even though people with schizophrenia have low fertility, it may be that they are carrying the genetic burden for the rest of us—that is, the large number of genes connected to schizophrenia are healthy and life-preserving for most of the population, producing schizophrenia only when the genes combine, rarely, in a very particular fashion (an extension of the theory of heterozygote advantage24 25). So, we owe them! Contrary to some characterizations, schizophrenia is not progressive in its nature: rather, people adapt to the disease over time.51 52 53 54 55 They might adapt to having diabetes, for example, just as they would likely strengthen research efforts on both these closely related groups of disorders.

The organization of government efforts to reduce the burden of mental disorders has become increasingly complex over the last several decades. In the early 1970s the National Institute of Mental Health (NIMH), part of the National Institutes of Health, was split into three institutes, including the NIMH, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA). The Substance Abuse and Mental Health Services Administration (SAMHSA) was created in the early 1990s. Many of the programs of these four units of the government overlap. For example, there are many separate surveys that estimate the use of marijuana or alcohol use in young people, some on a yearly basis (Monitoring the Future, funded by the NIDA52); National Survey of Drug Use and Health (funded by the SAMHSA),53 the National Epidemiologic Survey of Alcohol and Related Conditions (funded by the NIAAA)54 and National Comorbidity Survey and its replication55 56 (NCS and NCS—R, funded by the NIMH). There are programs on prevention of suicide in the NIMH and the SAMHSA, and programs of research on prevention of mental and substance use disorders in all four units. One logical consolidation is to combine the two units focused on substance use, NIAAA and NIDA, into one National Institute on Substance Abuse (“NISA”). There is extensive comorbidity between drug and alcohol use disorders,56 and many of the basic mechanisms of addiction are shared by the two groups of disorders, so consolidation would likely strengthen research efforts on both these closely related groups of disorders.

Since the formation of the SAMHSA, the public health aspects of the NIH units, especially that of the NIMH, have been diminished considerably. Even though the preventive interventions described above have a social aspect, the focus of research has been increasingly on the brain, missing the opportunity to design and implement effective new population-based interventions. Another departure from public health at the NIMH is the new disregard for diagnostic categories as a focus of research interest57 whereby emasculating the field of psychiatric epidemiology, the basic science of public mental health, because epidemiology requires an identifiable outcome. As well, the study of service systems and treatment research is hampered because there is a need for data on diagnoses as outcomes of preventive and clinical trials, and effectiveness of treatment systems as recorded in medical records. This new focus of the NIMH has puzzled the international community.58

Many SAMHSA programs have a public health focus on prevention in the population, and on treatment systems. Some of these programs are excellent, but others lack a research base. There is relatively little focus in SAMHSA programs on disorders of psychotic intensity (described above), which, though rare, are the most impairing and most in need of attention. It may seem strange, but there is only one epidemiologist at the NIMH, and only one psychiatrist at the SAMHSA! It might be useful and efficient to combine some programs of the SAMHSA into the two NIH units (NIMH and the new NISA mentioned above), to reduce duplication, on the one hand, and to ensure that they retain a public health focus, on the other hand. This consolidation would generate better ability to take advantage of the new developments in gene by environment interactions described above, because the programs would be more likely to stay abreast of the rapidly developing research advances. It would not be appropriate to simply eliminate the SAMHSA because there are so
many programs and services around the United States that depend on SAMHSA for guidance and funding, and there are many productive programs in the SAMHSA. The consolidation of these programs is a complex task and would require the work of a special commission to design the new units and to schedule the consolidation. The result would be more advances in useful research, more effective treatment systems and prevention programs, and more efficient use of funds.

REFERENCES


3. Organization WH. The Global Burden of Disease: 2004 update. Geneva: World Health Organization; 2008. The figures for mental and substance use disorders were estimated by subtracting the DALYs associated with Neurological Diseases (Epilepsy, Parkinson’s, Multiple Sclerosis, and Migraine) from the overall category of Neuropsychiatric Diseases, in Appendix Table 2.


Mr. RAHIM. Chairman Alexander, Ranking Member Murray, members of the Health, Education, Labor, and Pensions Committee, Senators Cassidy and Murphy, thank you for taking these initial steps to improve the lives of millions impacted by mental illness.

Let me first share my journey with mental illness. It began in 1998 as a freshman at Harvard University. Three weeks into my first semester, I was struck by my first terrifying panic attack. My journey continued when I had my first manic episode and second one in the spring of 2000.

My next 2 weeks were filled with sleepless nights. I showered less frequently and ate sporadically. I had visions of Jesus, heard cars talking, spoke foreign languages. My parents rushed me to a psychiatric hospital, and I was diagnosed with bipolar disorder. The last 18 years of my life have been defined by mental illness. Yet through support, proper treatment, and persistence, I have recovered and achieved wellness.

There are millions of Americans who are thriving in the face of mental illness: teachers who rise every morning to face their anxiety and their classroom full of students, veterans with lingering and visible scars of PTSD who will still provide for their families. Many are thriving, but many are not. To serve everyone living with mental illness, we must take steps to address stigma, access to medication, and peer support.

In 2012, I began speaking openly about my struggles to thousands of individuals with mental illness, their family members, law enforcement, faith-based communities, teachers, mental health professionals, and students. Since 2013, I have been a NAMI Queens/Nassau Let’s Talk Mental Illness presenter. I have been delivering presentations to students now, and I’ve spoken to more than 20,000 students across this country.

After one of my middle school presentations, a petite young African American girl walked up to me and started sharing that she was self-harming. When I asked her if she had told anybody, she said, “No, I have not,” and then she lowered her shoulders. I told her, “That’s OK. Thank you for being brave and telling me.” We walked her over to her school counselor, the same school counselor a friend and a family member advised her not to go to.

Because she saw the importance of openly addressing stigma, and that school saw the importance of openly addressing stigma, the young girl’s silence and reticence was dissolved. She was able to get the help that she needed.

Awareness and education is central to ending the shame around mental illness. Many parts of S.1945 address key components that will break down the barriers from seeking treatment.

For many, medication is also an integral part of treatment. Medication has and continues to play a key role in my life. I still take anti-depressants and anti-psychotics every morning. They are central to my recovery and wellness. Finding the right combination of meds was at times a very harsh task for me. But, thankfully, by working with my doctor, I found the right combinations.
The struggle to find the correct medication is an arduous task for many. Finding the right medication can literally be the difference between life and death. Paul, as I will call him, a young man I know, went through 10 different diagnoses, electroconvulsive therapy, and at least 50 different combinations of medication. Twenty years after his first manic episode, however, he is now a mental health advocate. Because he had access to medication, he is now helping others work toward wellness.

We must keep medications protected, accessible, and affordable to people living with mental illness. Doctors and patients must have a choice in finding the right treatment, as the wrong treatment can lead to vicious cycles of hospital visits, substance abuse, exhausted caregivers, and even death.

However, medication alone cannot sustain wellness. Another key component of this bill is peer support. The power of being able to relate to others going through similar experiences cannot be understated. The peer support group I have interfaced with is the quintessential example of the power of the peer.

In an email chain in this particular support group, a member mentioned that he had relapsed into depression. Within an hour, there were responses to his email, one member even saying that, “Hey, I'll come pick you up.” They truly understood the power and emotional strength of that support group, and that emotional support can shatter the weighted chains of depression. I’m happy to say that this group member is doing well, and he’s really doing well now.

Having language codifying what a peer specialist is and what peer support looks like is essential to standardizing an invaluable component of mental wellness—peer support.

Mr. Chairman, Ranking Member Murray, and members of the HELP Committee, I am testifying as a voice for people living with mental illness. My journey does not, however, represent the full breadth of experience living with mental illness. My presence here today, however, does give a face to millions of Americans who are struggling, striving, and thriving in the face of mental health conditions.

Recovery from mental illness should be an option for all. Bill 1945 is a pronounced step in that direction, and I deeply and respectfully urge this committee to move forward on this strong bipartisan bill. And I would say that millions of people are depending on a transformation of how we address mental illness in America.

Thank you so much.

[The prepared statement of Mr. Rahim follows:]

PREPARED STATEMENT OF HAKEEM RAHIM, ED.M., MA

I thank each of you for inviting me to testify before this committee. Moreover I am moved to be able to contribute my voice to an issue that has impacted me well over half of my life—mental illness.

In the spring of 2000, as a sophomore at Harvard University, I was hospitalized for 2 weeks in a psychiatric hospital in Queens, NY. While hospitalized, I was diagnosed with bipolar disorder. I took time off from Harvard and subsequently returned and graduated with honors. After receiving my bachelor's, I continued on to graduate school at Columbia University where I received a dual masters in psychological counseling. Currently, I am a mental health speaker, educator and advocate.

In 2012, I began speaking openly about my struggle with mental illness. To date, I have spoken to thousands of individuals with mental illness, their family mem-
bers, law enforcement officials, faith based communities, teachers and mental health professionals. Since 2013, I have worked with NAMI Queens/Nassau as their Let’s Talk Mental Illness presenter. In this role, I have spoken to over 20,000 college, high school and middle school students, delivering well over 300 presentations.

My advocacy work has helped bishops and pastors open up to their congregations; helped mothers and fathers better understand their children; and people with mental illness better understand their conditions. I believe the work I am doing is vital, and saving lives.

My journey does not encompass the full range of experiences of those impacted by mental illness. Living with mental illness is highly individualized; even people with the same diagnosis may have completely unique experiences. As a mental health speaker, educator and advocate, I have been fortunate to hear and see a spectrum of these experiences.

I have heard from people struggling to find work and housing because of barriers due to discrimination related to their mental illness; of parents concerned about their lack of ability to access treatment; and of people with mental illness who have been incarcerated due to their struggles with symptoms and not because of criminal intent.

Wellness should not be determined by favorable life situations, or serendipitous experiences. Rather, recovery from mental illness should be supported by established, effective, and easily accessible resources.

For this reason, Mr. Chairman, I and advocacy groups I am affiliated with, including NAMI, are very excited about this legislation. I support S.1945, drafted by Senators Cassidy and Murphy (members of this committee) and NAMI is a stronger supporter as well.

Mr. Chairman, Ranking Member Murray and members of the HELP Committee, recovery from mental illness should be a real option for all people living with mental illness. This bill is a pronounced step in this direction. I deeply and respectfully urge this committee to move forward with this strong bipartisan bill—millions of Americans are depending on a collective shift in how we treat and allow people to live their best lives in the face of mental illness.

Chairman Alexander, Ranking Member Murray, and Members of the Health, Education, Labor and Pensions Committee, I thank each of you for inviting me here today to testify before this committee. Moreover I am moved to be able to contribute my voice to an issue that has impacted me for over half of my life—mental illness.

My journey with mental illness began in 1998 during my freshman year at Harvard University. Three weeks into my first semester, I was struck by my first terrifying panic attack. At the time, I could not find words to describe the deep terror I felt, but I knew something was wrong. My journey continued when I had my first manic episode.

During the spring of 1999, I roamed the streets of my Long Island, NY neighborhood possessed with the delusion that I was a prophet and would save the world with my prophecies. Concerned, my parents sent me to Grenada to relax and be with family. However, there I plunged into a deep depression. I returned to Harvard that fall and struggled with anxiety and depression.

In the spring of 2000, I had a second manic episode. My next 2 weeks were filled with sleepless nights. I showered less frequently and ate sporadically. I had visions of Jesus, heard cars talking and “spoke” foreign languages. This time my parents rushed me to a psychiatric hospital. I was hospitalized for 2 weeks in Queens, NY. My attending psychiatrist diagnosed me with bipolar disorder and explained that I would be on several medications. Upon my release from the hospital I met with a Brooklyn-based psychiatrist who end up working with me for the next 9 years.

After adjusting to heavy medication, I returned to Harvard University to continue my studies in psychology. However, due to cognitive impairment and other complications, I left school. In 2002, I returned, refocused and persevered to graduate from Harvard with honors. After receiving my bachelors, I continued on to graduate school at Columbia University. I received a dual masters in psychological counseling, and after worked for several years as a college academic advisor. All throughout this journey I have contended with the ups and downs of depression, anxiety and complications from medication including weight gain and cognitive slowing. Yet through this struggle and isolation, I have found ways to thrive and use my pain as a vehicle to fuel my work.

In 2012, I began speaking openly about my struggle with mental illness. To date, I have spoken to thousands of individuals with mental illness, their family members, law enforcement officials, faith based communities, teachers and mental health professionals. Since 2013, I have been the NAMI Queens/Nassau Let’s Talk Mental
Illness presenter. In this role, I delivered over 300 presentations to more than 20,000 college, high school and middle school students.

My advocacy work has helped bishops and pastors open up to their congregations; a mother seek help for her son who was traumatized by police brutality and another seek professional help after her daughter, an Olympian medalist, died by suicide. I have seen a homeless student, beset by anger issues and diagnosed with bipolar disorder, completely transform after opening up to her school social worker. Students have shared their struggles with me and to adults in their lives because of my mental health presentations. I believe this work is vital in saving lives.

My recovery and this work would not be possible if I did not have a firm foundation anchored in good mental health and wellness. My life has been informed but not limited by my mental illness. I have found ways to thrive and attribute my recovery to perseverance, support and access. The combination of these three factors has been essential to my wellness.

My wellness has been sustained in part due to a strong support network. My family has and continues to play an integral role in providing emotional, mental and financial support. Having this essential and consistent foundation has aided my recovery in innumerable ways. Along with a supportive family structure, upon my return to college, I utilized the readily available support structures at Harvard, including psychiatric visits and psychotropic medications.

Medication has played a huge role in my recovery. Daily I still use key antipsychotics and antidepressants that aid in my stability. This journey to find the right combination of medication has been marked with different dosages, weight gain, cognitive impairment and long bouts of abysmal depression and paralyzing anxiety.

Along with medications, support groups have played a role in my recovery; the power of being able to confide in and relate to others going through similar experiences cannot be understated. Engaging with peers has shown me that even in my darkest times I am not alone. Along with peer support groups, programs like NAMI’s In Our Own Voice, have given me platforms to share my story with communities and other people struggling with mental illness. Communities are an essential component for wellness, hence I am currently developing an online platform for these communities to continue to grow and thrive and for the voices of people impacted by mental illness to be heard.

My journey does not encompass the full range of experiences of those impacted by mental illness. Living with mental illness is highly individualized; even people with the same diagnosis may have completely unique experiences. As a mental health speaker, educator and advocate, I have been fortunate to hear and see a spectrum of these experiences.

Through my personal advocacy and work with NAMI, I have heard from many people struggling to find work and housing because of a variety of barriers including discrimination related to their mental illness. I have spoken to hundreds of people in numerous support groups which have included NAMI Family to Family classes and Depression and Bipolar Support Alliance peer support group. During these conversations, parents have spoken about their struggle to support their loved one, whether due to lack of ability to access treatment or because their loved one refuses treatment. People with lived experience have shared that they are unable to access medication because of insurance issues or loved ones with family members who have been incarcerated due to their struggles with symptoms and not because of criminal intent. Some can point to an experience like mine—full recovery. However many have spoken to the other side of this experience.

Wellness should not be determined by favorable life situations, or serendipitous experiences. Rather, recovery from mental illness should be supported by established, effective and easily accessible resources. I have worked hard to sustain my recovery and wellness living with mental illness however; I have had structures that have lent to my recovery while many do not.

For this reason, Mr. Chairman, I and advocacy groups I am affiliated with, including NAMI, are very excited about this legislation designed to reform our public mental health system—a system which should afford wellness for all. S.1893, the Mental Health Awareness Act, is a good start, but given what I have experienced and have seen through my advocacy work, more is needed; individuals living with mental illness, and families impacted by mental illness need assistance sooner than later.

Both NAMI and I support S.1945, drafted by Senators Cassidy and Murphy (members of this committee). A few of the important provisions in S.1945 that I feel would go a long way toward reforming our mental health system and contributing to a better life for people living with serious mental illness and their families are:

- Grants to the States to better integrate physical and mental health;
• Establishment of a new Assistant Secretary for Mental Health and Substance Use at HHS;
• Creation of a new Interagency Serious Mental Illness Coordinating Committee and a National Mental Health Policy Laboratory;
• New transparency requirements and stepped up enforcement of the Federal mental health parity law;
• New requirements in the Federal Mental Health Block Grant program for outreach and engagement to the most difficult to serve.

Mr. Chairman, Ranking Member Murray and members of the HELP Committee, I am aware I am testifying as a voice for people living with mental illness. My experience does not represent the full breadth of the experience living with mental illness, however my presence here does give a face to the millions of people in America struggling, striving and thriving with mental health conditions. Recovery from mental illness should be a real option for all. This bill is a pronounced step in this direction. I deeply and respectfully urge this committee to move forward on this strong bill. Millions of Americans are depending on a collective shift in how we treat and allow people to live their best lives in the face of mental illness.

The CHAIRMAN. Thank you, Mr. Rahim, and thanks to each of you. We’ll now have a round of 5-minute questions for senators.

Mr. Rahim, based on your experience, what advice would you have to someone who knows a person who may need help? How do you persuade them that they should seek help, whether they’re a family member, a friend, a student, such as the ones you talked about?

Mr. Rahim. I get that question all the time. I speak at support groups, like NAMI Family to Family group, DBSA, and that’s the billion dollar question, because we can’t persuade anybody to do anything that they don’t want to do.

The CHAIRMAN. What’s your approach? What do you do?

Mr. Rahim. The key thing I say is education. We can’t change anyone’s behavior, but we can change how we respond to people. The key thing is educating ourselves, and there are a lot of support groups, there are a lot of educational programs out there that family members of people, say, students, can take, and it can change the way they interact with their friends or their loved ones, and thereby helping them understand what the loved one is going through.

When I was in psychosis, nobody could tell me that I was going through psychosis. But my parents were fortunate enough to bring me to the hospital. Because they changed their way of approaching my condition, they were able to get me help.

The CHAIRMAN. Dr. Eaton, what’s your experience? How do you persuade people who need help to seek help?

Mr. Eaton. I was going to say one thing that’s possible in this area is a program in high schools, which would be built into the health curriculum. There’s typically a health curriculum about diseases in high schools, and you can build into that curriculum without too much trouble a module on depressive disorder, psychosis, so people are aware of these and think of them as illnesses just like any other illness. That’s part of the stigma reduction idea, and they become less resistant.

There are also in high schools screening programs. The Teen Screen Program was implemented in thousands of high schools around the country, in which you screen high school students, oriented a little bit toward depressive disorder. You mentioned suicide as being the 10th most important cause of death, but for teenagers, it’s the 3rd most important cause of death. So programs in high
schools—I guess that’s what I’m saying—to make people aware of the issues around mental illness.

The CHAIRMAN. You were critical of the focus of NIH on——

Mr. EATON. NIMH. Mental Health.

The CHAIRMAN. I mean, the institute that deals with mental health.

Mr. EATON. Right, National Institute of Mental Health.

The CHAIRMAN. And our committee and the Congress has increased funding for that, and there’s a bipartisan interest in doing more. If you were there, what would your focus be going forward?

Mr. EATON. I’m completely supportive of more funds for mental health, justified by the burden of disease that I mentioned. We no longer can apply for grants with diagnostic categories as the outcome. It’s silly. So I would change that orientation.

SAMHSA is a very important agency, and I think to some extent the NIMH has disassociated itself from the public health orientation, partly because SAMHSA is there, but SAMHSA doesn’t have the expertise to do the public health research that the NIMH has. So I made a comment—it wasn’t here, but in the written comments—I worked at SAMHSA for 2 days a week last year. There was no psychiatrist there, not even one psychiatrist. As I left, one psychiatrist joined the SAMHSA. There was only one epidemiologist at the National Institute of Mental Health. So that’s a failure in public mental health.

The CHAIRMAN. Dr. Hepburn, you mentioned 30 years ago in mental health. I was a Governor at that time, and I’ve noticed that change. I just have a minute here, but what advice would you have for States based on your experience and perspective about what the focus should be as they move ahead with the dollars that they have, both State, Federal, and private?

Dr. HEPBURN. I think that that’s a basic question that commissioners have to deal with on a regular basis, trying to take care of as many people as possible, as cost effective as possible. And what that means is moving further upstream toward prevention and early intervention so that you can take care of more people as they start to show symptoms or where they’re at risk for symptoms.

One of the problems we had 30 years ago is that we were waiting until people had severe mental illness before we started treating them. Now, with the public health model, we’re trying to move further upstream to early intervention. So trying to spread the dollars out—we obviously still have to take care of the people who are severely mentally ill, but trying to get to people earlier, as we are with the First Episode Psychosis, and even earlier, trying to deal with kids and kids’ mental health.

The CHAIRMAN. Thank you, Dr. Hepburn.

Senator Murray.

Senator MURRAY. Thank you, Mr. Chairman.

Mr. Rahim, thank you so much for sharing your story with this committee and for all the work you’ve been doing with people across the country. It’s very impressive. Your message that people aren’t defined by their mental illness is really a powerful one, and I appreciate that.

Mr. RAHIM. Thank you.
Senator Murray. I wanted to ask you as you talk, particularly with young people, what are the most common forms of stigma that you hear about?

Mr. Rahim. Some of the most common forms are, I don’t want my friends to know. I don’t want my family members to know. Students want to talk about what they’re going through, but it’s their parents that don’t want to help them get the help. That’s the case sometimes.

Senator Murray. They fear their parents will——

Mr. Rahim. Yes. They fear that their parents will—oftentimes, there’s maybe a guilt associated around—is my child broken, or is my child sick? And sometimes it’s the parents. When the students come to them, when their daughters and sons come to them, they actually want to help, but sometimes the parents are reticent and not getting them the help that they need. But students—yes, a lot of them are open and willing to talk, especially making and putting that conversation out there.

Senator Murray. So having somebody else besides your parent to talk to is critically important.

Mr. Rahim. That’s one of the things.

Senator Murray. Resources in the community that they feel comfortable accessing. But I often hear from parents, too, that they don’t know who to call. My child is telling me they have this issue, but they don’t know who to call. What do you tell them?

Mr. Rahim. Sometimes there is that bridging the gap between what resources are out there and what is actually known. A key component is that education component, is what is out there, what is available, and knowing that it’s OK to seek those resources. Your child is not broken. You’re not wrong or bad if something happens to your child. It’s really providing that bridge, that knowledge gap, that there are resources, and it’s OK to use them.

Senator Murray. Great. Thank you very much.

Ms. Blake, let me turn to you. The work you do in the emergency department is a critical part of our health care system. We all know that, and I know the patients that come through your door are at the most vulnerable points of their lives. Otherwise, they wouldn’t be walking in that door.

So once a patient is stabilized, and we know they need more specialized care—we know that there is an acute shortage of inpatient psychiatric beds. You referred to that. It’s certainly a critical issue in my home State. One study ranked my State 48th out of 50 on the availability of psychiatric treatment beds. We’re seeing a lot more press and discussion of that in my State right now.

But I wanted to ask you what happens to a patient in the emergency department if there are no psychiatric treatment beds? You mentioned this in your opening statement. But what do you do?

Ms. Blake. What we do is essentially keep them there in that room. We give them three meals, and they are stuck there until we can either find a psychiatric facility that’s willing to take them or—sometimes if the 72-hour hold has gone over 72 hours, our emergency room physicians have no choice but to allow that patient to go.

Senator Murray. So they go back out into the community?
Ms. Blake. They go back out into the community. But, generally speaking, what will happen is they will go from our hospital to the next hospital that's closest and try to get in through that way.

Senator Murray. If they seek care. Otherwise, they end up without it.

Ms. Blake. Exactly.

Senator Murray. Dr. Eaton.

Mr. Eaton. Could I just mention that I spent time in Victoria, Australia. They have a linked medical records system. So if someone shows up in an emergency room, and they don't have a bed in that hospital, they can—they've been doing this for decades. They can dial up and find the nearest mental hospital bed in the entire province in a few minutes.

Senator Murray. And do you not have that access?

Ms. Blake. We do not have that access where I am. In preparation for coming for this, I did an informal poll of my colleagues throughout the country. This is not a problem just in Florida or in Washington. This is every single State in the country, and I would say this is the top issue in emergency departments right now across the country—is holding onto these patients. One hospital in the south part of Palm Beach County I visited earlier this year had 14 patients they were holding, waiting for psychiatric beds.

Senator Murray. As Mr. Rahim pointed out, people don’t know who to ask. Hospitals don’t have a place for them to go, and we have a huge hole in our system.

Ms. Blake. Exactly, and it’s because there is not enough resources out in the community to be able to place these people, No. 1, to get them screened and get them into treatment programs, but, No. 2, the followup from when they are released from that facility, because they’re put out back on the streets. And if they don’t have any place to go to followup, to get further treatment, their medications, to have someone that they can go to if they’re starting to have a problem—so many of these people are homeless.

If they get put back out, they have no place to go. They have no resources. They have no insurance. They have no way to followup with a physician. They have no way to get their medications. So they show up back in our emergency rooms.

Senator Murray. A vicious cycle.

Thank you, Mr. Chairman.

The Chairman. Thank you, Senator Murray.

I have next Senator Collins, Senator Baldwin, Senator Cassidy, and Senator Murphy.

Senator Collins.

Statement of Senator Collins

Senator Collins. Thank you, Mr. Chairman.

Dr. Hepburn, particularly in rural States like Maine, patients with serious mental illness all too often lack access to the care that they need. And as I look at Federal policies, at times, Federal policies exacerbate the problem of access. We still don’t treat mental illness the same way we treat physical illness in this country from the perspective of Federal reimbursement policies and programs, which is pretty stunning in this day and age.
You mentioned that Congress recently passed Senator Cardin’s bipartisan bill, which I was pleased to be a co-sponsor of, which extends an important demonstration project that helps address the psychiatric bed shortage that Ms. Blake has talked about and improve access to critical mental health care services and support. Maine is one of the pilot States under that program and has already seen very promising results, because Federal Medicaid matching payments are being allowed for freestanding psychiatric hospitals for certain emergency psychiatric cases.

Similarly, the Cassidy-Murphy bill, which I’ve co-sponsored, would go further by lifting the IMD exclusion for psychiatric patients with an average length of stay of 20 days or fewer. That should help more people get the assistance that they need. Could you talk a little bit more about this issue and how the restrictions on Medicaid funding to freestanding psychiatric hospitals affect access to care?

Dr. Hepburn. Yes. Thank you for the question. Access is a major issue. Following up on the previous discussion, there is a culture problem where individuals are expected to go into a psychiatric unit or a psychiatric hospital. If somebody is in the emergency room for another type of problem and there aren’t beds for that particular discipline, they put them into another open bed in the hospital. There isn’t any reason that individuals with psychiatric problems couldn’t go into a medical bed with a sitter, if some hospitals decide to do that. That’s one answer.

The second is increased use of technology may be another way to reach the rural areas. The third, as you talked about, the IMD Demonstration, has shown that private psychiatric hospitals have about the same cost per episode as acute general hospital psychiatric units.

Some 30, 40, or 50 years ago, the private psychiatric hospitals kept people for months, sometimes years. That has changed. The average length of time in a cost per episode is about the same. There really is not a good reason from a financial standpoint or from a clinical standpoint to differentiate between private psychiatric hospitals and acute general hospitals with psychiatric units.

Senator Collins. I think you raise an excellent point in your last statement. It says the practices of the past are dictating the reimbursements of today despite changed circumstances. And as we’ve talked to the administrators and psychiatrists, staff, families, and patients at one of the psychiatric hospitals in Maine, which is part of this pilot project, they are seeing exactly what you’ve said.

They’re not keeping people forever. They’re not abusing it. But they’re allowing people to get the care that they need because it’s being reimbursed for those individuals who are in the age span of 19 to 64, I think it is, that now cannot get reimbursement.

Doctor.

Mr. Eaton. Just another comment. Emerging technology may be helpful. So what I was talking about—record linkage in Victoria, Australia. That will be coming in the United States. We’ll be able to link records more easily, probably.

But also, in Baltimore, 85 percent of people with schizophrenia own a cell phone, so there is a way of contacting these people. And
there are technologies being developed. They're not really ther-
apiies, but they're locating devices and devices to talk. I think that's
in our future, also.

Senator COLLINS. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Collins.

Senator Baldwin had to step out to another hearing, so we'll go
to Senator Murphy.

STATEMENT OF SENATOR MURPHY

Senator MURPHY. Thank you very much, Mr. Chairman. Thank
you to you and Senator Murray for taking this issue so seriously
and for putting us on a path to a bipartisan product coming out of
this committee and also a path to bring this to the floor this year.
I think this is one of our opportunities in 2016 to be able to move
something substantive, something bipartisan, something that
makes a difference on the floor of the Senate.

I thank all of you for being here today.

I think we've covered this question of capacity well, and I thank
Senator Collins for her specific questions related to the IMD exclu-
sion.

But just for a minute, let's think about how this would relate to
our lives. If we were to bring our child to the emergency room
around dinner time, and we sat there with our child all evening,
we sat with our child overnight, and we didn't get appropriate care
for our child until noon the next day, we would call for people's
heads at that institution. We would be outraged.

That isn't the outlier when it comes to people being admitted to
the ER with mental health diagnoses. That's the average, and yet
we sort of have accepted it as commonplace.

But there's a reason why that's happening. We've closed down
4,000 mental health inpatient beds since 2007 in this country. In
the last 2 years alone, we went from 91 million Americans living
in an area that was designated as a mental health shortage juris-
diction for outpatient services to 97 million Americans. So we're
going the wrong way in capacity as need is increasing. It's no mys-
tery as to why we're hearing these stories.

But as Senator Murray pointed out, another failing of our system
is the lack of coordination, the fact that we have so many people
trying to do good things, but they're not talking to each other. And
for really complex patients, it's often not clear who's in charge for
a child. Is it the school? Is it the mental health clinic? Is it their
primary care physician?

Mr. Rahim, your story was so captivating, and you're so coura-
geous to continue to tell it. I wanted to ask you about this question
of coordination. I wanted to ask you a question about the barriers
that patients face in trying to find a quarterback for their care, the
worry that's involved in just trying to figure out which provider is
the best place to start, and where do they eventually go to get the
care they need.

How can we do a better job of coordinating all of the good things
that are happening in the system so that it's easier for patients to
navigate?
Mr. RAHIM. I can take a step back and share what happened with me about 17 years ago. My parents were able to bring me directly to a hospital in Queens. I was in there—and you talk about the waiting area being chaotic. I had hallucinations in the waiting area. I thought that I saw Jesus and prophets.

But I was able to get hospitalized that night, and I was able to get medication that night, and I was able to get in the ward that night, and I spent 2 weeks there. So I think that early care, as Dr. Hepburn was talking about, is so critical. But I was able to get that in that moment.

To speak to the larger issue and larger problem, I think that having that care—the immediacy of care is so critical. I know it was critical for me.

Senator MURPHY. Dr. Eaton, I wanted to explore very quickly an issue that you raised, which is this realization that if we don't spend money on mental health, we're going to spend money somewhere else, and that the fact is that a diabetes diagnosis alone doesn't put you in the top 5 percent of spenders in the Medicare and Medicaid system, and, in fact, a depression diagnosis alone doesn't put you in the top 5 percent of spenders. It's the combination of the two.

And as you point out, if you have depression, if you have a mental health diagnosis, you are, frankly, much more likely to acquire another major and expensive physical health disorder. Can you talk a little bit about the connection between a mental health diagnosis and then a very expensive, very burdensome physical health diagnosis and why a little bit of spending on the mental health side prevents you from spending a lot of money on the physical health side?

Mr. EATON. I wish I knew more, actually, but that finding, depressive disorder predicting to diabetes or stroke or heart attack—that's been replicated 10 times. It's unquestionable, and, therefore, the logic is very strong that on the one hand, treating the mental health disorder will almost certainly lower the risk for the physical disorder later on, but also preventing the mental—moving upstream, even farther than First Episode Psychosis. So if we can identify people at risk for psychosis, not in the first episode, or at risk for depressive disorder, that will have these downstream consequences.

And the problem is it's complicated because it takes a long time. We haven't done enough longitudinal studies to actually understand exactly how depressive disorder contributes to risk for stroke. We don't actually know that, and in the United States, we don't have the tendency to do these longitudinal studies, unfortunately.

I don't think I've answered the question well. But I guess I think we need longitudinal research to actually understand how it is that the body and the mind evolves over time from the age of 15, when somebody's at risk for suicide or depressive disorder, until the age of 45, when they have four times the risk of having a heart attack because of that.

Senator MURPHY. Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Murphy.

Senator Cassidy.
STATEMENT OF SENATOR CASSIDY

Senator Cassidy. Thank you all. Tremendous testimony. Although this is a topic which is in a sense inherently tragic, on the other hand, the fact that Senators Alexander and Murray and you all are here gives us some room for happiness, of optimism in the midst of this. So thank you all.

Dr. Eaton, let me ask—you describe in your testimony, written and spoken, about the lack of coordination between Federal programs. I'm drawing from that that you feel as if there needs to be some change in how these programs coordinate, or else we'll be spending Federal tax dollars in an ineffective way, et cetera. Your thoughts on that?

Mr. Eaton. In the written testimony—and this is the part of it that I know. I do epidemiologic research. There is huge redundancy in the epidemiologic research related to mental disorders. The NIAAA conducts its own survey. The NIDA conducts a survey. The SAMHSA conducts a survey. The NIMH—they're all very similar. I use them all——

Senator Cassidy. In a sense—I don't mean to cut you off. It's just that I have limited time. In a sense, it would be better to have one person saying, "You shall do this and you shall do that," as opposed to everybody deciding on their own that this is where we need to go?

Mr. Eaton. I think it would pay to study the coordination of those agencies. But it's a very difficult thing to figure out.

Senator Cassidy. Now, let me also ask—you brought up something that Representative Tim Murphy brings up in the House consistently on the House of Representatives side, that the SAMHSA really has a paucity of psychiatrists.

Mr. Eaton. They didn't have any when I was there.

Senator Cassidy. It's kind of amazing that the principal agency for addressing psychiatric illness didn't have a psychiatrist. Or maybe it's not amazing.

Mr. Eaton. It is amazing.

Senator Cassidy. It is amazing. I agree. The epidemiology—by the way, I told Dr. Hepburn when I saw your testimony regarding the need to start basing Federal research on some objective criteria as opposed to inertia, using DALYs as one example, it was like be still my heart.

Right now, I think you're talking about the societal cost. But do you include the cost of incarceration in your societal cost?

Mr. Eaton. Those DALYs do not include that cost, typically, and that's something that I didn't get into in my testimony. But, really, incarceration—this is a horrible, horrible problem. I think we now think—many of us think of it—that the prison and jail system is the de facto mental health system in the United States.

Senator Cassidy. My National Sheriffs Association president, who is from Louisiana, or at least past president, Greg Champagne, says he is the most active mental health provider in his parish.

Mr. Eaton. Yes. In Cook County, that's true, also. And we don't even have a good survey of mental disorders in prisons.
Senator Cassidy. Let me stop. We’ve heard testimony, Dr. Hepburn, that the right drug is so necessary in order to keep somebody in balance. I’ve learned, though, that when someone enters a jail, their medicines may be stopped or may be on contract. It will be a drug substituted, et cetera.

If we don’t have some way to divert folks who are mentally ill out of the jail, it may be they’re going into a setting which would make a dad gum ER look calm—super chaotic. But either no medicine or a different medicine because it is a different—is that a fair statement?

Dr. Hepburn. Yes, that’s one of the big concerns about not having a sequential intercept model that helps to keep people out of being arrested and out of jail. To the point that you made, if somebody comes in on medication and that medication isn’t continued, then it can have a negative impact on their ability to recover.

Senator Cassidy. Thank you.

Mr. Rahim, again, great testimony. Tell me, though—the fact that you’re speaking about peer groups as if it is something unique—maybe you’re just bragging on the one in which you’re involved. But I also got a sense from your testimony that the model needs to be expanded, that as good as it is, we actually don’t have peer groups proliferating across the country. This happens to be an exception of which you wish to speak. Is that fair?

Mr. Rahim. I know that there are peer groups in the country, and I think, knowing the power that——

Senator Cassidy. Now, there are peer groups. Are they all over the place?

Mr. Rahim. I couldn’t say that they’re all over the place, but I know there are peer groups. Certain organizations, like Depression and Bipolar Supporter Alliance—they are based on peers and wellness. NAMI does also have peer groups across the country. But I do think that that is a key component. If I knew that somebody—when I was going through the thick of my medication——

Senator Cassidy. Let me stop you because I’m out of time. So, in a sense, anything that would promulgate or increase the use of peer groups would probably be a good thing.

Mr. Rahim. One-hundred percent.

Senator Cassidy. One-hundred percent. Next, my last question. If we could put you in a bottle and sell you, the whole world would be better off. But oftentimes those who are mentally ill will not take their medicine. And the revolving door comes, and they feel well, and they stop taking their medicine, and they’re back with Ms. Blake.

What motivated you to take your medicine, and what do you recommend for those who do not take their medicine? What would you recommend to kind of encourage them to stay on that path of recovery?

Mr. Rahim. Medication does not define who you are. You are defined by your experience and not your mental illness. Defining mental illness is also how you think about yourself and the things that—how you are labeled.

Senator Cassidy. So the appropriate mind set, No. 1. What else?

Mr. Rahim. No. 1 is appropriate mind set, and No. 2 is in finding the right medication, knowing that you’ll have to go through a com-
hination. There is no one medication that is a panacea for mental illness, and that’s why more research is needed. So know that you have a different combination, know that you’re not defined by your medication or your mental illness, and having the ability to self-report to your doctor.

Know how the medications are affecting you. Know how they’re impacting your treatment as well as your body, and know that you’ll have some sort of response and reaction. I think those are key components. One, trial and error. There’s going to be different combinations. Two, know that it’ll have an impact on your body. Three, self-report. And, four, know that they do not define who you are. Mental illness does not define who you are.

Senator Cassidy. Thank you.

I yield back. Thank you, Mr. Chairman.

The Chairman. Thanks, Dr. Cassidy.

Senator Warren.

STATEMENT OF SENATOR WARREN

Senator Warren. Thank you, Mr. Chairman. Today, for most insurance plans, mental health parity is the law, but it sure doesn’t feel that way for people who need help. A 2015 survey conducted by the National Alliance on Mental Illness found that nearly 50 percent of respondents had been denied coverage for mental or behavioral health care, compared with only 14 percent denied for physical health care. And I hear way too many stories from people in Massachusetts about how hard it is to get insurance coverage for the care that they need.

So let me start here. Dr. Hepburn, what do we really know about how many people are being denied services they need, why they’re being denied, if they are filing complaints, and if they ever end up getting the care that they need?

Dr. Hepburn. It’s an important issue. Yesterday, I called the Maryland Parity Project because I wanted to get an update. What they indicated was that it’s very hard for them to know what the numbers are, because when people look at how difficult it is to submit a request for review, it’s so tedious and it’s so detailed, it’s going to take months to years to make a difference. So I asked for a recommendation, and they said something has to change in the process.

Senator Warren. Let’s talk about that in just a second. Let’s start with what you’re saying here. We just don’t have even good data on this.

Dr. Hepburn. No.

Senator Warren. On any of those four questions.

Mr. Rahim, if someone had trouble getting insurance coverage for mental health services, is there one place that anyone in this country could report a problem and get some help?

Mr. Rahim. That, I’m not sure of, and——

Senator Warren. That’s what I’m saying. Being that I’m a mental health advocate and I don’t know, that’s speaks to that.

Senator Warren. And that’s part of the problem we’ve got. You know, it’s hard to fix any problem if we don’t have reliable data.
Connecticut created an Office of the Health Advocate to try to help people navigate the insurance system and assist when they were denied coverage. In 2014, that office returned nearly $7 million to consumers. The most frequent cases they deal with every year are denials of mental health coverage.

My colleague from Massachusetts, Representative Joe Kennedy, introduced the Behavioral Health Coverage Transparency Act last month to try to create a patient parity portal to provide consumers around the country a one-stop shop for information about parity and a central place to submit complaints about coverage.

Let me ask you this, Dr. Hepburn. We’ll go back to the question about what to do about this. Would a central place for people to go to about insurance coverage for mental health problems help consumers and give regulators better information about where to focus their enforcement actions?

Dr. Hepburn. Absolutely, yes.

Senator Warren. So this is something that could make a real difference—

Dr. Hepburn. Yes.


I just want to say as this committee goes forward on mental health legislation, I would like to work with you, Chairman Alexander and Ranking Member Murray, on making sure that consumers have a central place to turn to for help when they are denied coverage and a central place where we will get the information so that we can enforce the law that’s currently on the books.

Thank you, Mr. Chairman.

The Chairman. Thank you, Senator Warren, for the suggestion.

Senator Franken.

STATEMENT OF SENATOR FRANKEN

Senator Franken. Thank you both, the chair and the ranking member, for these series of hearings.

Dr. Eaton, in your testimony, you talked about the importance of preventing mental illness.

So did you, Dr. Hepburn.

You, Dr. Eaton, highlight programs such as the Nurse Family Partnership Program, which has been effective at identifying high risk births and assisting moms after birth. I really do believe prevention is important. That’s why I authored and helped advance the Mental Health in Schools Act, which will increase access to mental health services in school settings.

Dr. Eaton, what percentage of individuals with mental illness experience onset before the age of 18?

Mr. Eaton. It depends on which mental disorder you’re talking about. But, I think probably before 18, for depressive disorder, the full fledged disorder is probably 20 percent. But the beginnings of it are available—50 percent of the people who will have depressive disorder full fledged in their lifetime, let’s say before the age of 30 or 35, are already experiencing symptoms at 15. They would be potentially identifiable, depending on if we can get the tools to do that.

For schizophrenia, it’ll be similar. Schizophrenia has much more sudden onset right at 18, 20, 25, something like that. But the signs
of psychosis and especially the negative symptoms are there at the age of 15 to 20, I think.

Senator Franken. I think this is why if we expand and enhance mental health services in our schools, we will serve ourselves well.

I want to ask about rural suicides, because a study made by the Journal of the American Medical Association shows that rural adolescents commit suicide at approximately twice the rate as teens in urban areas, and this disparity has just increased over time. Between 2004 and 2013, across all demographic groups, suicide rates rose by 7 percent in metropolitan areas, but by 20 percent in rural areas over the same period.

The research shows that these differences are driven by lack of treatment options in rural areas, provider shortages, and stigma. As the co-chair of the Senate Rural Health Caucus, I find this deeply concerning.

Dr. Hepburn, you have previously served on the National Suicide Prevention Lifeline Advisory Board and now represent the State Mental Health Program Directors. Can you explain why suicide rates have been driven up so dramatically in rural areas?

Dr. Hepburn. I think you answered it, which is basically access issues. One of the things I think is important is to look at how we can advance technology to try and get to the rural areas. At a time when the Internet is reaching people all around the world, there’s really not a good excuse for being unable to reach kids and young people in the rural areas.

One of the problems we sometimes get into is the lack of payment for those services that are done through tele-mental health, and I think that’s an important issue that needs to be addressed. In this day and age, tele-mental Internet services should be made available in the same way that every other service is available. And by doing that, we can increase access to those kids.

Senator Franken. Which is one of the reasons we need to make sure every area in America has the Internet, because this is something I hear when I go to rural Minnesota. I support programs that provide financial incentives to mental health service providers in rural areas, actually, we just need them in this country. We have a provider shortage. Is that not right? And would that be helpful?

Dr. Hepburn. Absolutely. We have a workforce shortage. I think I read the other day that the average age for people in behavioral health in terms of providers in the workforce is 58. So we have to use technology as a way of compensating for that.

Senator Franken. Thank you all for the work you’re doing. I think we’re beginning to understand how important this is in this Congress and in this country, and we’ve seen some good things happen in this Congress, beginning to happen, and I want to thank the chairman again and the ranking member.

The Chairman. Thank you, Senator Franken.

Senator Whitehouse.

STATEMENT OF SENATOR WHITEHOUSE

Senator Whitehouse. Thank you, Chairman. Following up a little bit on Senator Warren’s questions, it strikes me that one of the victories that we have achieved has been to bring mental health out of the shadows and de-stigmatize it. Not completely, not as
much as it should be, but there have been some real victories in that area. And I want to commend my former delegation member, Representative Patrick Kennedy of Rhode Island, on the work that he did on the Mental Health Parity and Addiction Equity Act, which has really helped make that the law of the land as opposed to just a good social change that we’ve made.

But in addition to the problem of trying to get insurance coverage, is there not also the underlying problem that our infrastructure for mental health treatment was basically built during a heavily stigmatized period when very few people came forward? So it was designed to address a fraction of the real mental health problem.

I don’t know what you all see, but in Rhode Island, we have some of the best mental health facilities in the country. Butler Hospital and Bradley Hospital are best-in-show, world class facilities, and yet they are kind of all there is. And you get beyond that, and you get into really difficult situations, and, very often, there has to be a crisis before somebody can get access and get into the mental health care system, not because the insurance company isn’t reimbursing it, but because there simply isn’t adequate coverage, particularly in children’s mental health.

I see that as the case in Rhode Island. You all have a perspective through your organizations nationally. Do you agree that that is a national problem as well?

[No verbal response.]

Senator WHITEHOUSE. All heads are nodding, let the record reflect.

Do you want to say something?

Mr. RAHIM. Yes. Senator Franken, so key about schools. When I’ve spoken in 12 different schools, we did a study, a 4-week followup. Are students actually going to seek help? Out of 2,000 students I spoke to, 184 actually went to a school social worker, a school psychologist, or a teacher because they said, “You know what? It’s OK to talk about what I’m going through.” So if they’re ready to seek that help, where do they go?

Senator WHITEHOUSE. Where do they go?

Mr. RAHIM. People are ready to talk, especially the young people. But where do you go once you’re ready for that help? That’s the question.

Senator WHITEHOUSE. Our victory in the stigma area has now created a problem in the infrastructure area, in my opinion.

In the Judiciary Committee, we will be considering a bill that is jurisdictional to the Judiciary Committee, which is the Comprehensive Addiction Recovery Act, which has a great deal of overlay with mental health issues, very often self-medication as a solution, not a good one, but one that people use when they’re really facing a mental health problem.

Could I ask as a question for the record if each of you would have a look—I think your organizations are probably already aware of the Comprehensive Addiction Recovery Act. If you wouldn’t mind checking to make sure, and if you have an opinion on it, that we have that. The hearing is going to be coming up in the next couple of weeks, and I’d love to make sure we’ve got your organization’s
position on the Comprehensive Addiction Recovery Act in our record here that I can take there.

Senator WHITEHOUSE. And then the last question that I have has to do with emergency rooms. Ms. Blake, that’s your world. You live in it. I’ve spent overnights in our emergency room just to witness what takes place in there. There’s an enormous amount of mental health response that’s delivered in the emergency room.

People come in in the middle of the night. What they really have is a mental health problem. The police have no place else to bring them. They take them to the ER. Now it’s your problem, and an ER isn’t really well suited for dealing with that.

Could you just comment a little bit more on how big a role that task that you’ve been given plays in your workload and how much it is diminishing what else you can do? But I’m also interested in the extent to which you feel comfortable that the electronic health records that you pull up when you bring that person in, or when they come in to you, or when they’re brought in to you, are accurate and complete as to the mental health history of that individual?

Ms. BLAKE. Yes, I know what you’re asking.

Senator W HITEHOUSE. I’ve got a feeling that some of the protections we’ve put in place back when this was heavily stigmatized to keep all this information private is actually keeping it from getting into electronic health records, so that in an ER, you aren’t aware of the situation.

Ms. B LAKE. Absolutely. I can actually give you an example of that. Not too terribly long ago, we had a 26-year-old gentleman brought to our emergency room. He was a heroin overdose. He was unconscious. We didn’t know a lot about him, except that he had used heroin, because he responded to Narcan when we gave him the Narcan.

We stabilized him, and in the process of taking care of him—I was taking care of him—I got a phone call from a gentleman in Virginia who was trying to locate his son who had been sent down to our county for treatment and rehab for substance abuse, who had walked away from his rehab center. It turned out—he gave me the son’s name, and it turned out it was the patient I was taking care of.

The problem was I could not tell him because of the HIPAA law that we had his son in our emergency room, No. 1, because the patient was unconscious and unable to give me permission to do so. But it turned out, too, that his son had a mental health care issue as well. He was bipolar, and he had been off of his medications which was contributing to his problem.

Now, had we been able to release that information or pull that information up somehow, then it might have changed the whole way that we treated this patient. But, more importantly, it broke my heart to not be able to tell this man that his son was safe in the emergency room and was going to be able to recover.

I think maybe if we look at some limited circumstances where certain information could be released—and I certainly understand the privacy issue, but it would be very helpful, because in order to access someone’s medical records, you first have to get permission from them in order to do so. And someone who might be in a men-
tal health care crisis may not have the capacity to be considered able to sign permission for it.

Senator WHITEHOUSE. Thank you. My time has expired, but that was a terrific story and a terrific point. Thank you.

The CHAIRMAN. Thank you, Senator Whitehouse.

Senator Murray, do you have any further comments?

Senator MURRAY. Mr. Chairman, I just want to say this has been a really important hearing, and I really want to thank all of our witnesses today. Clearly, we have a lot of work ahead of us.

We talked about making sure communities have access to mental health professionals, integrating the primary care with mental health care, prioritizing research, and breaking down barriers—continuing to break down barriers that stigma creates. That is a full plate, but it is an important one for us to tackle, and I look forward to working with you on moving this agenda forward.

The CHAIRMAN. Thank you, Senator Murray.

Ms. Blake, thank you for that story, and Senator Whitehouse for bringing that up. Touching HIPAA is like touching an electric wire. But maybe that’s what we’re paid to do sometimes. So as we look at our mental health legislation, we should consider that story and that circumstance, and given the way we work on this committee, perhaps we can help with that.

If you have a specific suggestion for the kind of exemption that that should be, we’d like to have it. Maybe your organizations have that kind of——

Ms. BLAKE. As chair of the Advocacy Advisory Council, that’s definitely something we can put on our agenda to discuss and see what people——

The CHAIRMAN. We’re moving pretty fast here.

Ms. BLAKE. We have a meeting today.

The CHAIRMAN. Good.

Senator WHITEHOUSE. They’re faster than us.

[Laughter.]

The CHAIRMAN. What Senator Murray and I hope to do is to move promptly through this committee those issues that are within our jurisdiction and do it at the same time that we’re working with the Finance-Judiciary Committees and with Senator Murray and Senator Blunt’s Appropriations Subcommittee so that we’ll be ready to deal with this issue. We have some very good work being done.

I thank you for the testimony today from all four of you. The hearing record will remain open for 10 days. Members may submit additional information within that time.

The next hearing of this committee will explore issues related to generic drug user fee agreements, and it will be on Thursday, January 28th.

Thank you for being here today. The committee will stand adjourned.

[Additional material follows.]
Thank you, Chairman Alexander and Ranking Member Murray, for continuing with this series of hearings on mental health and substance abuse. I know everyone on this committee is well aware of the fierce urgency of this subject matter. Although the vast majority of individuals with mental illness are not violent, recent years have given rise to tragedies that highlight the need for our Nation to better address this issue. The testimony at the first hearing on mental health, and the second hearing focusing on opioid abuse, has been enlightening, and will help me and the other members of this committee as we decide the best way to move forward on mental health and substance abuse issues.

Mental health is one of the country’s most pressing health care needs. Nearly one in five adults experiences a mental illness in a given year. Left untreated, these conditions can destroy lives and tear apart families. The Affordable Care Act built on the landmark mental health parity law by including mental health and substance abuse services as an essential health benefit, and by expanding access to private health insurance and Medicaid. We must work to build upon this progress by strengthening the behavioral healthcare workforce; finding new ways to integrate behavioral health and primary care; providing resources for crisis situations; and strengthening vulnerable communities. We must make good on the promise of insurance parity for mental health and substance abuse services, and work to ensure that cutting edge medical research into mental health and substance abuse receives adequate support and sustained funding.

Today’s hearing will provide insight into how we can improve Federal mental health policies. I appreciate the opportunity to hear from the witnesses, who will discuss the challenges faced by State governments, health care professionals, mental health researchers and those that suffer from mental health conditions. I look forward to working with the Administration, as well as my colleagues on the committee, as we use today’s testimony to build upon and improve Federal mental health policy.

Thank you, Chairman and Ranking Member, for holding this important hearing. My home State of Wisconsin is experiencing a uniquely severe shortage of mental health providers that is drastically reducing access to needed care. Over half of our counties have been designated as mental health professional shortage areas, and estimates show that we would need over 200 psychiatrists to start addressing this shortage.

This has particularly devastating consequences for the tens of thousands of Wisconsin children who are living with untreated mental health issues, forcing parents to wait for months to get their child into care, cross the border for care in another State, or forgo care altogether.
Wisconsin health and community leaders are collaborating on innovative programs to address these issues, but our kids are still in crisis.

RESPONSE BY BRIAN HEPBURN, M.D. 1 TO QUESTIONS OF SENATOR ISAKSON, SENATOR MURRAY, SENATOR CASEY, SENATOR WHITEHOUSE, AND SENATOR BALDWIN

SENATOR ISAKSON

Question. How does SAMHSA interact with other HHS agencies, Federal departments, and State agencies concerning the development and implementation of mental health policies? What improvements, if any, do you think could be made in this area?

Answer. SAMHSA has a long history of working with the State Mental Health Agencies (SMHAs) and Substance Abuse Agencies in developing programs through grants, sharing evidence-based practices, and seeking input regarding concerns about the upcoming implementation of new Federal programs. SAMHSA meets quarterly with advisory committees for all divisions at the SAMHSA headquarters, and also meets with those advisory committees in aggregate. Acting SAMHSA Administrator Kana Enomoto and Center for Mental Health Services Director Paolo del Vecchio have both long held close working relationships with the SMHAs, relationships founded on trust and a mutual understanding of the essentials of providing services to individuals with serious mental illness and children and youths with serious emotional distress.

A recent illustration of that close working relationship is how SAMHSA and the National Institute for Mental Health worked closely with SMHAs in the implementation of the 10 percent Mental Health Block Grant set-aside for treatment of First Episodes of Psychosis. Soon after enactment of the set-aside, SAMHSA reached out to the SMHAs to solicit input on how the program might best be implemented and then issued guidance to lead the way. Over the last 2 years, technical assistance has provided in the field and by phone to assist States in adopting the most effective, evidence-based approaches to achieve the set-aside’s goals.

SAMHSA has specifically provided leadership to our field by:

• involving persons experiencing mental illness in shared decisionmaking with their treating providers;
• promoting the importance of peer services (especially at a time when we are facing workforce shortages);
• promoting not just the medical model but also the importance of supportive housing and supportive employment in helping persons avoid disability;
• promoting integration of physical health care and behavioral health; and
• promoting telehealth and the use of health information technology to reach more people.

SAMHSA has been working very closely with officials in the Federal Medicaid program over the past few years on such items as developing quality measures that can be used across programs, and implementation of Section 223 of the Excellence in Mental Health Act conditions for participation. The two agencies have also been increasingly finding projects on which they can collaborate such as the recent CMCS Informational Bulletin on funding early intervention programs under Medicaid authorities. SAMHSA provides input into the National Quality Forum (NQF) Measures Application Partnership which develops recommendations to CMS on quality measures for the Medicaid and Medicare programs.

SENATOR MURRAY

Question. In your testimony you discussed the need for adequately funded crisis response services. I’m particularly concerned about the availability of crisis response services in areas with low population density that struggle to maintain services because of the low volume of calls. How can the Federal Government support State and local service providers to ensure that, when patients are in a time of crisis, they always have someone to call?

Answer. Recently the NASMHPD did a survey on how States fund crisis services. Some States pay for crisis services entirely with State general funds. Other States use a mixture of State general funds, block grant funds, local funds and Medicaid.

1 Stuart Gordon, NASMHPD’s Director of Policy, worked with Dr. Hepburn and many individual State mental health directors, in drafting the attached responses to questions that we received from HELP Committee members.
The percentage of the funds in the exact mixture for the individual States varies greatly. The rural communities are most vulnerable to not having adequate funding because they have a low volume of service utilization and therefore recover less reimbursement on a fee-for-service basis. They are also vulnerable because they have difficulty recruiting mental health professionals, such as psychiatrists. The poorer rural areas are also more vulnerable because there are no local funds which could help support their efforts.

The Federal Government could be helpful in resolving the problem in the rural areas by:

- providing funding to educate the public in how to assist friends and loved ones who are experiencing psychological distress. This would include being able to identify when an individual is in distress, supporting the individual and knowing where to find services for the individual. The goal is to provide the needed intervention as early as possible and avoid escalation into a crisis;
- providing adequate funding of the Suicide Lifeline Network to ensure individuals in crisis in every community will have someone immediately available who is trained in crisis response and knowledgeable about the resources available in the immediate surrounding community;
- providing greater funding for Crisis Intervention Team training of law enforcement responders and first responders to help ensure that situations provided remotely could be reimbursed, residential crisis services could be covered, residential crisis services would not be subject to the IMD exclusion, and peer services could be compensated.
- providing educational loan repayments for mental health professionals working in rural crisis programs;
- providing incentives to mental health professional training programs for training those professionals in tele-mental health; and
- providing incentives to develop social media applications directed toward persons in distress/crisis.

SENATOR CASEY

Question 1. As a member of the Committee on Finance as well as the Health, Education, Labor, and Pensions Committee, I frequently hear about the mental health needs of children in the child welfare system, and the challenges current and former foster children have in accessing the mental health services they need. Does the National Association of State Mental Health Program Directors have any recommendations or best practices for State Mental Health Agencies for ensuring that the mental health needs of current and former foster youth are properly met?

Answer 1. As an example, Indiana is utilizing a Children’s Mental Health Initiative to provide services to children who have become involved with the Department of Child Services due to their behavioral health concerns but do not have the funding for services. Also in Indiana, there is the Older Youth Initiative that provides youth with mental health services and supports as they approach turning 18 in the foster care system to assist in the transition to adulthood and self-sufficiency.

The Iowa Department of Human Services (DHS) has developed a practice guide, Children in Child Welfare: Mental and Behavioral Health Practice Bulletin, which acknowledges up front that most children who enter the child welfare system have experienced trauma. Thus, mental health screening by licensed mental health providers is one of the first steps taken after a child’s entry into the State welfare program. DHS data show that 88 percent of 359 children reviewed between August 2007 and October 2007 had their mental health needs assessed and met.

For a broader look, the Children's Bureau, in collaboration with the Georgetown University Center for Child and Human Development and through the National Technical Assistance Center for Children’s Mental Health, has released a series of papers, Integrating Safety, Permanency and Well-Being in Child Welfare, describing how a more fully integrated and developmentally specific approach in Child Welfare can improve both child and system level outcomes. The overview, Integrating Safety, Permanency and Well-Being: A view from the Field (Wilson), provides a look at the evolution of the child welfare system from the 1970s forward. The first paper, A comprehensive Framework for Nurturing the Well-Being of Children and Adolescents (Biglan), provides a framework for considering the domains and indicators of well-being. The second paper, Screening, Assessing, Monitoring Outcomes and Using Evidence-based Practices to Improve Well-Being of Children in Foster Care (Conradi, Landsverk, Wotring), describes a process for delivering trauma screening, functional and clinical assessment, evidence based interventions and the use of progress monitoring in order to better achieve well-being outcomes. The third and final paper, A Case Example of the Administration on Children and, Youth and Families’ Well-
**Being Framework:** KIPP (Akin, Bryson, McDonald, and Wilson) presents a case study of the Kansas Intensive Permanency Project and describes how it has implemented many of the core aspects of a well-being framework.

We also recommend a 2006 report co-authored by the Georgetown University Center’s National Children’s Technical Assistance Center, NASMHPD’s Children Youth and Families Division, and the National Association of Public Child Welfare Administrators entitled *Financing Behavioral Health Services and Supports for Children, Youth and Families in the Child Welfare System.* That study surveyed 24 States on their interagency financing strategies and found that 89 percent of child welfare agencies and 83 percent of mental health agencies were involved in those strategies. Medicaid was next at 65 percent, and juvenile justice at 61 percent. The vast majority of the responding States (79 percent) developed partnerships among the involved agencies to implement the funding strategies, and most of them (61 percent) formalized these partnerships.

As an aside, NASMHPD’s membership is unanimous in supporting the Administration’s initiative to reduce the inappropriate prescribing of psychotropic pharmaceuticals to kids in the foster care system [estimated at more than $3 billion a year]. That money can be better and more effectively used to enhance Medicaid financing for therapeutic foster care services and other intensive psycho-social interventions targeting the 50,000 children with the most serious emotional disturbances.

**Question 2.** In what ways do State Mental Health Agencies commonly work with their State child welfare agencies? Is there anything that the Federal Government can do to encourage or promote collaboration between State Mental Health Agencies and the child welfare agencies in their States?

**Answer 2.** SAMHSA’s Children Mental Services Program seeks to establish “systems of care” at the State level to encourage collaboration on a multi-agency basis. As noted above, State child welfare agencies such as Iowa’s recognizes that a child in the system has been more than likely to have experienced some level of trauma, and thus includes a mental health screening performed by licensed mental health and substance use treatment providers in the initial physical screening. Other agencies refer youngsters with the most serious behavioral health conditions to specialized services provided by NASMHPD member agencies.

A number of legislative modifications to the Children’s Mental Health Services program should be considered including (i) lengthening the average grant cycle under the program (e.g., adding at least 2 years to promote the sustainability of collaborations), (ii) authorizing the Administration’s fiscal year 2017 CMHI 10-percent set-aside proposal for funding prodromal approaches to preventing the onset of serious mental illness and the first episode of psychosis, and (iii) using the Children’s Mental Health Services Program to promote demonstrations of approaches such as that used in Iowa—a standard mental health/substance use screening and treatment planning protocol for all kids entering the foster care system nationwide.

The Federal Government should also consider providing guidance and funding for collaborations toward the mental health needs of children and families in need. The Indiana Division of Mental Health and Addiction (DMHA) and the Indiana Department of Child Services have collaborated to provide intensive home and community-based wraparound services for youth and families without funding known as Children’s Mental Health Initiative. See [http://www.in.gov/dcs/3401.htm](http://www.in.gov/dcs/3401.htm).

**SENATOR WHITEHOUSE**

**Question 1.** Along with a bipartisan group of senators including Senators Portman, Klobuchar, and Ayotte, I introduced a bill earlier this year called the Comprehensive Addiction and Recovery Act (S.524). The bill authorizes a series of grants to States and other eligible entities to promote an integrated approach including prevention, treatment, law enforcement tools, and recovery support to the substance abuse epidemic we are facing across the Nation. Among other things, the bill authorizes a series of prevention, treatment, and screening for, and treatment of, co-occurring mental health and substance use disorders in the juvenile and criminal justice systems and elsewhere.

Do you support the objectives set forth in S.524? How would enactment of S.524 improve your organizations ability to help address the opioid abuse epidemic?

**Answer 1.** Yes, like our friends at the National Association of State Alcohol and Drug Abuse Directors (NASADAD), NASMHPD strongly supports S.524, but would like to see all grants and programs proposed within the bill fully funded.

**Question 2.** What additional tools might you like to see at your disposal to address the overlap between substance abuse and mental health issues?
Answer 2. Perhaps language that clarifies that when grant moneys are utilized to treat an individual with a substance use disorder who also has a co-occurring mental illness or emotional disorder that may be impacting or be impacted by the severity or nature of the co-occurring disorder, grant moneys under CARA may be utilized to treat that co-occurring mental illness or emotional disorder without a violation of any SAMHSA program prohibition against the intermingling of program funds.

In a similar vein, in the late 1990s, SAMHSA initiated a dual diagnosis program/line-item for individuals with both mental health and substance use disorders. It never received much Federal funding, but efforts to revive the initiative in that form or some similar form other would be well-advised.

SENATOR BALDWIN

Question 1. Three Wisconsin health systems in the Fox Valley area have partnered to create a program, called Catalpa, to help improve timely access to mental health care for pediatric patients. This program provides crisis care for children and their families within 24 hours and then regular, followup care, led by a multidisciplinary team in the partnership network. At its main center, wait times have dropped from 54 days to about 5 days.

Senator, Dr. Hepburn and Ms. Blake, this is just one example of a program working to address the mental health services crisis facing our children. What steps would you recommend the Federal Government take to help solve our mental health provider shortage and improve access for children throughout the country?

NASMHPD is very supportive of the model that Wisconsin is now using. However, one of the difficulties has been getting funding for programs such as this. They are often funded by State general fund dollars which has slowed their expansion. Federal funding would be very helpful.

NASMHPD strongly supports President Obama’s fiscal year 2017 budget recommendation that a 10 percent set-aside be created in the Children’s Mental Health Services budget line to fund outreach to and treatment of at-risk troubled children before they reach a level of serious mental illness or serious emotional distress, and certainly before they experience their First Episode Psychosis. Such a program would utilize peers, teachers, counselors, and family members to help identify troubled youths in the schools and in the community and then invite them and their families in for family based cognitive behavioral therapy sessions led by licensed providers. This type of program addressing behavioral health needs further upstream should reduce the need for crisis-focused programs later in childhood development.

Question 2. Mental health is too often thought of as a separate part of the care continuum, resulting in a fragmented mental health care delivery system. To begin integrating mental health into primary care, our Medical College and Children’s Hospital of Wisconsin are participating in a State pilot program that offers primary care providers daily consultation services with child psychiatrists. Dr. Hepburn, how can we encourage more of our health systems and local support networks to work together to prioritize mental health and integrate these services into our larger delivery system?

Answer 2. Again, NASMHPD is very supportive of the model that Wisconsin is using. The model has been used successfully in Massachusetts and in Maryland and we would like to see it spread throughout the country. However, as with the first model you mention, the difficulty has been getting funding for programs such as this. They are often funded by State general fund dollars which has slowed their expansion. Federal funding initiatives and also allowing these consultations to be paid for by Medicaid would be very helpful.

An alternative approach might be to utilize telemedicine to help pediatricians consult with the 7,000 to 8,000 licensed child psychiatrists nationwide.

The model that seems to NASMHPD to have the greatest promise for integrating primary care and behavioral health care for persons of all ages is the Health Homes Demonstration Model for persons with chronic conditions enacted under Section 2703 of the Affordable Care Act. This works particularly well because the statute includes, among the conditions considered to be chronic and thus covered under the demonstration, persistent mental health conditions and substance use disorders. The Health Homes Demonstration requires participation of a team of health care professionals that includes physicians and other professionals such as a nurse care coordinator, nutritionist, social worker, behavioral health professional, or any professionals deemed appropriate by the State.

The home health services provided include comprehensive care management, care coordination and health promotion, transitional care and followup, patient and fam-
ily support, community and social support, and use of health information technol-

gy. While most health homes have a primary care provider as the designated

lead provider, there is no legal reason why a health homes model for pediatrics
could not have a pediatrician as a designated lead provider and, in fact, pediatri-
cians are identified in the list of providers that can so serve.

In contrast to the mostly hospital-based accountable care organizations, the
health home team can be free-standing, virtual, or based at a hospital, community
health center, community mental health center, rural clinic, clinical group practice,
academic health center, or any entity deemed appropriate by the Secretary. Also in
contrast to the ACO model, behavioral health providers have been active partici-
pants in the Health Home Demonstration project.

RESPONSE BY PENNY BLAKE, RN, CCRN, CEN TO QUESTIONS OF SENATOR
ALEXANDER, SENATOR CASEY, SENATOR WHITEHOUSE, AND SENATOR BALDWIN

SENATOR ALEXANDER

Question. During your testimony, you told a story regarding the disclosure of pro-
tected health information under the Health Information Portability and Account-
ability Act. In that case, you said that you were unable to disclose information to
a family member of a patient when that patient was unable to give consent. How-
ever, HIPAA does allow disclosure under these types of situations according to the
HIPAA Privacy Rule at 45 Code of Federal Regulations 164.510. What should the
Federal Government be doing to clarify situations where disclosure of protected
health information is permissible under HIPAA? Are there specific parts of HIPAA
that you feel are too restrictive or unclear?

Answer. Thank you for highlighting this key issue. Before I begin, please let me
recap the specifics of the circumstance, given the relevance to your question.

During the hearing, I noted that a 26-year-old gentleman presented at our emer-
gency room in Florida, unconscious with a heroin overdose, which we ascertained
because he responded to Narcan, a narcotics rescue agent. After the patient was sta-
bilized, I received a phone call from a man in Virginia trying to locate his son, who
had been previously admitted in the area for addiction treatment but had walked
away from the facility and was, thus, missing. The caller mentioned his name, but
due to HIPAA restrictions, I was not able to tell the man that his son was in our
care due to the HIPAA law.

In my response, I want to highlight two key issues—(1) lack of clarity within
HIPAA and our State privacy laws regarding the unique protections associated with
substance abuse and mental health records, and (2) how interoperable health care
records could have assisted us in treating the patient I described.

But, first, let me turn to the HIPAA clarity issue. While it is correct that 45 CFR
§ 164.510 does specify permitted disclosures to a “family member, other relative, or
a close personal friend of an individual” in the case of an emergency, such disclo-
sures are limited only to “information directly relevant to such person’s involvement
with the individual’s care” [45 CFR § 164.510(b)]. The regulation further clarifies
[45 CFR § 164.510(b)(3)] that such involvement may include “pick(ing) up filled
prescriptions, medical supplies, X-rays, or other similar forms of protected health in-
formation.” At the time that I talked to the parent, the patient was already stable.
Therefore, the disclosure would not have been to assist with the patient’s care but
to provide ease to a family member. As such, it is not clear that such a disclosure
is permitted by HIPAA.

The Emergency Nurses Association Code of Ethics, approved in February 2015,
was developed as a guide for carrying out emergency nursing responsibilities in a
manner consistent with quality of care and the ethical responsibilities of the profes-
sion. Regarding an individual’s right to privacy and confidentiality, this framework
states that “information pertinent to the care and welfare of a patient may be di-
vulged to those directly involved in the care of the patient.”

This matter is further complicated by the Florida statute requirements, which are
stricter than the Federal HIPAA requirements. Specifically, the Florida statute
states that “[p]atient records maintained by licensed Florida facilities, including hos-
pitals, are confidential and may not be disclosed without patient consent unless dis-
closure occurs to specified persons or in specified circumstances (e.g. to physicians
for treatment purposes, in response to a court subpoena, etc.).” FL ST § 395.3025.
Therefore, without the patient’s consent, I am unable to disclose such records due
to Florida law. As a result, even if one were to further clarify HIPAA, which is con-
sidered a Federal floor and not a ceiling, States (like Florida) can continue to enact
more stringent privacy requirements.
In direct answer to your question, I have highlighted the key issues with respect to the HIPAA requirements—namely, the requirement that the information disclosed to family members be limited to that which is "directly relevant to such person's involvement with the individual's care." This requirement, coupled with more stringent State privacy laws, is intended to make disclosure of personal health information difficult. But, as my example highlights, sometimes, it does not serve all those involved.

However, in the story I relayed, the patient was brought to the emergency department with suspected heroin overdose. Given the unique protections associated with substance abuse and mental health records under Federal and State law, it became unclear whether or not the ability to disclose personal health information without the patient's consent was still allowable.

When I recapped the story before, I only alluded to another key component: Had we been able to electronically obtain the patient's medical records at the time that he entered the emergency room, it could have changed the way we treated him. I understand that the HELP Committee is working to promote interoperability, and I hope that you will continue to do so.

ENA urges Congress to clarify situations where disclosure of protected health information is permissible, including requiring the U.S. Department of Health and Human Services (HHS) and State departments of health to clarify situations in which disclosures without consent are permitted, particularly when mental health or substance abuse are the cause for an individual's presentation to the emergency department.

In addition, we urge Congress to require HHS to mandate that certified EHR technology include fields for mental health and substance abuse diagnoses.

It would also be helpful if HHS encouraged local and regional health information exchanges (HIEs) to include mental health or substance abuse diagnoses as required data elements, as this information can be critical in emergency situations for treatment purposes. While it is our understanding that HHS cannot mandate this, it could incentivize this activity by making it a requirement of any grant funding for HIEs.

In the individual's care and notification purposes—(1) Permitted uses and disclosures. (i) A covered entity may, in accordance with paragraphs (b)(2) or (3) of this section, disclose to a family member, other relative, or a close personal friend of the individual, or any other person identified by the individual, the protected health information directly relevant to such person's involvement with the individual's care or payment related to the individual's health care.

2. (b)(3) Limited uses and disclosures when the individual is not present. If the individual is not present, or the opportunity to agree or object to the use or disclosure cannot practicably be provided because of the individual's incapacity or an emergency circumstance, the covered entity may, in the exercise of professional judgment, determine whether the disclosure is in the best interests of the individual and, if so, disclose only the protected health information that is directly relevant to the person's involvement with the individual's health care. A covered entity may use professional judgment and its experience with common practice to make reasonable inferences of the individual's best interest in allowing a person to act on behalf of the individual to pick up filled prescriptions, medical supplies, X-rays, or other similar forms of protected health information.

The emergency nurse respects the individual's right to privacy and confidentiality. The emergency nurse protects and safeguards the privacy of their patients, thus preventing uninvited intrusion into the patient's private life, medical history, and current condition. Information pertinent to the care and welfare of a patient may be divulged to those directly involved in the care of the patient. The HIPAA Privacy Rule protects the privacy of patient's health information and, even in the event of public scrutiny, emergency nurses are mandated to preserve the individual's right to privacy and confidentiality. Patient information utilized for peer review, third-party payments, quality improvement initiatives, or risk management processes may be disclosed based on an institution's policies, protocols, or legal mandates.

Question 1. In your testimony, you discuss the process that Good Samaritan Medical Center, and similar hospitals, follow when patients present with a mental illness. Is this process different for a child or young adult who is admitted with a men-
tal health problem? Do these patients have unique needs compared to those of adults with mental illnesses, and, if so, should the Federal Government provide any additional support or enact any policy changes to help health care providers address those needs?

Answer 1. At my hospital, the process for handling children and young adults as compared to other mental health patients is the same. Since our hospital does not have a psychiatric unit, we would transfer a mental health patient to one of the two hospitals in our area that admits patients suffering from an acute mental health issue. In such a situation, the patient is first medically cleared by an emergency physician in my hospital. The patient must then be accepted by the emergency physician of the receiving hospital and is transferred by ambulance or law enforcement vehicle to that hospital’s emergency department until a bed became available in their psychiatric unit.

Question 2. In your experience, what kind of training do nurses and other health care professionals receive regarding the patient privacy requirements placed on them by HIPAA? Do you feel that access to increased training would be helpful?

Answer 2. In our facility, we must complete a class annually regarding the HIPAA law. The class is taken online in a computerized format. Access to more in depth training would be helpful to nurses and other health care providers. However, based on discussions with colleagues across the United States, I believe the larger problem is the lack of clarity in the HIPAA language.

Additionally, States may have further restrictions on health care information, making the situation more complex for providers. Finally, hospitals protect mental health records even more stringently. As a result, health care providers tend to err on the side of caution when asked to divulge information.

SENATOR WHITEHOUSE

Question 1. Along with a bipartisan group of senators including Senators Portman, Klobuchar, and Ayotte, I introduced a bill earlier this year called the Comprehensive Addiction and Recovery Act (S. 524). The bill authorizes a series of grants to States and other eligible entities to promote an integrated approach—including prevention, treatment, law enforcement tools, and recovery support—to the substance abuse epidemic we are facing across the Nation. Among other things, the bill tries to increase screening for, and treatment of, co-occurring mental health and substance use disorders in the juvenile and criminal justice systems and elsewhere.

Do you support the objectives set forth in S. 524? How would enactment of S. 524 improve your organization’s ability to help address the opioid abuse epidemic?

Answer 1. The Emergency Nurses Association (ENA) strongly supports the Comprehensive Addiction and Recovery Act. Enactment of S. 524 would improve the ability if ENA’s 41,000 members to address the opioid abuse epidemic in several ways. I will focus on three important provisions contained in the legislation.

First, making naloxone available for use in the first few minutes of an opioid overdose by laypersons, law enforcement officers and other first responders makes a tremendous difference in the outcome for a person who has overdosed. I am proud to say that I helped to get legislation passed in Florida last year making naloxone available in these circumstances. As a result, patients are now much more likely to receive naloxone in the field from first responders. Later, when they arrive in the emergency department, we monitor the patients as the naloxone wears off and, in most cases, we are able to discharge them within several hours. In the past, when patients were much less likely to have access to naloxone as soon as they experienced a heroin overdose, many suffered brain damage caused by lack of oxygen because they had stopped breathing. We would place these patients on respirators in ICU for days just to keep them alive. Tragically, even some who survived an overdose would continue to suffer from long-term cognitive issues.

Second, the bill authorizing the Centers for Substance Abuse and Treatment to award grants to States, units of local government or nonprofit organizations located in geographic areas that have a high rate of heroin or other opioid abuse to expand treat activities, including medication assisted treatment programs, for the treatment of addiction in the geographical areas affected. This provision will be of great benefit to hospitals. Many of the patients we encounter have no place to go for the treatment of their addiction, especially if they do not have financial resources for private programs. Providing programs in the community that can help them safely withdraw from opioids and then manage their ongoing care would not only prevent them from needing emergency care, but it would save communities the costs associated with emergency medical services or police responding to cases of heroin and opioid overdoses.
Finally, the bill's National Youth Recovery Initiative authorizes the Director of Office of National Drug Control Policy to make grants to high schools and colleges to provide support to their students who are recovering from substance use disorders. This section of the legislation would assist both in the prevention of overdoses and achieving long-term recovery. This would lessen the burden on hospital emergency departments, which are not an optimal place to treat patients with substance abuse and often related mental health issues.

Question 2. What additional tools might you like to see at your disposal to address the overlap between substance abuse and mental health issues?

Answer 2. There are several tools that would help to address the overlap between substance abuse and mental health issues. One important change would be to enhance community-based treatment resources for both mental health and substance abuse patients. This will allow emergency departments to direct patients and their families to treatment options in the local community immediately upon discharge.

The time after discharge is when patients are most vulnerable and most likely to seek treatment for their addiction. Sending them directly to a treatment facility or outpatient program greatly increases their chances of recovery from their addiction. I have several friends and acquaintances who are recovered heroin addicts. They all say that they were fortunate to have family that cared enough to get them into treatment at a time they were in crisis.

Also, there is unfortunately still a prejudice by some in the health care field toward addicts. Therefore, it is important to educate health care providers, as well as the public, that addiction is a medical condition that often has a mental health component, and that both must be addressed as part of a successful treatment protocol.

SENATOR BALDWIN

Question. Three Wisconsin health systems in the Fox Valley area have partnered to create a program, called Catalpa, to help improve timely access to mental health care for pediatric patients. This program provides crisis care for children and their families within 24 hours and then regular, followup care, led by a multidisciplinary team in the partnership network. At its main center, wait times have dropped from 54 days to about 5 days.

Dr. Hepburn and Ms. Blake, this is just one example of a program working to address the mental health services crisis facing our children. What steps would you recommend the Federal Government take to help solve our mental health provider shortage and improve access for children throughout the country?

Answer. From your description, Catalpa appears to have all of the components for a successful program. Access to emergency and crisis intervention immediately with referrals and followup resources are the key to a successful community based program. Regarding the mental health provider shortage, I would suggest examining the incentives the Federal Government has provided to address the ongoing shortage of registered nurses. These include the Title VIII Nursing Workforce Development programs that make scholarships and loans available to nurses and nursing students through a variety of grants. Similar programs and incentives could be made available for those embarking on a career in mental health and psychiatry.

In addition, the expanded use of technology should be considered. We have a shortage of neurologists in my area, so we use telemedicine to evaluate patients for possible interventions for stroke symptoms and it works well. Telepsychiatry is in use in some hospitals across the United States.

Also, policymakers should expand the role of nurse practitioners to allow them, with proper education and certification, to evaluate patients with mental health issues for the need for inpatient treatment. Frequently, in my area, we are told that the delay in having a patient transferred to a psychiatric facility is due to the psychiatrist not being available to review their records and evaluate them for intake. Allowing advanced practice registered nurses to review and evaluate patients would save both time and money.

RESPONSE BY WILLIAM W. EATON, PH.D. TO QUESTION OF SENATOR WHITEHOUSE

Question. Along with a bipartisan group of senators including Senators Portman, Klobuchar, and Ayotte, I introduced a bill earlier this year called the Comprehensive Addiction and Recovery Act (S.524). The bill authorizes a series of grants to States and other eligible entities to promote an integrated approach—including prevention, treatment, law enforcement tools, and recovery support—to the substance abuse epidemic we are facing across the Nation. Among other things, the bill tries to increase screening for, and treatment of, co-occurring mental health and substance use disorders in the juvenile and criminal justice systems and elsewhere.
Do you support the objectives set forth in S.524? How would enactment of S.524 improve your organization’s ability to help address the opioid abuse epidemic? What additional tools might you like to see at your disposal to address the overlap between substance abuse and mental health issues?

Answer. I support the objectives set forth in S.524. Thanks for the opportunity to comment.

[Whereupon, at 11:31 a.m., the hearing was adjourned.]