

**Statement of Paul Gionfriddo, President and CEO of Mental Health America**

**U.S. House of Representatives Committee on Energy and Commerce,**

**Subcommittee on Health**

**Regarding HR 2646, The Helping Families in Mental Health Crisis Act of 2015**

**June 16, 2015**

**Summary**

H.R. 2646 is an important start to passing comprehensive mental health reform in America. Its emphasis on moving upstream in the process – i.e., on intervening before Stage 4 – is a critical step forward toward treating mental illnesses like we treat every other chronic disease in America.

As it stands, HR 2646 addresses five fundamental areas of mental health: Promote screening and early intervention, build community-based systems of care, enhance the behavioral health workforce, Integrate health and behavioral health care, and enforce parity in coverage of health and behavioral health services. All are critically needed.

It appropriately emphasizes screening, secondary and tertiary prevention, and integration, while creating a stronger central federal authority to advance mental health policy. It focuses resources on meeting the needs of children and young adults. This testimony makes recommendations for building out those areas. It promotes both innovative programming and the replication of evidence-based models. It underscores the importance of evaluation. It recognizes the importance of protecting the legal rights of people with mental illness, making some revisions to HIPAA, and moving treatment and services from jails to communities. This testimony includes recommendations for changing HIPAA standards to promote integration. It includes peers as an important part of the future behavioral

healthcare workforce, working in clinical settings – and this testimony includes some recommendations for making that happen.

We recognize that the legislation in its current form is not a finished product and that it will be changed and amended as it moves through the legislative process. So long as it continues to emphasize prevention strategies, early identification and intervention, integration of health, behavioral health and other services, and lay the groundwork for recovery, we believe we and others will be able to support it fully.

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Mr. Chairman, Ranking Minority Member Green, members of the Subcommittee on Health, my name is Paul Gionfriddo, President and CEO of Mental Health America, the nation's leading community-based non-profit dedicated to helping all Americans achieve wellness by living mentally healthier lives. Thank you for the opportunity to testify regarding H.R. 2646, The Helping Families in Mental Health Crisis Act of 2015.

We applaud this subcommittee, and, in particular, Congressman Tim Murphy and Congresswoman Eddie Bernice Johnson for their bipartisan leadership. As a parent of an adult son with schizophrenia, and as a former mayor and state legislator in Connecticut, I know how difficult it can be to reach across the aisle, identify consensus and pass meaningful legislation, particularly on an issue as thorny as mental health. We appreciate the efforts of the sponsors to take into consideration all the feedback they received from us and others throughout the year – and to change so many of the provisions that deeply worried people living with mental illness and working toward recovery.

I will not cover the entire proposal in these brief remarks, but will focus on some of the areas that are important to us.

H.R. 2646, while not perfect, is an important start to passing comprehensive mental health reform in America. Its emphasis on moving upstream in the process – i.e., on intervening before Stage 4

– is a critical step forward toward treating mental illnesses like we treat every other chronic disease in America, and toward changing the trajectories of lives impacted by illnesses that people acquire – most frequently during childhood – through no fault of their own.

As it stands, HR 2646 addresses five fundamental areas of mental health: Promote screening and early intervention, build community-based systems of care, enhance the behavioral health workforce, Integrate health and behavioral health care, and enforce parity in coverage of health and behavioral health services. All are critically needed.

Mental Health America has some concerns, which I will address shortly. We recognize that the legislation in its current form is not a finished product and that it will be changed and amended as it moves through the legislative process. We are hopeful that today is the start of an ongoing conversation among all of us—policymakers, providers, and advocates—to address concerns and improve upon this critical legislation. So long as it continues to emphasize prevention strategies, early identification and intervention, integration of health, behavioral health and other services, and lay the groundwork for recovery, with thoughtful consideration of amendments, we believe Mental Health America and others will be able to support it fully.

### **Screening and Early Intervention**

The proposed legislation includes funds for early childhood intervention and treatment programs and for longitudinal studies of their effectiveness. However, these are currently limited to no more than three programs nationwide. Mental Health America would prefer a larger program, so as to open the door to additional programs should more funding become available.

Because serious mental illnesses frequently emerge during childhood, services to children and young people must be emphasized in any reform legislation. HR 2646 puts some needed focus here. In the innovation grants, it directs at least one-third of all the dollars to screening and early intervention

services to people under the age of 18. And in the demonstration grants program, half of the dollars are directed to people under the age of twenty-six.

In the spring of 2014, Mental Health America launched online screening tools through our website at [www.mhascreening.org](http://www.mhascreening.org). To date, nearly one half million screens have been completed. Nearly half of those who complete a screen are under the age of 25. Two-thirds of those completing screens have screened as positive or in the moderate-to-severe range for the conditions for which they have screened. But two-thirds of those indicate that they have never been diagnosed with a mental health condition.

Just as we do with every other chronic condition, we frequently reach people initially through screening. In the proposed legislation, there is a welcome emphasis on screening and early intervention – in the innovation grants, the demonstration grants, the youth suicide prevention program, and the campus mental health program, among others. And in legislation that frequently emphasizes both evaluation and building on evidence-based programs, we appreciate the setting aside of dollars for innovation – because today’s evidence-based program is yesterday’s well-evaluated innovation.

There is an additional opportunity here that we would hope the committee will consider – and that is to make changes to the EPSDT program, and to the essential health benefits, to guarantee that services that are identified as needed in response to screening are covered fully by public and private insurance.

In addition, it is our hope and mine personally that at some point during this process, members of Congress will consider the importance of integrating health and educational services for our children. My son Tim has schizophrenia. He is thirty years old today, living mostly on the streets of San Francisco. He first showed signs of the disease when he was a young child. Throughout his school years, we sought to gain special education services for him and were frequently rebuffed by school districts.

At the time – this was in the 1990s – I had a friend and colleague who had worked on writing the regulations for what would become the Individuals with Disabilities Education Act (IDEA). I once asked him, referring to Tim, “is this who you had in mind when you wrote those rules?” “Paul,” he replied, “we were thinking of kids in wheelchairs.” As a result, we did an outstanding job of integrating children with significant physical disabilities into regular educational environments, enabling them to live productive lives as adults. But we didn’t do so well with children like Tim. Today, according to US Department of Education data, approximately 375,000 children in the country receive special education services because of an “SED” label. That represents only one child in every 28 that the National Institute of Mental Health (NIMH) says has a “serious” mental health condition or concern.

There are many ways we could tackle this. The most obvious and money-saving would be to amend the special education law to permit IEP-mandated services to be paid for by health insurance as a payer of first resort, so that school districts could reserve their limited special education funds for services that can’t be paid for through another funding source. That way, schools wouldn’t be so reluctant to include the kinds of community-based clinical services in an IEP that children like my son Tim need to succeed.

#### **The New Federal Agency and the Interagency Serious Mental Illness Coordinating Committee**

Mental Health America endorses the additional empowerment and elevation of the lead federal behavioral health agency in this legislation, and the creation of the Interagency Serious Mental Illness Coordinating Committee (ISMICC). MHA has supported SAMHSA, and believe that it has done commendable work with very limited resources. But our nation’s mental health needs are so critical that federal leadership in this area must be enhanced and better centralized. We look forward to working with members of Congress to make certain this new agency is as successful as it can be.

While the responsibilities being assigned to the Assistant Secretary and the ISMICC are appropriate, there are two others not in the proposal that we would ask you to give to them. The first

would be to establish a common standard other than “danger to self or others” as a trigger to treatment for SMI, because this – while a popular standard in wide use – is not a clinical standard. The second would be to develop a national plan that would result in an end to the incarceration of nonviolent people with serious mental illnesses within a decade.

### **Peer Workforce Development**

We endorse the intent of this bill to enhance the mental health workforce. At Mental Health America, we have a special interest in the peer workforce. Many of our affiliates around the nation are direct service providers and have done outstanding work in developing and supporting the peer workforce in general, non-clinical settings. In this legislation, we see an opportunity to develop a properly-credentialed peer workforce that could work competitively in clinical settings, too.

We have been working with Kaiser Permanente on a pilot this year. We train the peers and along with our local MHA affiliates provide oversight and supervision. The work of the peers is directed (and supervised day-to-day) by the clinical professionals on whose team they work.

Mental Health America believes that the draft language in HR 2646 should be strengthened to promote the inclusion of properly trained and supervised peers on clinical care teams, and should focus on this in particular. I have submitted suggested draft language in Attachment 1.

### **Assisted Outpatient Treatment**

Mental Health America has not supported a national mandate to states to enact Assisted Outpatient Treatment (AOT) laws, nor do we support state laws that do not include additional dollars for community outpatient services. Our position on AOT, adopted unanimously by our Board of Directors in March 2015, is that it should be used “only as a last resort,” (Position Statement 22) in a limited way, and only when there are adequate local services to serve the needs of everyone who wants to access them voluntarily.

We therefore support the approach this legislation takes not to mandate AOT, but to give states that have AOT laws a 2 percent funding enhancement. AOT should continue to be a choice made by states, not mandated by the federal government, and sections in this legislation that appear to be in conflict with this should be reviewed and revised if need be.. And those that choose to enact AOT should be required to evaluate the effectiveness of their programs and to demonstrate that they have used their new dollars to enhance community-based systems of care.

### **HIPAA**

We support the loosening of HIPAA rules in Section 401, because these rules need to be changed if we are serious about integrating health and behavioral health care. HR 2646 takes one very limited step toward allowing information to be shared more freely. It spells out six conditions that must be met for information to be shared with a caregiver, who can then share it with a provider on behalf of a patient. It may be exceedingly difficult and time-consuming for a provider or provider entity to prove that all these conditions are being met simultaneously. So they may not even try.

I worked on behalf of a community health collaboration in Austin TX from 2001 to 2005. One of our projects was to implement a shared electronic health record among more than two dozen provider locations. We learned what everyone learns who tries to integrate care – it can't be done with only part of a health record. If a provider relies on an incomplete record to make decisions about care, he or she does so at his or her own peril – and at the peril of the patient as well.

In our Position Statement 27, Mental Health America lays out the problem:

The federal government and some states have identified information that should be MORE PROTECTED than other information covered by HIPAA. MHA generally opposes special protections of this kind because there is no evidence that additional formalities actually increase privacy, and such special protections compromise integration of care. Examples of “super-confidential” information include: genetic information and information pertaining to school

records, substance abuse, mental health conditions, HIV testing, and sexually transmitted diseases, as defined and protected by specific federal and state laws and regulations. MHA does support the HIPAA exemption for psychotherapy notes, as defined in 45 CFR 164.501.

There are other proposals before your committee that also seek to address this matter. One proposal suggests as an alternative that we look again at the guidance for sharing offered last year to providers, to see whether some of this guidance should be codified. Another may favor a time-limited authorization for the sharing of some behavioral health data.

Here is what we would suggest. If we are serious about integrating health and behavioral health care, then the goal here should be easier sharing of information among providers. The only way to do this is to clarify the law to eliminate the “super authorization” needed to share behavioral health information.

What is more, while promoting integration making this change will still give the individual the right to control the release of his or her protected health information.

#### **Protection and Advocacy Services for Individuals with Mental Illness**

HR 2646 retains funding for Protection and Advocacy Services. We support this. It also proposes to focus these services “exclusively on safeguarding rights to be free from abuse and neglect.” We at MHA are concerned that the final statement of scope for needed protection and advocacy services may be too narrowly drawn to fully protect the rights of all people with mental illness. I hope and believe that someday soon my son Tim will decide to leave the streets and re-engage with society. When he does, I have no doubt that he is going to have to rely on effective legal counsel to obtain the housing, employment, and the supports he will need.

#### **Budget Neutrality**

We understand the constraints under which members of Congress work. We applaud the effort to manage the loosening of the IMD exclusion to make it budget neutral and look forward to discussing

this further as the details of the approach emerge. And we understand the need to offset new expenditures with reductions in other areas. I want to note that many advocates are worried that members of Congress will find the offsets to support new programs in this legislation from existing community mental health programs, resulting in the loss of programs around the country that are lifelines to people with serious mental illness.

We do not believe that is the intent of the sponsors and want to state emphatically that we at Mental Health America would not support this either. These programs have been underfunded for too long already, and HR 2646 takes some first tentative steps toward remedying this situation. If you want to find offsets, please look to our jails and prisons. By sending so many of our children like my son Tim to those 21<sup>st</sup> Century asylums, that's where we've put the funding that could be used to support the community-based initiatives in this legislation and more, and that's why we have yet to address the fundamental issues facing so many of our children like my son Tim.

In closing, for more than a century Mental Health America has appreciated that addressing mental health and illness is a complex and emotional issue. But it is well past time to address them in a comprehensive, thoughtful way. We must work together to remove the stigma associated with seeking help for mental health concerns, and the discrimination that occurs against those who live with them. We must put into place a mental health system that allows us all to move upstream, provide the behavioral health services individuals need and deserve early, and enforce parity in coverage. We must address mental health and mental illness before Stage 4.

Thank you for the opportunity to testify before you today and I am happy to take any questions you may have.

## Attachment 1

### Peer Support Specialist

(2) Peer-Support Specialist Defined. In this subsection the term “peer-support specialist” means an individual who-

- A. Has made a commitment to his or her own recovery from mental illness or substance use and uses their lived experience plus skills learned in formal training to facilitate support groups, act as a systems navigator, mentor, educator, advocate, and work one on one with individuals living with a mental illness or a substance use disorder. When working in a clinical setting they work in consultation with a licensed mental health or substance use treatment professional, and are supervised by an administrator trained in the concepts of recovery and peer support with the oversight of a licensed professional. When working in a peer-run program they are supervised by a peer administrator with access to a licensed professional when needed;
- B. Has been an active participant in mental health or substance use treatment;
- C. Does not provide direct medical services;
- D. Does not perform services outside of his or her area of training, expertise, competence, or scope of practice.

(3) Contents, - Each report under this subsection shall include information on best practices with regard to the following:

- A. Hours of formal work or volunteer experience related to mental health and substance use issues.
- B. Types of peer specialist exams required.
- C. Code of ethics.
- D. Additional trainings required prior to certification, including areas such as –
  - i. Integrating physical medicine and mental health supportive services;
  - ii. Ethics;
  - iii. Scope of practice;
  - iv. Crisis intervention
  - v. Identification and treatment options of mental health disorders;
  - vi. State confidentiality laws;
  - vii. Federal privacy protections, including under the Health Insurance Portability and Accountability Act of 1996; and
  - viii. Other areas as determined by the Assistant Secretary in consultation with peer support experts.
- E. Requirements to explain what, where, when, and how to accurately complete all required documentation activities.
- F. Required or recommended skill sets, including:
  - i. Helping consumers identify risk indicators, including individual stressors, triggers, and

indicators of pre-crisis symptoms;

- ii. Explaining basic crisis avoidance techniques;
- iii. Explaining basic suicide prevention concepts and techniques;
- iv. Identifying and responding appropriately to personal stressors, triggers, and

indicators;

- v. Effective listening techniques
- vi. Identifying an individual's current stage of change or recovery
- vii. Teaching individuals how to access or participate in community mental health and related services;

viii. Developing pre-crisis, crisis, and recovery plans; and

- ix. Identifying circumstances when it is appropriate to request assistance from other professionals to help meet the individual's recovery goals.

G. Requirements for continuing education credits annually