Statement of David L. Shern, Ph.D. President and CEO, Mental Health America Before the Health Subcommittee, Energy & Commerce Committee Hearing on Helping Families in Mental Health Crisis Act of 2013 April 3, 2014

Mr. Chairman and members of the Committee, I am Dr. David Shern, Interim President and CEO of Mental Health America. Mental Health America is the nation's oldest advocacy organization concerned with all aspects of mental health and mental illness. From our founding, we have worked to not only improve the treatment conditions for persons with mental illnesses, but also to prevent and cure mental health conditions. Today, we have a formidable scientific basis for prevention and treatment of mental health and substance use conditions. While much is yet to be discovered in these areas, our current challenge is to apply what we know can work, which includes state of the art treatment and supports with the full involvement of persons with these illnesses in all aspects of their care. MHA has 228 affiliates located throughout the U.S.

I am a research psychologist by training and was Dean and a Professor at the University of South Florida, directing a large mental health research institute before joining MHA in 2006. I have spent my career studying systems of care for persons with severe mental illnesses (SMI), including persons who are most in need of care. I have directed federally funded research projects that have investigated the optimal ways to serve individuals who have not been well served traditionally by our public mental health system, including homeless, street dwelling individuals with severe illnesses and, often, co-occurring addictions. This later program integrated treatment and rehabilitation services with a strong emphasis on consumer choice and program accountability for the outcomes achieved by persons who were served. It has evolved into a national model housing program for persons who are homeless and have severe illness—Pathways to Housing—that is now a national model for an evidence-based program to serve this population. Therefore, I have deep experience in many of the issues addressed in this legislation and with alternative approaches for serving individuals who many would characterize as difficult to treat. It has been a great honor to lead MHA for most of the last eight years in an attempt to better bridge the gap between what we know can help individuals with SMI and what is routinely available to them in communities throughout this nation.

In addition, I am a family member of a person who had a severe mental illness. My nephew has bipolar illness that was particularly difficult during his late high school years. Even with the best connections in the US, we were unable to get him the services that he needed in his home town and he required out of state placement in a residential treatment facility. All has turned out well for him at this point but I have a strong personal connection to the difficulty in obtaining the care that is needed.

In my case there was an extensive evidence base regarding the care that my nephew needed but evidence-based care was not available for him. There remains much to be done to adequately implement what we know could make a big difference in the lives of persons with these conditions and the people who care about them. As such, we agree with the premise of the legislation that our current systems are broken and in urgent need of repair and we congratulate Representative Murphy for his efforts to address these problems through federal legislation. It is a bold attempt to address many aspects of our current system that are in need of repair. It includes many laudatory features such as the reauthorization of the Mentally III Offender Treatment and Crime Reduction Act, the Garret Lee Smith suicide prevention program, and the National Child Traumatic Stress Network, and enhancing support

for community-based behavioral health programs and fostering health information technology, increased funding for research, grants for integration of care, education in the schools and justice system, codifying anti-depressants and anti-psychotics as protected classes. All these steps will undoubtedly improve the infrastructure and programming in mental health.

Finding an Effective Balance of Interventions, Services and Supports: However, there are other aspects of the bill that are of great concern to MHA and many other advocacy organizations. We strongly believe that some aspects of the legislation, while well intended, will ultimately result in damage to the system and the people served by these systems. While we share the ends sought by the legislation, we differ on the several of the means proposed to achieve these ends. The issue is finding an effective balance of interventions, services, and supports

A bit of history of the American mental health system might help to frame our concerns. There was a time, not long ago, where the leading psychiatric thinking held that receiving a diagnosis of schizophrenia was tantamount to a death sentence. It was asserted that the course of illness was inexorably one of increasing deterioration—moving from positive symptoms of delusions, hallucinations, agitation to negative symptoms of emotional withdrawal, non-responsiveness to a vegetative state. These observations were largely drawn from individuals who spent decades in psychiatric hospitals. Starting in the 1970s and 80s, long-term follow-up studies of individuals who were released from state hospitals were conducted with startling results. The best known of these was conducted by Courtney Harding at Yale who obtained information from over 90 percent of a group of long-term patients released from the Vermont State Hospital. What Harding found was a group of largely recovered individuals— the majority of whom were indistinguishable from other 'normal' community residents. These findings have now been replicated over 10 times with differing samples of persons with schizophrenia. Clearly, our science regarding the course of illness was wrong and based on biased observations of persons who were institutionalized. In part, we were seeing the effects of the environments in which people were living and not the inexorable effects of their illness.

Recovery—Designing Services that are Person-Focused and Skill-Based: These findings began to change everything we knew about the possibility of recovery from severe mental illness. Harding and colleagues went on to further study the difference in outcomes between Maine and Vermont patients with Vermont having a more rehabilitative-oriented system of care than Maine. She found that long-term patients who resided in Vermont recovered more quickly and completely than individuals in Maine suggesting that the organization and delivery of services made a difference in facilitating recovery.

Importantly, this later study suggested that designing services that were person- focused and skill-based could make a big difference in the outcomes that individuals achieved.

It is well known today that the movement from large, institutionally based care to community based care called deinstitutionalization was fundamentally flawed. The vision of community integration that inspired the movement and the horrible circumstances of large, custodial institutions that compelled it were, unfortunately, not sufficient to achieve the outcomes that were desired for persons with severe mental illnesses. We now know that the lack of adequate individualized and coordinated community supports including housing, income, educational and employment supports as well as access to effective treatment services, including crisis support and acute inpatient care led to the horrible outcomes of homelessness and incarceration that are addressed in the proposed legislation. We now know what is needed to effectively serve individuals with the most severe mental illnesses, many of whom have

addictions. Our challenge is to successfully implement this knowledge in a fragmented, underfunded treatment and support system. I think that there is little disagreement here.

How to Implement Knowledge—Need for an Adequately Funded Treatment and Rehabilitative System: Where we disagree is how best to achieve these ends. From our perspective, the proposed legislation misinterprets our history and undermines many of the system components that have contributed to progress. It seeks judicial remedies for what are clinical challenges. What we need is an adequately funded treatment and rehabilitative system in which identified points of system accountability are established for individuals who are most in need of care. One that assertively engages these individuals where they are—both physically and psychologically—and helps them craft a recovery plan that is responsive to their individual needs and circumstances. Given the historical patterns of discrimination against persons with mental illnesses, this system must also protect their rights and assure that they have a voice in designing the systems of care to meet their needs. A witness at the Committee's hearing last week—Dr. Arthur Evans—argued that we need a comprehensive strategy for people in psychiatric crisis, that the hospital must be seen in the context of the larger community support, and the number and use of hospital beds is largely driven by the lack individualized, coordinated, comprehensive community-based services and supports.

Improve Protection and Advocacy Rather than Dismantle: Provisions in the proposed legislation that seek to undermine the Protection and Advocacy (PAIMI) function by dramatically reducing its funding do not serve these ends. While the system surely can be improved and might benefit from the use of more alternative dispute resolution techniques like psychiatric advanced directives and mediation-oriented dispute resolution, the wholesale abandonment of the PAIMI function would be disastrous in our current systems. Improved accountability and new technologies for this system are needed, not dismantling it.

Similarly, elimination of the IMD exclusion in Medicaid without maintenance of efforts provisions for the states could potentially incentivize expensive inpatient care settings at the expense of community alternatives. We have long known that an organized system of care is needed and, as Dr. Evans noted in earlier testimony to this committee, the need for inpatient beds is largely dependent upon the number and type of community treatment alternatives that are available. With an adequately funded crisis system, respite housing, peer supports, rehabilitative services and, importantly, assertive outreach to individuals who are most in need with single points of responsibility for their care and outcomes—as has been achieved in New York—inpatient treatment can be used most effectively. Inpatient care can help stabilize individuals who are acutely ill, keep them and others safe and rapidly return them to their communities with adequate follow-up so that they can resume their life goals and community participation. Adding resources to the most expensive and restrictive element in the system without an overall plan for designing a state of the art system of care including safe alternatives to inpatient care would be irresponsible and very expensive - particularly in the light of Medicaid expansion with 100 percent federal funding for expansion services. A CBO score on this provision would be helpful in fully understanding its fiscal impact. Insert need for fiscal project for modifying the exclusion.

Additionally, current provisions in the ACA (Section 2707) are examining whether eliminating the prohibition against payments to IMDs for services rendered to Medicaid recipients aged 21 to 64 improves psychiatric care for people with mental illness and lowers states' Medicaid program costs. It only seems sensible to await the results of this demonstration before making further changes to the IMD exclusion.

Need Adequate, Consumer-Focused System of Care: It is an adequate, consumer-focused system of care that we know will make a difference in the outcomes experienced by persons with severe mental illness. The Assisted Outpatient Treatment (AOT) provisions in the proposed legislation would condition receipt of mental health block grant funds on the successful implementation of this coercive mechanism in each of the states. The logic here is that compelling persons most in need into care will improve their outcomes. The evidence to support this assertion is thin. The best research indicates that it is only when adequate systems of care exist that AOT interventions have shown positive outcomes. Additionally, none of the research to date has estimated the number of persons who avoid any contact with the treatment system as a result of the potential coercion. My own experience with the homelessness treatment program I mentioned earlier in my testimony indicates that this is a real concern. Our treatment systems should be welcoming rather than frightening. Most states currently have an AOT provision available but it is rarely effectively used because it cannot create a system of care by ordering treatment. Clearly, we need to concentrate on the development of the system and compelling people into a non-existent system makes no sense. Punishing states by removing resources that could be used to develop such a system (i.e. the block grant) makes even less sense.

Incorrectly Linking Mental Illness to Violence Deters People from Seeking Help: Much of the recent focus on AOT was motivated by recent mass shootings and the perceived link between violence and mental illness. It has been known for many years that there is no simple link between mental illnesses and violence—except that persons with severe mental illnesses are much more likely to be the victim of violence than other individuals. We now know from careful epidemiological research that there are a small group of individuals with a very specific symptom cluster that are more likely to exhibit some violent behavior broadly defined to include pushing or hitting others. When these symptoms are treated the risk of violence diminishes. Dr. Jeff Swanson at Duke University who conducted this work and who is generally seen as a national expert of violence and mental illness estimates that if all mental illnesses were cured we would see a 4 percent reduction in violence. Clearly, 96 percent of the problem is not related to diagnosable mental illnesses. Similarly, in a systematic examination of 34 instances of mass shootings perpetrated by adolescents between 1958 and 1999, Meloy and colleagues estimated that the common characteristics among the shootings involved sex (male), social isolation, substance use, a preoccupation with gun and being a victim of bullying. Less than a quarter of the shooters had a documented psychiatric history and only about 6 percent were psychotic at the time of the shootings. The best predictor of violence is violence. If we want to effectively address these issues we should directly target evidence of violent behavior. Linking mental illnesses and violence will do little to address the overall problems of violence and only serves to further stigmatize mental health conditions and to depress help seeking.

This is not to say that persons who are a danger to self or others should not receive priority access to care. An assertive outreach program to individuals who are identified at significant risk for harmful behaviors to either self or others that involves concerned family and friends as key treatment team allies is what is needed. Targeted outreach and access to a range of treatments and supports—including inpatient care when it is needed—would go a long way toward better serving persons with SMI, keeping communities and individuals safe as well as promoting recovery.

SAMHSA Has Improved Treatment System: From our perspective the Substance Abuse and Mental Health Services Administration (SAMHSA) has led in efforts to develop these systems for both adults and children. The proposed legislation includes changes to SAMHSA. Some assert that the agency's priorities are misguided and resources are not spent effectively. Further, some feel that the agency promotes a particular agenda that encourages individuals to forgo traditional treatment strategies including medication. From our perspective, none of these allegations are correct.

SAMHSA and its progenitor Centers in the NIMH, NIDA and NIAAA prior to their separation in 1993 have been responsible for many of the treatment system improvements experienced during the last 40 years. It was the SAMHSA Community Support Program of the 1970's that first brought attention to the plight of adults with severe mental illnesses in the community. This program realized the critical nature of case management services, the need for income, employment and housing supports and the needs of persons who were trans-institutionalized in nursing, boarding and assisted living facilities following their discharge from state hospitals. Similarly, it was SAMHSA that first focused systematically on the needs of children with severe emotional problems through the CAASP program that incubated the successful national Systems of Care Initiatives supported by Congressional appropriations. It was SAMHSA that first documented the rates of mental illnesses among persons who were homeless and launched a series of demonstration programs that have been shown to be effective in engaging, housing and serving these individuals. It was SAMHSA, following creation of the Block Grants in 1980, which encouraged states to more effectively target funds toward the adults with severe mental illnesses and children with severe emotional disturbance through the states' new leverage with the Community Mental Health Centers. It was SAMHSA that supported the need for integrated substance use and mental health services through a series of initiatives targeted at individuals with dual diagnosis. It was SAMHSA that partnered with HRSA to launch a national effort to better coordinate primary care and specialty mental health services in community health and mental health clinics to address the tragedy of premature mortality among persons with severe mental illnesses. In short, these exemplar programs strongly underline SAMHSA's historical and continuing leadership to address the nation's mental health needs.

How to Best Coordinate Supports and Services: In their recent book – Better but Not Well –Richard Frank and Sherrie Glied noted that we have made significant improvements in the treatment of individuals with severe mental illnesses and that much of the improvement is attributable to income support and housing programs as adjunctive to mental health treatment. Something we've known for nearly a century is that mental illnesses impoverish individuals. They strike individuals as they are launching their adult life and, owing to the lack of access to effective treatment, can sentence an individual to a life of poverty with the constant risk of homelessness. The income and housing support programs along with the expansion of Medicaid services to better meet the treatment needs of individuals has had a beneficial impact for persons with severe mental illnesses. SAMHSA, along with the advocacy and professional community, has had a key role in promoting these efforts within the federal government. In noting that the needs of individuals with SMI involve more than treatment involving several federal departments, Frank and Glied proposed the establishment of a White House Office charged with coordinating the varying federal programs that impact persons with SMI. We would support the development of such an office.

The current legislation proposes establishing an Assistant Secretary for Mental Health and Substance Use Disorders in HHS with the goal of better coordinating the HHS programs impacting persons with mental illnesses. We would not oppose such an initiative if both mental health and substance use programming were overseen by such an office and particularly like the Policy Laboratory as part of the office. However, since the SAMHSA Administrator now reports directly to the Secretary, we see little advantage in creating such an office. Our impression is that the interagency coordination with HHS and across government departments has been improving during the last several years and mechanisms to further stimulate collaboration are desirable. Given the large number of departments outside HHS that have important impact on the public's mental health we would enthusiastically support a White House office.

Other changes suggested for SAMHSA would create additional Congressional oversight for their programs and statutorily increase the involvement of licensed mental health professionals in the

oversight and functioning of the agency. Additionally, the legislation seeks to limit services supported by SAMHSA to those that have an evidence base. As noted earlier, the problems of persons with SMI involve more than mental health treatment services. Appropriate involvement of expertise from each of the sectors relevant to the well-being of adults with SMI is certainly appropriate including expertise in justice, education, housing and labor among others. Perhaps most importantly, the voices of persons served by the system, both primary consumers and concerned family members, are of critical importance. Prescribing levels of licensed mental health professional involvement will make it more difficult to practically obtain the broad range of expertise needed for SAMHSA programs. We would propose either eliminating the 50 percent requirements or reducing the percentage to 25 percent. We would propose that 51 percent of any advisory group be composed of mental health consumers and family members who, obviously, could also be mental health professionals or persons with expertise in allied areas. This is consistent federal policies starting with the Developmental Disabilities Services and Assistance act of 1970.

Peer-Delivered Interventions Hold Great Promise: As noted earlier, SAMHSA has played a key role in stimulating the development and testing of innovative treatment and support programs. Programs focused on engagement in care with the use of innovative strategies including peer support are among these innovative programs. Peer delivered interventions hold great promise in increasing adherence to meaningful recovery plans as well as addressing the emerging workforce challenges that we will have in health care overall. We feel that it is critical that SAMHSA maintain the ability to help support these programs with rigorous evaluations to determine their effectiveness. Restricting programs to those which already have an evidence base will have a chilling effect on the field since SAMHSA is one of the only sources of funding for innovation that may then be more rigorously tested by NIMH, NIDA, NIAAA and other entities once some evidence base and program specifications are developed.

Finally, we heartily endorse the sense of the legislation that meaningful involvement of concerned family members and others in the individual's social networks is an essential feature of any treatment and recovery plan. We greatly share the concerns of family members of people with severe mental illness, including those who have testified before the Committee. It is clear that no one knows more about a person's situation than the individual and their close family members and friends. But privacy of medical information is also of primary concern. As we understand HIPAA, it permits the sharing of information with the consent of the individual and in emergency or crisis situations. We would support public education efforts to better inform practitioners regarding current HIPAA regulations, including codification of the Office of Civil Rights' interpretation of access to medical information. We urge that people be consulted about and have a meaningful opportunity to oppose any release of their personal medical information.

Given the comprehensive nature of the proposed legislation we think that it provides an excellent opportunity to further strengthen the implementation of the Mental Health Parity and Addiction Equity Act of 2008. We suggest that the legislation call for an organized effort by the Department of Labor in conjunction with HHS to collect information on compliance with MHPAEA that results in annual transparent, de-identified reports of all enforcement actions and an updated compliance guide that is easily accessible to plans, employers, employees, etc.

We therefore applaud the committee for this important work and especially Representative Murphy for his leadership in this matter. As is clear from our comments, we share a common vision for what is needed to improve care: A person-centered approach with a full range of treatments and supports to facilitate an individual's recovery from severe mental illness. Successful engagement in care requires an acceptable and accessible service system focus on the individual needs and desires and informed by meaningful family involvement.