National Coalition for Mental Health Recovery

June 8, 2016

Contact information: Val Marsh, Executive Director * val.marsh@ncmhr.org * 240/468-7202

Comments on the Helping Families in Mental Health Crisis Act of 2016 (HR 2646)

NCMHR is unable to support the most current draft of HR 2646, despite significant changes, for the following reasons:

1. **We do not support the creation of the proposed position of Assistant Secretary of Mental Health, and believe that section of HR 2646 should be deleted.** Adding additional staff at HHS merely provides an additional layer of bureaucracy that would be duplicative and an unnecessary use of federal dollars. Further, any insertion of medical authority over SAMHSA would be a huge step backward to institutional policies and models. We strongly support SAMHSA's policies of recovery and wellness, which we believe yield positive outcomes, are cost-effective and humane.

2. **We do not support prohibiting the P&As' from lobbying Congress under the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act and call for this section of the bill to be removed.** PAIMI was created by Congress in the 1980's specifically to help the most vulnerable among people with mental health conditions; those in institutional settings. Ironically, PAIMI was a labor of love for NAMI's first lobbyist, Dick Greer. Mr. Greer was instrumental in convincing Congress that problems of abuse and neglect cannot be stopped merely on an individual case basis. Egregious conditions have proven impossible to eradicate in institutions like psychiatric hospitals, prisons, jails, detention centers and more. **Silencing the voice of one of the few organizations that advocates on behalf of powerless people in desperate circumstances is unconscionable.**

3. **We do not support HR 2646's call for a full audit of SAMHSA by an external entity and recommend it being removed from the bill**. The continued focus on disempowering SAMHSA is deeply troubling. We reject this attempt to undermine the very entity within the federal government that has provided leadership in actualizing the most fundamental, core belief of mental health consumers – **recovery.**

   One of SAMHSA's greatest achievements is its instrumental role in promoting recovery in ways that have helped people across the country. Not supporting principles and initiatives of recovery means accepting the premise that people are unable to recover. This is patently false. Our entire membership is comprised of people who have recovered and who are in the process of recovering. Many these same members were given grim prognoses by traditional mental health practitioners. And yet they thrive as

contributing citizens in their communities and lead productive lives. Despite the outdated models of low expectations, we have learned that believing in and acting on recovery instills hope and empowers people to achieve a quality of life they have too often been told was impossible. **Low expectations are not merely unjust; they are also significantly more expensive over time, especially in the form of recurring inpatient care.**

4. **We reject the proposal for the creation of a National MH Policy Laboratory. It is duplicative and an unnecessary usage of federal dollars. Further, this entity does not mandate any consumer representation**. There are so many consumers who have the credentials delineated in HR 2646. We are doctors of medicine and psychiatry, psychologists, researchers, academicians, mental health professionals and more. Some of our best, nationally recognized research analysts gained their expertise not in formal academic settings, but with sheer determination and relentless dedication, fueled by their lived experiences. **It is unacceptable for the federal government to create and support a policy/research entity that will make critical decisions about us without us.**

5. **We do not support the expansion of Medicaid funding for Institutions for Mental Diseases (IMDs) or other inpatient settings**. This is often referred to as "loosening the IMD exclusion." http://lac.org/wp-content/uploads/2014/07/IMD_exclusion_fact_sheet.pdf Increased funds for hospital care means continuing to support the unacceptable status quo, and advances the agenda of forced treatment in the absence of decent voluntary care. The need for inpatient care should be PREVENTED with earlier supports in the community. Why wait until a person has deteriorated so badly? Why wait until a person must lose their civil liberty?

   Deinstitutionalization came to pass, in part, with the sobering recognition of a national shame. **Conditions in psychiatric hospitals easily devolve into egregious snake pits**. It is as true today as it was in the 1950's. The Department of Justice is still investigating hospitals and legal action is still needed too often to remedy abuse, neglect and unnatural deaths. Additionally, **increasing hospital beds flies in the face of the Olmstead decision. It is segregation, not integration.**

   We believe dollars would be better spent on community programs can that help a person in distress much earlier, thereby preventing the high costs of hospitalization. **Peer-run respite programs, for example, have proven very effective, and the associated costs are a fraction of the per diem rate for inpatient settings.**

   The current lack of adequate community support has created a mental health system that is crisis-driven. It provides too few services that are too late and that result in unnecessary and coercive means of treatment. In addition to causing needless suffering, continued/increased funding for inpatient settings ultimately supports the most expensive form of care possible at the far end of the continuum of care. **The inevitable result is rationing**. Thus the cycle of crises continues unabated. **It is the equivalent of offering intensive care as the treatment of choice for people with heart conditions.**

This is the true crux of the problem we face with mental health care in the United States. It is not a problem of "undeserved" rights; it is a problem of inadequate resources that are poorly allocated. It is only illogical and inhumane, but is also a very poor investment of public dollars.

Further, because a crisis-driven system can never develop the capacity to address the sheer numbers of people who have deteriorated unnecessarily. Jails, prisons, emergency departments, and homeless shelters will remain overburdened. Such inappropriate "care" is rife with trauma and inhumane treatment, and represents the newest version of segregation.

6. **There is no scientific basis to support the concept of "anosognosia." We strongly object to it being codified into law in any manner**. HR 2646 introduces "anosognosia" as a legitimate symptom of mental illness, to serve as a rationale for relaxing HIPAA standards and for coercive care. Anosognosia is a **highly controversial issue** in the mental health field. The literature indicates a long history of studying anosognosia as it relates to Alzheimer's disease, strokes, and brain injuries. It was "borrowed" into the mental health field specifically to justify forced treatment.

7. **We do not agree with relaxing HIPAA standards. Instead, we recommend a program called "Open Dialogue."** We understand that families, caregivers and professionals often need to exchange information. Open Dialogue is a clinical approach that was developed in Finland, in a region of the country that once had the highest hospitalization rates. It is an extremely effective approach that provides a venue for open sharing of information among consumers, families and providers. The use of this program would allow for information to be shared while preserving HIPAA's protections for the individual**. In addition to facilitating communication, studies show Open Dialogue has yielded recovery rates of up to 80%.**

8. **We recommend at least $50,000,000 in funding for community outreach teams which are recovery-based and respectful of rights such as the Community Based Flexible Supports of Massachusetts and peer-run respites as possible choices by states under MH Block grants rather than Outdated ACT teams**. HR 2646 only recommends increasing funding for ACT teams, yet the proposed funding is grossly insufficient and the focus is skewed, once again, toward coercive care.

9. **We do not support the proposed any changes to the Block Grant process**. We believe that such changes are unnecessary and entirely too prescriptive. The proposed changes represent federal interference in a process that was specifically designed to facilitate local control. **States should retain the right to decide how best to utilize their funds.**

10. **We do not support the bill's extension for the pilot programs of assisted outpatient treatment (AOT).** The newest revisions continue to extend federal grants that would encourage states to expand coercive, court-ordered outpatient treatment programs. These

programs of forced treatment do not help people get better. Further, it inserts the court system in decisions that should be between individuals and their treatment providers. These coercive interventions not only strip people of their rights, but it is virtually impossible to discontinue such "treatment." AOT is extremely harmful, ineffective, adds unnecessary costs and, ultimately, discourage people from voluntarily seeking help using services that work for them.

11. **We recommend adding language that calls for the Director of the Center for Mental Health Services to work with consumers and other stakeholders in the mental health system to promote the expansion of recovery support services and a system of care oriented toward recovery**.HR 2646 calls for the director of the Center for Substance Abuse Treatment "to work with States, providers and individuals in recovery, and their families, to promote the expansion of recovery support services and systems of care oriented toward recovery." Once again, **we must ask why is the principle of recovery in mental health is not supported in HR 2646, especially in light of unfettered support for recovery among individuals with substance use disorders?**

Additional comments

12. **Consumer-driven services complement more traditional mental health programs and yield highly effective outcomes. Additionally, they are significantly less expensive than other forms of community care. We recommend language and funding for peer support specialist grant programs and other consumer-driven supports.** Consumer-run respites have been described above. Additional programs, such as consumer education, peer specialists, intentional peer support, consumer-run drop-in centers and more are among the many consumer-driven programs and supports that instill hope, provide a path to recovery, offer choices to consumers, and empower us to achieve the highest quality of life possible. And, we believe it is only possible if consumers are respected, active partners and providers of care, with a significant voice at every point of policy and program development, implementation and oversight.

13. These are troubling times for mental health consumers. **More than 50 years after deinstitutionalization, mental health systems across the country are still unable to provide the appropriate care in the community that was promised long ago**. As stated previously, we believe this is a problem of inadequate resources being poorly allocated. We must ask ourselves why this is so, and we come back to the fundamental issues of stigma and discrimination.

    Time and again, research has proven that the public perception of the relative "dangerousness" of people with mental health conditions is unfounded. Sensationalized, distorted media coverage and the sustained influence of some stakeholders have fueled arguments for forced treatment and an overly medicalized system of care. The march toward re-institutionalization and coercive care is abhorrent to us. Having a mental health condition does not constitute a life sentence to poverty, marginalization, aberrant behavior or an inability to become a fully functioning citizen who can contribute meaningfully to his/her community. **We know that recovery is possible because we are the evidence.**

"Nothing About Us Without Us"