

Coalition for Mental Health Reform

Concerns with the Helping Families in Mental Health Crisis Act of 2015 – passed in the House of Representatives – July 6, 2016

August 4, 2016

The Coalition for Mental Health Reform is made up of disability, civil, and human rights organizations working with people with psychiatric disabilities for the improvement of legislative outcomes for mental health reform.

On July 6, 2016 the US House of Representatives voted on The Helping Families in Mental Health Crisis Act of 2015 [by a 422 -2 vote](#). As a coalition we worked to make sure that many harmful provisions in the original draft of this bill were removed and/or edited. We are grateful for the House Energy and Commerce Committee members work on this language.

Although this legislation passed with a large majority of the House Representatives in support, we continue to have some concerns with the bill's language as passed. We hope that ultimately the Senate version of mental health reform legislation titled [Mental Health Reform Act of 2016 \(S. 2680\)](#) which was voted out of the HELP Committee on March 16, 2016, will go to the floor for a full vote soon.

Our concerns with H.R. 2646 are as follows:

As per the July 1, 2016 version:

<http://docs.house.gov/billsthisweek/20160704/HR2646.pdf>

1. Sec. 101 Assistant Secretary for Mental Health and Substance Use

The Substance Abuse and Mental Health Services Administration (SAMHSA) has played a critical role over the past few decades to raise the bar for what should be expected for people with the most serious mental health conditions and from state and local systems and providers. HR 2646 creates the new position of Assistant Secretary for Mental Health and Substance Use to oversee SAMHSA, which preferences individuals with a MD or a PhD in psychology. The insertion of medical authority over SAMHSA would be a huge step backward to institutional policies and models. Further, the position adds an additional layer of bureaucracy that is unnecessary. We do not support the creation of this new position.

2. Sec. 107 Grievance Procedure for (Protection and Advocacy for Individuals with Mental Illness (PAIMI))

There is an already existing grievance procedure within the PAIMI Act, and no evidence has been provided that this already existing system is not working. Thus, we believe

that there is no need for the creation of a new grievance procedure based at the Department of Health and Human Services here in Washington, DC.

However, if such a new procedure is to be created, we are concerned that this new procedure could issue decisions that would be contrary to a particular state or territory's ethics or bar rules or current attorney grievance procedure because of a lack of knowledge of the intricacies of all 56 state and territory's rules. Such a situation would put an advocate in the position of either having to follow a decision of the agency that oversees the funding of the PAIMI program, or violate his or her state or territory's code of ethics, bar rules, or grievance procedures. Advocates should not be put into this catch 22. Thus, the language would need to be clear that a decision under this independent procedure cannot contradict the state or territory's code of ethics, bar rules, or grievance procedures.

Additionally, the language should make it clear that a decision made through this new procedure has to be based on an interpretation of the Act itself and whether the actions taken by the advocate are contrary to the requirements of the PAIMI Act, not the wishes or desires of the individual overseeing the grievance procedure here in Washington, DC.

3. Sec. 111 Advisory Councils; Section 110 B. Authorities of Centers for Mental Health Services and Substance Abuse Treatment; and Sec. 501B National Mental Health and Substance Use Policy Laboratory

The multiple advisory councils and the members of the Policy Laboratory created by this legislation will be under the authority of the Administrator of Substance Abuse and Mental Health Services Administration (SAMHSA) with stringent and discriminatory protocols that leave out the voice of people with psychiatric disabilities. We believe that at least 1/3 of public members of the advisory council and policy laboratory should be people with psychiatric disabilities and that the bill should establish a process for appointments and service. We believe that this will not necessarily require an increase in the number of overall members of these bodies or reduction in representation from other groups, as people with psychiatric disabilities may also be members of the other groups that must be represented on these bodies. For example, people with psychiatric disabilities may also be family members of others with psychiatric disabilities, mental health professionals, and representatives of leading advocacy organizations.

4. Sec. 206. Providing EPSDT services to children in IMDs

The current language would provide federal Medicaid funding for evaluation, prevention, screening, diagnosis, and treatment services provided to individuals under age 21 who have been placed in institutions for mental diseases (IMDs). Although the federal government already provides funding for inpatient psychiatric services delivered to youth and young adults living in IMDs, payment for other health care services for individuals in IMDs has traditionally been the responsibility of the States.

It is well established that lengthy placement in IMDs is harmful to children and young adults. By requiring states to shoulder the costs of health care services for individuals in IMDs, current Medicaid laws help to incentivize states to develop community-based care programs and avoid overreliance on long-term institutionalization. Section 206 would remove this incentive. Moreover, because Section 206 lacks any time limitation, it would continue to provide federal subsidies even for placements in IMDs that have continued for months or years.

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5. Sec. 207. Electronic visit verification system required for personal care services and home health care services under Medicaid

Section 207 of H.R. 2646 has nothing to do with mental health or substance abuse services. This section was added by the House Energy and Commerce Committee last month for the first time in the committee markup of the bill which sought no input from the Disability Community that would be subject to - and harmed by - this provision.

Electronic Visit Verification (EVV) services are based on outdated and erroneous assumptions. First, they assume that disabled people and seniors who use attendant services are homebound because most systems use a home phone to verify that an attendant has arrived or finished a shift. Today, attendant service users receive services and supports throughout the community and use cell phones which can be shared. EVVs also purport that electronic systems are more effective than other forms of visit documentation, however these systems have been demonstrated to be less secure and less effective in prosecuting fraud than non-electronic systems which provide transparency, require multiple sign-offs and have verified signatures. Finally, these systems rely on predetermined schedules which are not used in consumer directed attendant programs.

Additionally, the systems will impact the independence and privacy rights of people with disabilities by imposing a defacto homebound requirement on Medicaid attendant service users, preventing the disabled individual from monitoring submitted hours, and in some cases providing geo-tracking data to the government on the movements of disabled people. Finally, states that require EVV may be found to be joint employers of attendants and liable for overtime payments. This requirement is simply a handout to companies providing EVV services for personal care and home health services under Medicaid and cannot pass into law. We oppose the EVV requirement because it is harmful to individuals with disabilities, ineffective at addressing fraud and has the potential to increase state liability. (To read more go to: <http://www.advocacymonitor.com/ncil-position-opposing-electronic-visit-verification/>)

6. Sec. 401. Sense of Congress on Health Insurance and Portability and Accountability Act (HIPAA)

In this section the use and defining of people with serious mental illness as having a condition called Anosognosia which is defined as “a person not having the ability to be aware of their illness” and indicating that this would make them unable to make “sound decisions” regarding their care, is offensive to many. According to the literature, anosognosia is a condition whereby stroke and paralysis related victims deny the presence of those conditions, due to physiological damage to the parietal lobe of the brain. While there is no scientific evidence to tie this form of brain damage to mental illnesses, some have misapplied this term in order to justify coercive treatment and reduced privacy rights. We do not support this language.

7. Section 503. Increased and extended funding for assisted outpatient grant program for individuals with serious mental illness

Assisted Outpatient Treatment (AOT laws) and laws that require a civil court to order involuntary inpatient or outpatient treatment for an individual if the court finds that an individual, as a result of mental illness, is a danger to self or others “is persistently or acutely disabled, or is gravely disabled and in need of treatment” are discriminatory. This type of treatment will bring law enforcement directly to the front door of many with psychiatric disabilities. This would have an adverse effect on the work being done to provide community based, peer-to-peer treatment. It also has the potential to increase the punishment and unfortunately violent encounters between police and people with mental illness.

State of the art outreach, engagement and follow up services that are delivered on an immediate, intensive and sustained basis provide powerful strategies to respond to the urgent needs of people and families in crisis. Recognizing that a number of these successful approaches employ voluntary approaches and that there remains no conclusive evidence that AOT is more effective than these approaches, we urge Congress to authorize pilots that evaluate the effectiveness of both voluntary and court mandated approaches.

We believe that the appropriated funds for the AOT programs should be used for testing or piloting research programs on voluntary alternatives.

8. Sec. 717. Peer Professional Workforce Development Grant Program

This section would provide the Secretary of Health and Human Services the ability “to award grants to develop and sustain behavioral health paraprofessional training and education programs, including through tuition support”. It also authorizes “the appropriations of \$10,000,000 for the period of fiscal years 2018 through 2022” to fund this program.

While we appreciate the intent to increase awareness about peer run and other rehabilitative approaches, the crisis we face in community mental healthcare requires that we re-direct these funds to expand direct access to critically needed peer support

services. We recommend that \$10 million should be afforded to states and localities to expand the broad array of peer run approaches across the nation.

It would be more successful for the lives of persons with psychiatric disabilities to provide more community based care and peer-to-peer services. This would provide better opportunities for these individuals to remain in the community in accordance to *Olmstead v L.C.* This mental health legislation should be one that strengthens and improves many of the current programs working to change lives as well as protect the civil and human rights of persons with psychiatric disabilities.

Conclusion

In closing, we understand that H.R. 2646 passed out of the House but multiple concerns remain for advocates and people with psychiatric disabilities. We hope that these concerns will be addressed prior to Congress passing any legislation that will be sent to the President's desk for his signature. The civil and human rights of persons with psychiatric disabilities must be a part of the implementation of these mental health reforms and H.R. 2646 does not provide this in its current format.

We look forward to the opportunity to work with Congress to address these concerns and to assist with the passage of a mental health reform law. Please contact Dara Baldwin, Senior Public Policy Analyst, National Disability Rights Network at dara.baldwin@ndrn.org or 202-408-9514 ext. 102 with any questions or concerns.

Coalition for Mental Health Reform members

Autistic Self Advocacy Network (ASAN)
Bazelon Center for Mental Health Law
The National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)
The National Association for Rural Mental Health (NARMH)
National Coalition for Mental Health Recovery (NCMHR)
National Council on Independent Living (NCIL)
National Disability Rights Network (NDRN)
National LGBTQ Task Force Action Fund
New York Association of Psychiatric Rehabilitation Services (NYAPRS)

Resources:

Letters of Support for Mental Health Reform Act of 2016 (S. 2680):
<http://www.ndrn.org/en/public-policy/mental-health/protect-paimi.html>