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November 3, 2015

Honorable Fred Upton
Chair, House Energy and Commerce Committee United States House of Representatives
2183 Rayburn House Office Building
Washington, DC 20515

Honorable Frank Pallone
Ranking Member, House Energy and Commerce Committee United States House of Representatives
237 Cannon House Office Building
Washington, DC 20515

Re: Letter of opposition to the Helping Families in Mental Health Crisis Act 2015 (H.R. 2646)

Dear Mr. Chairman Upton and Ranking Member Pallone:

NCIL is the longest-running national, cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: Centers for Independent Living (CILs); Statewide Independent Living Councils (SILCs); individuals with disabilities; and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

NCIL maintains an active Mental Health Civil Rights Subcommittee (a subcommittee of NCIL's Legislative & Advocacy Committee) composed of people from across the country who are current consumers of the mental health system, have lived experience with mental health diagnoses or have an interest in civil rights issues specific to people labeled with psychiatric disabilities. NCIL's Mental Health Civil Rights Subcommittee was primarily responsible for writing this letter.

While we agree that there is an imperative need to update the current mental health services system, we have serious concerns about the provisions set forth in the Helping Families in Mental Health Crisis Act of 2015. Some of our concerns were outlined in a July 26, 2015 letter submitted by the National Disability Leadership Alliance (NDLA) -- NCIL was a signatory to that letter and is an active member of NDLA. We ask that you do not support the movement of H.R. 2646 until the concerns outlined in that letter, as well as those detailed below, are addressed. Essentially, many of the provisions in this legislation, if enacted, will destroy years of progress and bring us

needlessly back to outdated, discriminatory and dangerous treatment of people with a mental health diagnosis. Our concerns are detailed below but in general pertain to the following:

-- The bill is based on an inherently false assumption that people labeled with psychiatric disabilities are dangerous and pose some sort of threat to society. This assumption is untrue as people with psychiatric disabilities are disproportionately more likely to be the victims of violence rather than perpetrate it ourselves.

-- The proposed bill would implement significant changes in SAMHSA threatening existing, evidence-based effective programs such as peer support as well as placing mental health professionals solely in charge of decisions directly affecting people with psychiatric disabilities. The bill would also increase the use of forced treatment as block mental health grants for states would be contingent on states supporting involuntary outpatient treatment. Numerous studies have shown that forced treatment drives people away from the mental health system instead of encouraging people who want mental health treatment to voluntarily obtain it. Likewise, the bill also proposes to increase institutionalization with changes to the IMD exclusion.

-- Additionally, the bill would also seriously erode civil and human rights by limiting the work in which Protection and Advocacy for Individuals with Mental Illness (PAIMI) is permitted to engage. In a June 9, 2015 document distributed by the National Disability Rights Network (NDRN) the potential impact this change would have is detailed. "The national network of Protection & Advocacy (P&A) organizations have been assisting children and adults with psychiatric disabilities and their families since 1986 under the PAIMI program, to prevent abuse and neglect, ensure access to the services and supports, and protect civil and human rights. In Fiscal Year 2014, the P&As provided advocacy assistance to 13,936 individual clients through the PAIMI program, with issues including dangerous restraint and seclusion practices; failure to provide medical or mental health treatment; inappropriate and excessive use of medication; sexual assault; financial exploitation; lack of discharge planning; and discrimination in employment, housing and other areas. P&As successfully closed through the PAIMI program 313 systemic advocacy projects and litigation cases that potentially benefits over 27 million individuals...and investigated 993 suspicious deaths."

-- Finally, this bill proposes to create lower standards of privacy for people labeled with psychiatric disabilities due to the proposed changes to HIPAA regulations.

In Title I, the legislation would create an Assistant Secretary for Mental Health and Substance Use Disorders with "...requirements on the Assistant Secretary that would include limiting grant funding to only those programs and activities that use evidence-based or emerging evidence-based best practices." Enactment of these provisions would end innovative or newly created programs that usually obtain this research once they are established.

Title II of this legislation is Grant Reform and Restructuring, and it would “...establish new requirements for states to be eligible for the Community Mental Health Block Grant (MHBG).” The title would require states, in order to receive MHBG funding as well as a 2% incentivizing increase, to have in effect a law that provides for involuntary outpatient treatment (commitment) that requires individuals to obtain outpatient mental health treatment or Assisted Outpatient Treatment (AOT), 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.” This would require that in order for the state to obtain any MHBG grant funding it must have a law that provides for involuntary outpatient commitment (IOC). This would have an adverse effect on the work being done to provide community based, peer-to-peer treatment.

Many states have been moving away from this form of behavioral health services and implementing community treatment. This follows the spirit of the Affordable Care Act (ACA) by using community-based services, peer-to-peer services, rapid response services and others. IOC is not effective and is obtrusive and invasive towards persons with disabilities’ rights and their lives. IOC has not been shown to prevent violence. Dr. Swanson of Duke University told Behavioral Healthcare: “People who understand what outpatient commitment is would never say this is a violence prevention strategy.” (Bazelon’s – IOC Myths & Facts)

Another part of Title II would affect a number of grant programs in the area of workforce development. One change would reduce the budget of the Minority Fellowship Program (MFP). Its budget would be reduced from \$10.669 million to \$6 million, which is approximately a \$5 million loss. This program provides important funding for individuals from underserved minority populations to obtain graduate degrees in mental health professions and is currently administered in SAMHSA.

There is plenty of public health evidence-based research on the issues of race and healthcare. NCIL supports and includes diversity and cultural competency in all of its work. We have a Diversity Committee and multiple cultural competency committees covering the issues and concerns of various disenfranchised communities. The decrease in funds for this program could have a significant impact on the lives of millions of people from diverse backgrounds who are unwilling to go to mental health professionals who are not representative of their community. This large decrease in funding will reduce the number of fellows trained annually and significantly harm the ability of the program to create real change in mental health care for people of diverse backgrounds.

Title II would also cause serious harm to the budgets of multiple grant programs focused on suicide and trauma. The National Child Traumatic Stress Initiative (NCTSI), “improves treatment and services for children, adolescents, and families who have experienced traumatic events.” The legislation would decrease NCTSI’s budget by \$100,000 less than its FY 2015 budget and keep this number until FY 2018. This program works to assist children and youth exposed to violent and traumatic incidences

around the country, including in our inner cities. Many children who are the victims of trauma often become children with a physical disability and have a mental health diagnosis. The NCTSI will assist these children with their recovery.

H.R. 2646 also reauthorizes the Garret Lee Smith Act grant program for FY 2016 – FY 2020. Programs within this grant include the Suicide Prevention Technical Assistance Center grant program (SPTAC), the Youth Suicide Early Intervention and Prevention Strategies grant program (YSEIPS) and the Mental Health Substance Use Disorders Services on Campus (MHSUDSC) grant program. However, each program's budget would be significantly decreased, resulting in less people receiving services. The SPTAC program would go from \$5.988 million to \$4.957 million; YSEIPS from \$35.427 million to \$29.738 million and MHSUDSC from \$6.488 million to \$4.975 million.

The language to reauthorize all the Garret Lee Smith Act grant programs also contains an abortion prohibition. The above three programs have this prohibition in current law, but this legislation would extend the prohibition to the Projects for Assistance in Transition from Homelessness (PATH) program. There is no abortion prohibition restriction in the current statute for the PATH program, but the Hyde restriction "that is included in the annual appropriations legislation would apply." This legislation goes beyond the Hyde language as it also applies to the payment for abortion services and also to referring for abortion services.

Title IV of this legislation concerns protections under the Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act (FERPA). In this section, the legislation creates a new exception to the HIPAA privacy rule that reduces the privacy protections of confidential health information for persons with mental illness or developmental disabilities such as Autism with a co-occurring diagnosis, which is discriminatory. This new exception removes the HIPAA privacy protections that protect people's rights by making sure their providers do not disclose their treatment information to family members and/or caregivers. This would only be for people with serious mental illness and those with developmental disabilities with co-occurring diagnosis. Should this pass it can create a "slippery slope" as legislatures could try to do this for other diagnosis like HIV and AIDS, substance abuse, cancer, etc.

"With respect to a student who is 18 years of age or older, an educational agency or institution may disclose to the caregiver of the student, without regard to whether the student has explicitly provided consent to the agency or institution for the disclosure of the student's education record, the education record of such student..." This provision would allow multiple medical professionals to be able to provide health information to caregivers. In some cases, these paraprofessionals described in this legislation have a very minimal and unsubstantiated connection to the student. They would have no need to access the student's personal educational records. This could cause harm for the student's future in various ways and defies many civil and human rights afforded to these students.

Title VIII of this legislation in Subtitle B, Sections 811 - 816 would, if passed, eliminate basic civil and human rights protections for those with mental illness and eradicate the ability for the entire Protection and Advocacy network to engage in advocacy to strengthen those important rights. The data shows that yearly, the PAIMI program positively impacts millions of individuals with psychiatric disabilities, their families, and the community. PAIMI staff routinely work with individuals, families, and the police to foster better understanding and relationships and the provisions in this bill would end this type of important work.

In closing, we urge you not to support this legislation. This legislation is based on false assumptions about people with psychiatric disabilities. It will undermine the past, current and future work of SAMHSA, threaten the continuation of the critically important work of PAIMI, and erode basic rights to privacy under HIPAA for people diagnosed with a mental health condition. Please oppose this legislation and move forward with mental health legislation 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.

Please contact Kelly Buckland at (202) 207-0334 or via e-mail kelly@ncil.org if we can provide any additional information or be of further assistance.

Sincerely,



Kelly Buckland
Executive Director



LouAnn Kibbee
President