



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

Sept. 17, 2015

Hon. Fred Upton  
Chair, Energy and Commerce Committee  
2183 Rayburn House Office Bldg.  
Washington, DC 20515

Hon. Frank Pallone  
Ranking Member, Energy and Commerce Committee  
237 Cannon House Office Bldg.  
Washington, DC 20515

Dear Chair Upton and Ranking Member Pallone:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Rights Task Force write in regard to the Helping Families in Mental Health Crisis Act (H.R. 2646). CCD is a coalition of national disability-related organizations working together to advocate for national public policy that ensures full equality, self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

While we all agree that the public mental health system is in dire need of reform and the services that individuals with psychiatric disabilities need are far too often unavailable, we have serious concerns about this bill. Instead of addressing the dramatic gaps in community services that plague our public mental health system, this bill would remove critical protections for individuals with psychiatric disabilities and promote involuntary treatment. We urge you not to support the Helping Families in Mental Health Crisis Act (H.R. 2646). We would like to work with the Committee to move forward mental health legislation that addresses important gaps in our community service systems, and protects the rights of individuals with psychiatric disabilities.

Specifically, we are concerned that the bill would prohibit the primary legal advocacy protection program for individuals with serious mental health conditions from doing a wide range of critical activities. It would also strip away important privacy protections from these individuals, and would eliminate federal funding for innovative community services and instead promote involuntary outpatient commitment, which undermines individuals' trust of mental health services and has little evidence supporting its effectiveness. The bill is also likely to

increase needless institutionalization of individuals with psychiatric disabilities, at the expense of needed community services.

### **The bill eliminates critical legal advocacy on behalf of individuals with psychiatric disabilities**

The bill would gut the primary system of legal advocacy protection for individuals with psychiatric disabilities, the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program, leaving them without means to enforce their legal protections from discrimination in key areas of life such as education, employment, housing, health care, community living, voting, and family rights. The PAIMI program has been a leading driver of improvements in mental health service systems for the last several decades. As a result of this program, tens of thousands of children and adults have secured better lives, receiving the services they need to succeed in school, obtaining the chance to live successfully in their own homes, becoming employed or retaining employment, staying housed, and receiving needed health and mental health care.

Yet this bill would prevent the program from conducting advocacy on virtually all issues except for abuse and neglect. Far from helping families of individuals with serious mental health conditions, these provisions would have a devastating impact on advocacy to assist children and adults with mental health needs secure fundamental improvements in their lives. It is hard to imagine a more detrimental change for individuals with serious mental health conditions.

### **The bill reduces privacy protections for individuals with psychiatric disabilities**

The bill would strip away privacy protections under the Health Insurance Portability and Accountability Act from individuals with psychiatric disabilities and provide them with lesser privacy safeguards than everyone else. It would give broad latitude to service providers to override the wishes of individuals with psychiatric disabilities to keep information about their mental health treatment confidential. Ironically, it is people with psychiatric disabilities who are often most in need of privacy protections due to widespread prejudices and stereotypes. HIPAA privacy protections are also critical to individuals experiencing abuse at the hands of caregivers; permitting caregivers to trump those protections could have troubling consequences. Moreover, HIPAA already allows disclosure in the circumstances cited by proponents of the bill—where a person poses a danger, where a person lacks capacity to consent or object to disclosure, and in emergency circumstances. Changing the law will do little to remedy a problem not caused by the law; to the contrary, the changes proposed by this bill would drive many people to avoid seeking treatment in order to safeguard their privacy.

### **The bill would redirect federal money from innovative programs to involuntary outpatient commitment, which is expensive and ineffective**

The bill would prohibit states from receiving federal mental health block grant funds that are used to support innovative services unless they are using involuntary, court-ordered outpatient commitment, a costly and ineffective approach that runs counter to recovery, independence and choice. It would also significantly reduce funding for important and innovative community-based services in favor of involuntary treatment.

### **The bill would increase needless institutionalization**

The bill would fundamentally change the Medicaid program by allowing states to obtain federal Medicaid reimbursement for inpatient psychiatric hospital services for non-elderly adults. These services have been the responsibility of states since the beginning of the Medicaid program almost fifty years ago, due to concerns about the warehousing of individuals in psychiatric hospitals (inpatient psychiatric care in a general hospital has always been reimbursable through the Medicaid program). The exclusion of federal funds for these services has been an important means of promoting community integration and better care. Federal reimbursement for these services would result in large numbers of individuals being served needlessly in psychiatric hospitals, driving mental health systems backward. While the bill would permit federal funding only if there were no increase in net spending in the Medicaid program, adding inpatient psychiatric hospital and residential treatment services for non-elderly adults as a Medicaid service would allow funds to be shifted from community services to institutional care, and would open the door in future years for potentially billions of dollars in federal spending on psychiatric hospitals and other institutions at the expense of community services.

### **A new bill is needed**

We pledge to work with you to craft new legislation that appropriately addresses the needs of individuals with significant psychiatric disabilities and their families. Any new bill should focus on the expansion of the critical community-based services that reduce hospitalization and incarceration but are in short supply in our service systems—including supported housing, mobile crisis teams, assertive community treatment, peer support services, and supported employment. The Medicaid program is the primary funder of public mental health service systems, and incentives to expand the community services above through the Medicaid program should be the centerpiece of any mental health legislation. Such legislation should not promote further institutionalization.

We would welcome the opportunity to meet with you to discuss specific ideas for new legislation. Please contact Dara Baldwin at the National Disability Rights Network, (202) 408-9514, or Jennifer Mathis at the Bazelon Center for Mental Health Law, (202) 467-5730 ext. 1313.

We urge you not to support H.R. 2646 but instead to craft a new bill that focuses on expanding the kinds of services identified above.

Respectfully submitted,

American Association of People with Disabilities  
2013 H Street NW, Fifth Floor  
Washington, DC 20006

American Foundation for the Blind  
1660 L Street NW, Suite 513  
Washington, DC 20036

The Arc of the United States  
1825 K St NW #1200  
Washington, DC 20006

Association of University Centers on Disabilities  
1100 Wayne Avenue, Suite 1000  
Silver Spring, MD 20910

Autistic Self Advocacy Network  
2013 H Street, NW  
Washington, DC 20006

Bazon Center for Mental Health Law  
1101 15<sup>th</sup> Street NW, Suite 1212  
Washington, DC 20005

Disability Rights Education & Defense Fund  
3075 Adeline Street, Suite 210  
Berkeley, CA 94703

Lutheran Services in America Disability Network  
100 Maryland Avenue, NE  
Washington, DC 20002

National Association of Councils on Developmental Disabilities  
1825 K Street, NW Suite 600  
Washington, DC 20006

National Council on Independent Living  
2013 H St. NW, 6th Floor  
Washington, DC 20006

National Disability Rights Network  
900 Second Street NE, Suite 211  
Washington, DC 20002

National Down Syndrome Congress  
30 Mansell Court, Suite 108  
Roswell, GA 30076

Paralyzed Veterans of America  
801 18th St NW  
Washington, DC 20006

Quality Trust for Individuals with Disabilities  
5335 Wisconsin Ave., NW, Suite 825  
Washington, DC 20015

United Spinal Association  
1660 L Street NW, Suite 504  
Washington, DC 20036