

DISABILITY RIGHTS NEW MEXICO

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Promoting and Protecting the Rights of Persons with Disabilities

LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE TESTIMONY¹ OF JIM JACKSON RE HR 2646 October 19, 2015

- Disability Rights New Mexico is the "Protection and Advocacy agency" for New Mexico. We would be affected by this bill along with all of our colleague agencies around the country
- HR 2646 would impose a gag order on DRNM and all other P&A agencies (Section 811)
 - o prohibits P&As from attempting to "influence" federal, state or local government
 - o prohibition applies regardless of funding source (not just applicable to federal funds)
 - o if HR 2646 enacted, I would be prohibited from making this presentation
- HR 2646 would drastically limit the scope of P&A services to persons with mental illness
 - o restricts P&A agencies to addressing only abuse or neglect issues
 - o prohibits use of federal funds for enforcing legal rights:
 - housing, special education, employment, discrimination under the Americans with Disabilities, access to Medicaid behavioral health, etc.
 - about 40% of DRNM caseload in FY 2014 involved legal rights issues
 - o prohibits use of federal funds for most of our systemic advocacy efforts
 - Involvement in DOJ case against APD; participation in city/county task force on mental health; NM Supreme Court Rules Committee on guardianship procedures, competency evaluations for persons with mental illness; restoring access to behavioral health services in NM post July 2013 "transitions"
- Other problems with HR 2646
 - o See accompanying letter from Consortium for Citizens with Disabilities
- There are positive aspects of 2646:
 - o Increased funding to Federally Qualified Health Centers for behavioral health services; improved access to prescription drugs; strikes the 190 day limit on inpatient psychiatric hospitalization under Medicare

DRNM believes that the public mental health system needs significant improvement, and that a significant investment of additional funds is needed in order to make services accessible and available to all who need them. HR 2646 is not the right way to achieve these goals.

¹ No federal funds were used in the development or presentation of this testimony





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 reimburseable 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,

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The Arc of the United States 1825 K St NW #1200 Washington, DC 20006 American Foundation for the Blind 1660 L Street NW, Suite 513 Washington, DC 20036

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

Bazelon Center for Mental Health Law 1101 15th Street NW, Suite 1212 Washington, DC 20005

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Disability Rights Education & Defense Fund 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 820 First Street NE, Suite 740 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

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