



December 23, 2015

Concerns: National Disability Rights Network (NDRN) and the Protection and Advocacy (P&A) Network Continue to Have Concerns with Provisions In The Helping Families In Mental Health Crisis Act (H.R. 2646)

After the House Energy and Commerce Committee, Health Subcommittee markup, a number of troubling provisions continue to remain in the bill that we hope will be addressed as the bill moves forward. The information below is a brief explanation of the provisions impacting the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program and describes our concerns.

In 1986, President Ronald Reagan signed into law the Protection and Advocacy for Individuals with Mental Illness Act which created the PAIMI program that is administered by the nationwide network of Protection and Advocacy (P&A) agencies in every state and territory. The purposes of this program were clearly laid out in the 1986 law to: (1) ensure that the rights of mentally ill individuals are protected; (2) protect and advocate the rights of such individuals to ensure the enforcement of the Constitution and Federal and State statutes, and (3) investigate incidents of abuse and neglect of mentally ill individuals.

Since 1986, the PAIMI program has been pursuing these goals of ensuring that the rights of individuals with psychiatric disabilities are protected and that incidents of abuse and neglect are investigated and resolved. The PAIMI program ensures rights protection for people both in the community and in institutions on a variety of issues, including employment and housing discrimination, lack or inappropriate medical treatment, failure to provide educational or transportation services, and protection of civil and constitutional rights like the Americans with Disabilities Act. Over this time, the PAIMI program has addressed over 350,000 individual cases, provided hundreds of thousands of people with information and referrals, millions more have participated in trainings, thousands of death investigations have been completed, and hundreds of millions have benefited from PAIMI systemic advocacy on all of these topics.

Section 711 (3) (B)

This language would prohibit the PAIMI program from advocating concerning an individual refusing medical treatment or acting against the wishes of the caregiver. This language is concerning because it would, for example, forbid the PAIMI program from doing the work they performed on an example of Medicaid fraud in New York where doctors were performing unnecessary prostate and cataract surgeries (a form of medical treatment) on individuals with psychiatric disabilities. See [New York Times Article, "Broken Homes/The Operators: Voiceless, Defenseless and a Source of Cash" by](#)

[Clifford J. Levy, April 30, 2002](#) and [New York Times Article, “Queens Home for Mentally Ill Settles Lawsuit for \\$7Million” by Clifford Levy August 5, 2004.](#)

In addition, this language gives caregivers ultimate veto power to continue to abuse, neglect, or financially exploit an individual with a psychiatric disability without concern that their motives and actions could be questioned. For example, the work of the Disability Rights Center (DRC) of Kansas to investigate and shut down the Kaufman House of Horrors in Kansas could not have occurred if this language had been in law. The Kaufmans, as guardians of the individuals living in their house, could have kept out DRC like they did with Adult Protective Services and other state entities that attempted to find out what was occurring there. This editorial from a newspaper in Kansas [“More Harm than Good: Federal bill is not the way to change mental health system” by Ron Sylvester December 4, 2015](#) and this article from [DRC on the Kaufman House](#) demonstrate the concerns with this provision as written.

In 2014 Nancy Jensen, a survivor of the Kaufman’s actions, testified in front of the House Energy and Commerce Committee about what happened. Her [testimony](#) is compelling.

Section 712

Despite some changes in the subcommittee markup, this language still limits the PAIMI program to working on abuse and neglect cases. The document titled [PAIMI Limitations Remain](#) explains the continuing problems and concerns with this language. Ultimately, if enacted into law, Section 712 continues to restrict the PAIMI program from doing critical work like employment or housing discrimination, helping children receive education services, ensuring people have access to effective mental health treatment, or that our veterans with PTSD are able to take their service animals into colleges or public accommodations like a restaurant and be served. For example, the [testimony](#) of Mary Jean Billingsley, the parent of a son with psychiatric disabilities, in front of the House Energy and Commerce Committee in 2015 demonstrates some of the work that this provision would forbid.

Section 714

Section 714 establishes an additional grievance procedure on top of the grievance procedures that already exist in the current law. An additional grievance procedure adds a layer of administrative burden that is unnecessary and duplicative of the already existing procedures. Additionally, this new grievance procedure will add more time and delay to reaching a final resolution of the grievance, delaying the ability to address problems people with psychiatric disabilities are facing.

Section 715

While Section 715 reinforces the type of advocacy work that the PAIMI program already performs, as is discussed in the document referenced in the discussion of Section 712 above, Section 715 does not solve the problem that the statute continues to limit the work of the PAIMI program to abuse and neglect work.

Section 716

Section 716 adds a new training requirement to the PAIMI Act that ignores the existing training and technical assistance that the P&As already receive, as well as the work of the PAIMI Advisory Council that was created in the original law. The PAIMI Advisory Council is an entity that provides advice to the P&As and includes individuals who have received or are receiving mental health services and family members of such individuals, with at least 60 percent of the membership comprised of individuals who have received or are receiving mental health services or who are family members of such individuals. In addition, the Council includes attorneys, mental health professionals, individuals from the public who are knowledgeable about mental illness, and a provider of mental health services.

The Council was established to provide advice and assistance to the P&As who at the time when the PAIMI program was created had only had one program focused on individuals with an intellectual or developmental disability. Over the 30 years the PAIMI program has been in effect, the Advisory Councils all around the country through their assistance and insight have made the staff of the PAIMI program recognized as the experts in working with individuals with psychiatric disabilities, their families, and the mental health system.

In addition, the current technical assistance that the P&A Network receives has been recognized as providing, “cohesiveness across the 57 P&As in thwarting challenges to the human and civil rights of individuals with disabilities, including developmental disabilities and mental illness.” This new provision would be a diversion of resources from helping individuals with psychiatric disabilities and their families to training and technical assistance that PAIMI staff is already receiving and implementing.

We are willing and ready to discuss addressing these concerns. Any questions or concerns please contact Eric Buehlmann, Deputy Executive Director for Public Policy at eric.buehlmann@ndrn.org or at 202-408-9514 ext. 121.

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The National Disability Rights Network (NDRN) is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and the Client Assistance Programs (CAP) for individuals with disabilities. Collectively, the Network is the largest provider of legally based advocacy services to people with disabilities in the United States.