Statement of Mary Jean Billingsley before
The House Energy and Commerce Committee Health Subcommittee
for a hearing entitled “Examining H.R. 2646, the Helping Families in Mental Health Crisis Act.”

June 16, 2015 10:00 am

Good morning Chairman Pitts, Ranking Member Green. Thank you for the opportunity to testify today on this important topic that has touched me and my family personally.

My name is Mary Jean Billingsley. I have earned a Master’s Degree in Counseling and Personnel Services. More importantly, I am the mother and co-guardian of Tim Costello. My son Tim is 22 years old and is dually diagnosed with both significant mental illness and developmental disabilities. Tim lives in Johnson County, Kansas.

We are one of the “families” with a positive outcome that would not have been possible if the “Helping Families in Mental Health Crisis Act of 2015” was law when my son encountered his situation. Several provisions of this legislation would have a detrimental impact on the work of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program in addressing Tim’s needs. The changes to the PAIMI program in this bill would not help families. Those changes, in fact, would harm families. I fear if this bill had been law, the challenges we faced in helping our son Tim would have been insurmountable.

Tim’s mental illness manifests itself with certain behaviors. Because of these behaviors, Tim was placed at Lake Mary, a psychiatric institution for youth under the age of 21, in 2010. In the summer of 2011, Tim was going to be discharged with no plan and without proper supports in place. Without these supports Tim's discharge was doomed to fail. We were devastated.

Because Tim has both significant mental illness and a developmental disability, it felt like the different providers were trying to pawn Tim off on each other. Tim was always someone else's "problem." Without the right supports, Tim was going to continue to cycle in and out of institutions, at a high cost to both taxpayers and Tim's ability to recover. Tim wanted to live in the community. Our family wanted Tim to live in the community. This is a right granted under the Americans with Disabilities Act (ADA), allowing him to get needed treatment in the community instead of at an expensive psychiatric institution.

We contacted the Disability Rights Center of Kansas (DRC), the federally mandated Protection and Advocacy agency for people with disabilities, which operates the PAIMI program. Because of the PAIMI program, DRC and their staff has the knowledge and authority to engage in all kinds of advocacy for people with disabilities. Because of the PAIMI program, DRC was able to help me and my family with this complex and multi-faceted situation.

Every brick wall the system threw up against us, the PAIMI program gave DRC the knowledge and authority to work to tear it down. Kansas policy made it impossible for young adults like Tim to transfer out of psychiatric institutions to community long-term-care programs with needed supports. DRC staff were able to negotiate a change in this Kansas agency policy allowing Tim's stay at the psychiatric institution to be characterized as a nursing home stay in order to allow Tim to obtain services through the Money Follows the Person (MFP) program. MFP allowed Tim to obtain the needed long-term supports in order to live successfully in the community.

The PAIMI program gave DRC and their staff the knowledge and ability to advocate changing Kansas policy creating unnecessary and expensive institutionalization that was contrary to the ADA. This bill would prohibit PAIMI-funded programs engaging in this much needed systemic and legislative policy work, even with non-federal dollars. DRC's ability to advocate for public policy change with non-federal dollars ensured Tim's civil and human rights under the ADA were protected.

Everything was finally working for Tim and allowing him to live successfully in the community. We thought our problems were over. We found out they were only beginning. Tim then faced discrimination simply because of his disability. Some local governments in Johnson County, Kansas started using zoning and land use ordinances to attempt to close Tim's community group home as well as others. A "Not in My Backyard" attitude prevailed – targeted against Tim and others because some did not want "those people" living in their neighborhood. We again contacted DRC for assistance to counter this housing discrimination.

After failed attempts to proactively work with the local governments, Tim and 16 other similarly situated individuals with disabilities engaged DRC to file disability discrimination complaints with the United States Department of Housing and Urban Development (HUD). The complaints alleged violations of the Fair Housing Act and Kansas law. These discriminatory local policies were attempting to deny persons with disabilities the opportunity to live in communities the same way people without disabilities are allowed. The HUD case is currently pending. If this bill were law, the PAIMI program would have been prohibited from helping our son with legal advocacy in this housing discrimination case because it is not "abuse or neglect." Thankfully, the current PAIMI law has no such limitation.

Without the help of DRC and the PAIMI program, Tim would still be cycling in and out of institutions. Based on my understanding, the resolution of Tim's current housing discrimination case may require DRC to seek a change in policy through legislation or a local ordinance, which they currently can do using non-federal funds. H.R. 2646 would prohibit the PAIMI program from engaging in this type of public policy advocacy, even with non-federal dollars. This severely limits the remedies available to people like my son, Tim.

Often the issues faced by people with mental illness are not abuse and neglect, but the protection of civil and human rights. Tim's case, like those of so many people with disabilities, was multifaceted and complicated. Thankfully the PAIMI program gave DRC staff the ability and knowledge to engage in every aspect of protecting Tim's rights. The PAIMI program must also have the flexibility to allow those agencies to use non-federal dollars in order to engage in legislative or local government public policy advocacy to be completely effective.

Tim's prior institutionalization and current housing discrimination involves numerous disability rights issues including unjust denial of Medicaid services, violation of rights under the ADA, and housing discrimination. His situation also required advocacy to force the mental health and developmental disability systems to put their turf battles aside and serve Tim.

The complicated and interconnected nature of these issues requires the PAIMI program give Protection and Advocacy agencies the authority to engage in all disability rights issues, not just "abuse and neglect." Without the PAIMI program, Tim's rights would not be protected.

In closing, this bill would limit the authority of the PAIMI program to cases of “abuse and neglect,” making it far easier to discriminate against and violate the rights of people with mental illness. It would also eliminate advocacy for public policy changes even with non-federal dollars on behalf of Americans with a disability, including mental illness. Those provisions are bad for families and bad for Americans with mental illness, like my son Tim.

Thank you for this opportunity to testify. I look forward to any questions you may have.