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## **Proposed Changes to the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program in H.R. 2646 Would Negatively Affect People with Psychiatric Disabilities**

We created this document to share it with advocates and policy leaders to combat the potential misperception that by taking the funding reduction out of the bill that Rep. Murphy has solved the concerns with the PAIMI program.

- 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; responded to 32,898 requests for information and referral services; participated in 1,903 education and training activities attended by over 82 thousand people, and investigated 993 suspicious deaths. The number of individual cases along with these systemic activities clearly show that reform of the mental health system in this country is needed.
- While we appreciate the acknowledgement by Representative Murphy of the importance of the PAIMI program by dropping the 85% reduction in PAIMI funding, the program activity restrictions and other provisions discussed below would eliminate and overly restrict a lot of the critical work that the P&As are uniquely designed and empowered to conduct. None of these proposed changes are based on evidence of the failure of the PAIMI programs to follow the mandates of the PAIMI statute.
- The first restriction which would only allow the PAIMI program to provide advocacy in situations of abuse and neglect would preclude positive

outcomes like where the veteran facing employment discrimination was helped by the PAIMI program to keep his employment, the child who is being denied educational services graduates high school and moves on to employment, or the individual who faces housing discrimination and keeps their home rather than being homeless. There are no other advocates to step in and do this work.

- Another proposed change bars PAIMI advocates from raising concerns with decisions made by doctors, families or guardians of people with mental illness. This change would have made impossible the New York P&A's advocacy to stop unnecessary prostate and cataract surgeries on people with psychiatric disabilities in a Medicaid fraud scheme. Further, P&As regularly encounter cases of guardians and family members who can be involved in financial exploitation, abuse, and neglect that would be unaddressed and leave individuals with no recourse.
- A further restriction would require the PAIMI program to ensure that caregivers have access to the protected health information of an individual with a psychiatric disability. This restriction turns the PAIMI program in a way that is contrary to the original intent of the program to provide advocacy for individuals with serious mental illness to providing legal advocacy for the caregiver of the individual with a psychiatric disability. It also creates a situation where this work would violate a lawyer's code of ethics as the lawyer's client is the individual with a psychiatric disability and this would require them to work to release information that his individual may have requested remain confidential, thus putting the lawyer into a conflict of interest situation.
- The legislation also creates a new grievance procedure on top of an already existing grievance procedure that is mandated by the statute. An additional grievance procedure adds a layer of administrative burden that is unnecessary and duplicative.
- Additional changes would limit the use of unrestricted funds for lobbying activities that are currently allowed under federal guidelines. P&As follow the legal rules and do not use federal funds for lobbying, but like other organizations, may use unrestricted funds they have raised to perform this work. An essential part of our legal advocacy role is providing an opportunity for people with disabilities to be heard in the public policy arena. Effectuating a positive change, e.g. in a Medicaid statute or regulation benefitting tens of thousands of people in a state, is a much more effective and efficient means to achieving a positive outcome than conducting individual Medicaid appeals. Limiting the ability of P&As to use their own unrestricted monies to pursue policy outcomes would close a critical avenue for improving the lives of people with mental health disabilities.

- If enacted, these changes would deny people with psychiatric disabilities access to a legal advocacy system that individuals with other disabilities will have, relegating people them to a second class status.
- Government rating systems like the Program Assessment Rating Tool (PART), and independent studies, e.g. from the Human Services Research Institute, have found the PAIMI program to be effective and having a major impact on protecting the rights of persons with disabilities.

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