

Testimony of Mary Zdanowicz

Since the early 1990s I have been an advocate for the most severely mentally ill and their families who face countless barriers when trying to get treatment for a loved one. Many obstacles are due to federal policies that do more harm than good. There was little hope that Congress would remedy these problems until Congressman Tim Murphy (PA) introduced the *Helping Families in Mental Health Crisis Act* (H.R. 3717) in December 2013.

There are myriad examples of federal funding gone wrong. I come from the Commonwealth of Massachusetts, home of the beloved Senator Edward Kennedy. Among his most important legislative achievements was the *Protection and Advocacy for Mentally Ill Individuals Act of 1986* (“PAIMI”). The first Congressional finding cited in PAIMI was that “individuals with

mental illness are vulnerable to abuse and serious injury.” At the time, there were more than 250,000 psychiatric beds in the country, but states were not equipped to monitor the care of so many patients. The Senator planned a federally funded system, independent from states, for monitoring and protecting the rights of the mentally ill. Now, nearly thirty years later, fewer than 35,000 state psychiatric beds remain. As a result, non-profit organizations created under PAIMII, such as the Disability Law Center, Inc. (“DLC”) in Massachusetts, have changed their focus, but not always in a good way. It is doubtful that Senator Kennedy would have sanctioned the use of federal funds for lobbying against state legislation. Between 2010 and 2013, DLC reported spending \$267,388 for lobbying; over \$100,000 was paid to professional lobbyists.

I was the Executive Director of the Treatment Advocacy Center (TAC) for many years. TAC’s mission is to eliminate barriers to

treatment for individuals with the most severe mental illnesses and pursues its mission without any governmental funding. TAC supports legislation for assisted outpatient treatment (AOT), which is a form of court ordered treatment for individuals who need medication to survive safely in the community, but who may be unaware of their illness due to a neurological disorder called anosognosia. PAIMI organizations (such as Protection & Advocacy or Disability Law Centers) used federal funding to lobby against AOT legislation in New Jersey, Pennsylvania, New Mexico, Florida, Maine, and many others.

It is more common to find PAIMII organizations lobbying in the halls of state capitols than monitoring for abuse in psychiatric hospital wards. I have personal experience to share as an illustration, although it is difficult. My sister has severe schizophrenia and has been in state psychiatric hospitals for

most of her adult life. Most facilities have provided quality medical care and protection for my vulnerable sister. But in 1998 she was moved from New Jersey's largest hospital when it closed to a smaller state hospital with less than 500 patients. Due to a shortage of beds, the census in the hospital reached 758 patients by 2007. Hospital staff were overwhelmed and the overcrowding made it a dangerous place. I knew some of what was going on and managed to have my sister moved to a safer hospital. The extent of the abuse became apparent when I later obtained my sister's records. (Exhibit A). I am still haunted by the patients who had nobody to protect them. Where was the federally funded PAIMI organization? They were in Trenton lobbying against New Jersey's AOT bill, a bill that ultimately passed.

Most PAIMII organizations appear to be unable to strike a balance between an individual's right to liberty and society's

obligation to protect its vulnerable citizens from harm. For example, the Massachusetts DLC conducted a study of community services ranging from hospital discharge planning to housing programs for people with mental illness. The report asserted that a guardian for person incapacitated by mental illness should not be involved in decisions about whether protective measures should be employed in the individual's community residential living. One situation that DLC reported as a violation of individual rights concerned a resident who was "wearing a GPS device because he has a history of wandering and getting hurt." Compare that with the Alzheimer's Association position that "the use of electronic tracking devices and related technology may be an appropriate part of a comprehensive safety plan."

Section 1141 of H.R. 3717 would place sensible restrictions on PAIMI grantees so they could no longer use taxpayer dollars to

lobby. PAIMI programs would return to their roots of investigating cases of abuse and neglect against a very vulnerable population.

Redefining PAIMI's mission and reducing funding will remove the impediment so that states can provide quality care to the most severely ill. Congressman Murphy's bill will begin the necessary steps to rein in an out-of-control agency in SAMHSA to focus its resources on caring for the most seriously mentally ill to. The reform of the Institution for Mental Disease Exclusion (IMD), which prevents states from receiving Medicaid reimbursement for psychiatric patients in state and private facilities, will slow the closure of state psychiatric hospital beds. The SAMHSA and CMHS reforms, such as linking the \$450 million mental health block grant to requiring states to adopt need-for-treatment standards and assisted outpatient treatment, will reintroduce the notion that severe mental

illnesses exist and until they are cured, barriers to treatment must be eliminated.

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