

Theresa Coyle, Conservator for Michael Messina

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Testimony

Regarding: 1915(c) Home and Community-Based Services Waiver, CT Acquired Brain Injury Waiver II

My name is Theresa Coyle. My brother Mike Messina became brain injured in 1983 at the age of 19 from a car accident which left him with severe cognitive impairments. I have been his advocate for many years through many different care situations. As family members we must take leaps of faith every day, hoping our vulnerable loved ones will be treated with the respect and dignity they deserve. We put our trust in providers to provide caring and person centered services. We put our trust in agencies and political representatives to hear our concerns and help secure the funding necessary to provide quality care to our loved ones.

Since my brother's injury he has been subjected to hospital placements where he was restrained day after day in a body net due nursing staff claiming inability to manage his behaviors, punishment in barren rooms at a state hospital for behaviors over which had no control, and residence in programs where he was subjected to abuse and neglect without his family's knowledge until it was too late to protect him. I am in the process of moving my brother into an independent living situation closer to home where I will do everything in my power to protect him and keep him safe. If these proposed waiver changes make this impossible or prevent his support provider from securing adequate and qualified staff, Mike may again be unsafe and at risk of the kind of abuse and neglect he has already endured. For me, this is unacceptable.

Soon after my brother's accident, after an extensive advocacy campaign and with no state agency in position to take responsibility for the brain injured population, President Reagan's office made a call to CT Governor William O'Neill and asked CT to show leadership and resolve what was then called the "Messina case". Governor O'Neill called a meeting with his commissioners and other agency representatives. An agency was chosen, a grant was written and a few survivors like my brother received their necessary community based services out of state. A few years later, when it was clear that more money was needed in our state for brain injury services, Commissioner Ginsberg of what was then called DHR appointed Lori DiGalbo and others with the task of writing of our ABI waiver. At the time, I was the Director of an organization providing community supports to persons with brain injuries. I am positive that the main focus in writing our ABI waiver was upon survivors receiving person centered services in models of care that promoted their safety, maximum possible control over their lives and full community integration. It is imperative that this ABI waiver continue to reflect its historical basis and intended purpose.

We have come a long way in our state in the past three decades, largely due to the advocacy efforts by survivors, family members and providers working in unity with agencies and political representatives. After all of the continued good efforts of many in our state, we must not go backwards to a time when no responsibility was taken to work together to protect the brain injured population. It is people's whole lives that will be affected by every decision that is made with the ABI waiver. Moving forward in ways that will protect survivors must be the focus, not going backwards in ways that will harm them. I am very proud of my brother. Still, with all that he has endured since his accident, he faces each day with a smile and a positive attitude, trusting those around him to support him and care for him. Among those that he is trusting now to do the right thing is you. Please listen to our voices and protect our loved ones.