

Testimony on the Closure of Hamburg State Center

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Thank you members of the Legislature for the opportunity to provide testimony to you today. My name is Celia Feinstein and I am the Executive Director of the Institute on Disabilities at Temple University. We are Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research and Service and we are a statewide program. We are one of a network of 67 programs throughout the nation that are funded by the Administration on Intellectual and Developmental Disabilities within the US Department of Health and Human Services to conduct training, service, technical assistance, research and dissemination activities on behalf of people with developmental disabilities in this Commonwealth. I have had the great pleasure of being associated with the Institute on Disabilities for 40 years.

When I first came to the Institute, back in 1978, a court had just decided that the 1154 people living in an institution for people with intellectual disabilities near Philadelphia had to move to smaller, community-based facilities. That institution located in Spring City, PA in Chester County was the Pennhurst Center. The case was later certified as a class action suit, with the ARC-PA and the U.S. Department of Justice joining as plaintiff-interveners, and the Pennhurst Parent Staff Association as defendant interveners. In an opinion written on December 23, 1977, Judge Broderick asked the parties to negotiate a settlement in the case. When negotiations stalled, the judge issued his now famous March 17th order. This was the first time in the history of intellectual disability litigation that a Federal Court Judge determined that an institution was incapable of providing constitutionally appropriate care and habilitation; he further concluded that the Pennhurst class members should be provided services in less restrictive settings in the community.

Following Judge Broderick's ruling, in recognition of the potential national significance of the Pennhurst case, leadership in the U.S. Department of Health and Human Services, decided to support a five year longitudinal study of the court-ordered deinstitutionalization of Pennhurst Center. The purpose of the study was:

- to measure the relative growth of residents in the institution and in the community in order to determine the impact of relocation on people with intellectual disabilities;

- to assess the impact of deinstitutionalization on the families of Pennhurst class members and the communities in which they live;
- to compare the costs of providing services in the institution to those in community settings;
- to assess the legal history of the Pennhurst case; and
- to address significant issues growing out of the implementation of the district court's decree.

As the federal government predicted, the Pennhurst case did have national implications. More than 20 states filed litigation patterned after Pennhurst. In many of those states, longitudinal studies were commissioned, with results quite similar to those found in Pennhurst. I have had the privilege of participating in many of those studies and have continued to be amazed as the untapped potential of people with intellectual disabilities is recognized and cultivated.

The major question to be answered by the Institute on Disabilities was, "Are people better off having moved from Pennhurst to the community?" After more than seven years of research in the Pennhurst Longitudinal Study, I can answer that question with a resounding Yes! In every way we were able to measure it, people were better off in the community than they had been at Pennhurst. We asked the question along many dimensions, including behavior, choice and control, environment and satisfaction.

Another area of particular interest to the study team was the impact of deinstitutionalization on families. The Pennhurst situation was characterized by polarized views by families about deinstitutionalization. We surveyed each family before their family member left Pennhurst, and then again, approximately six months after their relatives left Pennhurst. The results were astounding, as if from night to day. Prior to the moves, 55% of the families strongly disagreed with the decision to move their relatives. After the move occurred, however, 66% of the families strongly agreed with the decision to move their families to the community. Clearly the fear of the unknown persuaded families to disagree with the move to the community. Once the move happened, families were like converts; they strongly supported the actual experience of their relatives.

In addition, contrary to popular belief, it is not the people with mild disabilities that are most likely to succeed in the community, but rather people with the most significant disabilities. As the Pennhurst study showed, there was no one for whom a community placement was not possible. As a corollary to that, I was once told that for every person living in an institution there is a similarly situated person living in a community program. I would like to add to that corollary by saying, for every person living in an institution, there is a similarly situated person living successfully in the community, **and** a similarly situated person living at home with their family.

Once the study itself ended, the Office of Developmental Programs (ODP) continued to fund parts of the study as part of its continuing quality improvement system for Pennhurst class members. I am pleased to report to you that almost 30 years later, families continue to be satisfied with the place where their relatives live. Through Independent Monitoring for Quality (IM4Q) these quality of life assessment activities continue, with teams comprised of people with disabilities and families interviewing individuals with intellectual disabilities to assess their satisfaction, choice and control, relationships, inclusion and other dimensions of quality of life. Data are analyzed at the state and national levels through the National Core Indicators.

With regard to data at the national level, according to the State of the States in Intellectual and Developmental Disabilities (Braddock et.al. 2015), the population of state institutions has decreased by 12.7% nationally and by 9.4% in PA. With four institutions still open, PA is in the top 50% of states with institutions. As of 2017, fourteen states (DC, NH, VT, RI, AK, NM, WV, HI, ME, MI, OR, ASL, MN and IN) have closed all of their public institutions. PA has not proven to be a leader in this area – far from it. We are barely keeping pace with the rest of the country. The annual cost of supporting a person in a state institution is \$255,692 nationally, and \$378,016 in PA.

It has been suggested that Polk and Whitehaven could be downsized and used for things such as respite. To that I say ask the families, but not the families whose sons and daughters live in institutions. Ask the families who have kept their sons and daughters at home for 20, 30 40 and 50 years. Or ask the families of young children who are living at home, going to school with their brothers and sisters and friends. I'm sure that none of them would find a state center to be a suitable place for their relatives - even for a weekend!