

## **PENNSYLVANIA STATE REPORT**

**By Susan Jennings, VOR State Coordinator for Pennsylvania**

Pennsylvania operates five state centers for individuals with intellectual disabilities: Ebensburg, Hamburg, Polk, Selinsgrove, and White Haven.

Nancy Thaler, one of the principal architects of the CMS “Final “Rule”, is militantly opposed to the existence of our Pennsylvania State Developmental Centers and was appointed by Governor Wolfe as Pennsylvania’s Deputy Secretary of the Office of Developmental programs, which oversees the Centers.

Thaler argues that in order to achieve financial sustainability, she envisions creating a system where only family supports and adult foster care, exempt from costly employment and tax laws, are available, doing away with out-of-home placements and all congregate care settings for the disabled. Thaler completely fails to address the reality of the intensive needs of the severely and catastrophically impaired individuals who will outlive their parents for decades. Nor does she adequately acknowledge the shortcomings and paucity of the adult foster care system.

Governor Wolfe unilaterally decreed closure of Hamburg Center in January, 2017 with a projected closure date of 18-24 months. There were 80 Hamburg residents at the time of the announcement. 74 of those residents were put on a Planning List. 16 months later, 17 were placed “in the community”, 2 were sent to Nursing Homes, 8 were opposed to community residency and requested ICF placements, 3 were removed from the list with no reason given and 3 died. 41 residents remain at Hamburg Center as of May, 2018. ODP vigorously refused to provide follow-up status reporting to outside parties on the fate of any of the State Center residents placed “in the community”.

PA State Representative Kerry Benninghoff from Center County, introduced legislation, House Bill #1650, partially authored by the ARC, to close all the Pennsylvania State Centers down by 2023. In response, we parents, friends and families of State Center residents formed a grassroots political organization we named KIIDS – Keeping Individuals with Intellectual Disabilities Safe to oppose H.B. #1650. In the space of 4-5 months, we garnered nearly 10,000 signatures on our petition opposing H.B. #1650, and had our support for the need for State Centers made public in newspapers, T.V. broadcasts, Facebook, churches, fairs, festivals and at our website at [www.thekiids.org](http://www.thekiids.org). To compare and contrast the advantages of the State Centers to the abuses and neglect my son suffered “in the community”, my son’s story was showcased in a short video entitled “*The Least of These*” and in a featured article published in the December 17 edition of *Exceptional Parenting* magazine.

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A group of KIIDS leaders made a trip to the State House in Harrisburg and lobbied our Pennsylvania State legislators about the vital need for our State Developmental Centers as specialized residences designed and staffed to address the unique and intensive needs of our loved ones, a home base where they are welcome, understood and safe. We pointed out that the State Centers prevent 911 calls to police, psychiatric inpatient holds, emergency room visits due to aggressive outbursts, long-term hospitalizations, incarceration in overcrowded jails, crisis care placements and nursing home type facilities, all of which cost taxpayers much more than the Centers. As a result of KIIDS efforts, many of H.B #1650 bill's sponsors dropped off, the bill lost political support and the bill has been put on hold indefinitely.

Thaler has now turned her attention to converting private Intermediate Care Facilities to community group homes.

I testified before the federal Interagency Autism Coordinating Committee in their April 27 meeting at Bethesda, Maryland about the need for "institutional care" and Intermediate Care Facilities along with other autism mothers and advocates. We were warmly received and one of the committee members invited the CMS staffer listening in to come to one of IACC's meetings and address the ICF issue.

KIIDS representatives visited with Pennsylvania House and Human Services Chairman Gene DiGirolamo, to plan a hearing in September, 2018 to advocate for the continued existence of Pennsylvania's State Developmental Centers before the Pennsylvania legislature.

