

PENNSYLVANIA STATE REPORT

By Susan Jennings

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

The Office of Developmental Programs in Harrisburg is eager to close all the state facilities at some point and sell the properties.

Admission to the Pennsylvania state centers has been arbitrarily closed to Pennsylvania residents. New admissions can only occur through a costly and protracted court battle with ODP through the legal mechanism of a 406 Petition.

While States are required under the DD Act to provide legal representation through their Protection and Advocacy systems to all individuals with disabilities accessing services, PA Protection & Advocacy, Disability Rights Network, only protects the interests of individuals who choose community settings so Pennsylvanians who require an ICF level of care must pay all their own legal costs to gain admission to a state center.

Over the last 20 years, because of this closed door admissions policy, the resident population at Pennsylvania's state centers has decreased by nearly 70%, from almost 3000 people to 888. ODP is aware that 90% of these current residents of state centers are severely or profoundly disabled compared to 16% of individuals in the community based system.

According to community group home providers, funding issues, Chapter 51 regulations, processing delays, and restrictive exceptions processes have discouraged them from accepting more involved cases or offering new services. This translates into a statewide scarcity of community group homes available.

According to the Pennsylvania Waiting List Campaign, 13,519 individuals with intellectual disabilities and 1,771 individuals with autism are waiting for services in the state of Pennsylvania to date while the state maintains and pays for the fixed costs and utilities for empty licensed buildings on the state center campuses.

Current Pennsylvania Governor Tom Wolf appointed Nancy Thaler, (the architect of the traumatic Western State Center closing in 2000 by then Governor Ridge), as his DHS Deputy Secretary.

In 2000, the unilateral closure of Western Center was announced by Governor Ridge, and two days later a fleet of DPW contracted vans took all residents from their living quarters and transported them, unprepared, to equally unprepared

"community" placements in group houses and other facilities. Parents and relatives, who came to protest or at least find out where their family members were going, were cordoned off from their residents by the PA State Police. The result of the forced outplacement process resulted in the deaths of thirty-eight former Western Center residents which were documented but never investigated as promised by DPW. Another result, as predicted, was the hugely increased cost for necessary intensive care of ICF/DD level individuals in community placements and an insufficient number of providers.

The PA Department of Human Services Secretary Ted Dallas announced that DHS plans to close Hamburg State Center in Berks County within the next 18 to 24 months. A public hearing was held on January 30, 2017 where family and nursing staff expressed their vehement objections to this closing, but it was indicated to us that the decision had already been made.

PA State Representative Kerry Benninghoff from Center County intends to introduce legislation to close all the Pennsylvania State centers down by 2023. According to Benninghoff *"There is no doubt in my mind that the community based system of supports is a superior alternative to institutional settings."*

However the parents and guardians of thousands of disabled Pennsylvanians have fought the state and won, or at wrestled it to the ground in safeguarding sheltered workshops.

The most important thing the disabled get out of the workshops is the company and camaraderie of other adults like themselves, and their guardians get a vital respite from the 24-hour-a-day care they provide their loved ones.

The Center for Medicaid and Medicare Services made regulations and Pennsylvania issued an edict mandating that the disabled must spend 75% of the time "in the community" which would effectively shut the workshops down. The parents and guardians of 13,000 people served in 110 of these workplaces across Pennsylvania became alarmed and began to fight back with legal help from a tough trial lawyer named Ted Schwartz.

Thanks to the efforts of Atty Schwartz and his team, the new deal is that the workshops only have to offer their clients the opportunity to be in the community 25% of the time. Finally, the state appears to recognize that one size does not fit all, that for many workshop clients, employment in the community is never going to happen and that the new rules would place a terrible burden on their families.