

Disability Rights Pennsylvania

Testimony on the  
Closure of White Haven State Center

To The

Pennsylvania State Department of Human Services

Given by:

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Thank you for the opportunity to provide input into the closure of White Haven State Center. My name is Peri Jude Radecic, Chief Executive Officer of Disability Rights Pennsylvania. Disability Rights Pennsylvania is the designated federal protection and advocacy system for Pennsylvania.

Disability Rights Pennsylvania (DRP) supports the decision of the Pennsylvania Department of Human Services (DHS) to close White Haven State Center. The closure of Polk and White Haven State Centers continues the national and state trend toward community inclusion of people with disabilities.

For the last 50-100 years, services for individuals with developmental disabilities were often provided solely through state operated institutions. Now, institutionalization is the exception, rather than the rule. More individuals with disabilities in Pennsylvania receive services and supports in the community than in state operated institutions. The reasons are many for this shift to community services and supports. The federal government, under Medicaid, allowed states to create waivers for institutional care. Families and individuals with disabilities opened Medicaid in 1981 to funding not just institutional living but community living as well. Now more families and individuals with disabilities select community living as a choice as evidenced by the numbers in Pennsylvania. These supports include residential services, day programs, community integration skills, therapies, home health care, home modifications, assistive technology, and respite services.

Changes also came in the 1970's in response to state and congressional actions. Exposés by news reporters showed horrific instances of abuse and neglect at many centers, including here in Pennsylvania. Institutions closed as a response to those reports.

However, the big driver for de-institutionalization has been our robust community service system in Pennsylvania.

Some might say that litigation has worked to close institutions. Litigation has been used as a last resort when individuals who wanted to transition into the community have been prevented from leaving. Litigation has been used as a last resort when states have failed to put plans in place to provide meaningful choice. Litigation has also been used as a last resort when federal and/or state law has been violated.

In addition, federal law and policy changed to end the unnecessary segregation and isolation of people with disabilities. The bi-partisan Americans with Disabilities Act (ADA) of 1990 found that “historically, society has tended to isolate and segregate individuals with disabilities, and such forms of discrimination...continue to be a serious and pervasive social problem.” 42 U.S.C. § 12101 (a)(z).

At the bill signing ceremony in 1990, President George H. W. Bush, told us that he wanted people with disabilities to have the opportunity to "blend fully and equally into the rich mosaic of the American mainstream." The ADA was always intended to end the segregation and isolation of people with disabilities.

The U.S. Supreme Court in *Olmstead v. L.C.* (1999) 527 U.S. 581 ruled that unnecessary institutionalization of people with disabilities constitutes discrimination under the ADA. *Olmstead* extends the ADA's promise that unwanted segregation and isolation is illegal and must end.

According to statistics published by the Coleman Institute for Cognitive Disabilities at the University of Colorado\*, thirteen (13) states plus the District of Columbia have no state-operated institutions and have been able to provide home and community-based services to people with intellectual and developmental disabilities.

Over the past 40 years, more than 230,000 people with intellectual and developmental disabilities have been transitioned into the community. As of June 2015, 21,103 individuals remained institutionalized across the country. In Pennsylvania, only 716 individuals remain in the State Centers, while 36,774 individuals receive services through the Home and Community Based Waivers.

There is ample evidence that community integration and the Medicaid-funded Home and Community-Based system in Pennsylvania can support each resident at White Haven. Everyone will receive the specialized services, supports, medical care, and other services they need according to person-centered, individualized needs. In addition, closure will strengthen the home and community-based services system in Pennsylvania.

Under the system set up by the Pennsylvania Department of Human Services, if, after being engaged and informed about all the options for community living, the person decides they want institutional care, they can still make that choice. But to say that individuals cannot live in the community is simply not true. For every person who resides at White Haven, there is a peer in the community. With appropriate supports and services, all people with disabilities can live successfully in the community. 96% of people with intellectual disabilities who need services receive those services in the community, these individuals have varying degrees of behavioral health, physical health, and communication needs.

There are many reasons why our system of institutionalization must evolve.

The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis 187 (1985) showed that individuals with disabilities, including individuals with complex needs, experienced benefits after transferring into a community setting.

Closing Polk and White Haven will save the State money long-term and allow the Commonwealth to serve more people in the community. As residents leave the Center due to natural causes, the costs per resident rises as the total population decreases. Currently, DHS estimates that it costs approximately \$409,000 at Polk and \$435,000 at White Haven per resident annually. While the costs to transition over the next 12-24 months may increase as DHS must continue to operate Polk and White Haven and transition residents into the community, the average cost to serve an individual in the Consolidated Waiver is \$143,154 according to DHS.

Moving forward, DRP recommends that DHS continue the stakeholder process. The stakeholder process is important as it will provide an open forum for families and DHS to give and receive important information. In addition, stakeholder meetings are critical to educate individuals and families about waiver services, particularly how community-based systems work. Finally, stakeholder meetings promote engagement.

As DHS moves forward, it is important that:

The residents of White Haven design and receive supports and services nearest based on their individual needs.

Transition and service planning be person-centered.

There is monitoring and oversight for quality management and safeguards against abuse and neglect. This includes monitoring the transition process and outcomes.

Provider rates are appropriately set to ensure all quality community, medical, and behavioral health services are available, especially for those with complex and intensive support needs. In addition, there must be an expedited rate exceptions process to approve any necessary expenditures that exceed the rate ceilings to meet transition timelines.

DRP strongly supports the closure of White Haven and Polk State Centers. Our staff looks forward to working with DHS and all parties to ensure the successful closure of Polk and White Haven as well as the transition of every resident.

\*Lulinski, A., Tanis, E.S., & Nelis, T. (2018). Us of state institutions for people with intellectual and developmental in the United States. Data Brief (1). Boulder: State of the States in Intellectual and Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities, University of Colorado. States are: District of Columbia (1991); New Hampshire (1991); Vermont (1993); Rhode Island (1994); Alaska (1997); New Mexico (1997); West Virginia (1998); Hawaii (1999); Maine (1999); Michigan (2009); Oregon (2009); Alabama (2012); Minnesota (2002); Indiana (2007).

## **About Disability Rights Pennsylvania**

Disability Rights Pennsylvania has been the federally mandated protection and advocacy system in our state for over forty (40) years. Our mission is to protect and advocate for the rights of persons with disabilities so they may live the lives they choose, free from abuse, neglect, discrimination, and segregation. Our vision is a Commonwealth where people of all abilities are equal and free.