

**Pennsylvania Senate Health and Human Services Committee**  
**Hearing on State Center Closures**  
**Testimony of Kristin Ahrens, Deputy Secretary of the Office of Developmental Programs**  
**Department of Human Services**  
**October 21, 2019**

Good afternoon Chairwoman Rapp, Chairman DiGirolamo, Chairman Cruz, Chairman Frankel and members of the House Health and Human Services Committees. I am Kristin Ahrens, deputy secretary of the Office of Developmental Programs at the Pennsylvania Department of Human Services. I understand that there is a lot of anger and fear following our decision to close Polk and White Haven State Centers.

I would like to begin by affirming two things we all agree on. We believe that people with intellectual disabilities should be treated with dignity and respect and deserve compassionate, person-centered care that meets an individual's developmental, behavioral, and physical health needs to help them live an everyday life. We also know our state centers deliver that care every day to their residents.

The Wolf Administration firmly believes that all people deserve the opportunity to live among their family and peers in integrated, supportive homes. The administration is leading with this philosophy through our work to increase opportunities for seniors with medical needs, people with intellectual disabilities, and people with significant behavioral health needs to live more freely in their community and still maintain access to necessary supportive services.

DHS is constantly evaluating the status of all programs and facilities under our jurisdiction to ensure quality, integrity, and sustainability of operations. This includes monitoring for quality, census, staffing and facility needs, and necessarily includes budgetary considerations. As we conduct this work, at times it becomes clear maintaining current operations and properties is unsustainable. This process includes monitoring our state-run institutions, like our state centers. In 2017, this monitoring led us to announce the closure of Hamburg State Center. Over the last several months, it became apparent that maintaining four state centers indefinitely is no longer sustainable.

We do not take these decisions or actions lightly. All of us at DHS know that there are very strong, often competing, perspectives on how we care for people with intellectual disabilities and autism (ID/A). I think it is imperative to think about this decision in the broader context of how this system has both changed and stayed the same over the last century.

One of the challenges of the ID/A service system is that we are constantly pushing forward with new models of service but continue to manage legacy systems as well. We advance and develop new ways of serving and caring for this population, but these new services often do not completely replace prior or existing models of care. This is the situation we see ourselves in with intermediate care facilities, both state-run centers like Ebensburg, Polk, Selinsgrove, and White Haven, and private facilities.

Pennsylvania's state center system was designed at the turn of the 20th Century, when institutionalization of individuals with intellectual disabilities was considered the standard of care. At the time, the prevailing philosophy promoted the idea that people with intellectual disabilities could be "trained" in segregated and specialized environments to return to their communities and, when they could not be returned to their communities, that these institutions protected them from themselves and the community.

Up until the last few decades, state centers were more focused on providing basic custodial care rather than the compassionate, person-centered care that they do today. In the mid-20th century many of the state centers were over-crowded, underfunded, and, in some cases, inhumane due to poor conditions and standards of treatment. At times, residents were even used as human test subjects for medical advancements like the polio vaccines. At the peak of institutionalization in the mid-20th Century, more than 13,000 people lived at 23 state centers and ID units around Pennsylvania. The majority of Polk and White Haven residents were first admitted to the centers during this period.

But the world has changed dramatically since the 1960s. Back then, caring for a loved one with significant needs at home was often impossible for families who did not have the means to afford the sometimes intensive services needed. Institutionalization was the standard of care, and community systems were extremely limited or completely unavailable. In 1981, Congress enacted the Medicaid Home and Community-Based Waiver. Sustainable funding for community-based services allowed states to invest in establishing a strong infrastructure of community-based services for people with ID/A, and the national trend of deinstitutionalization accelerated through the 1980s and 1990s. ODP currently serves more than 40,000 people in community settings – more than a quarter of these individuals in 24/7 residential services that provide care akin to what is currently offered at Polk and White Haven.

The shift away from segregation has also been seen in education. In 1974, the Pennsylvania Association for Retarded Children (PARC) challenged a state law that prevented children with intellectual disabilities from accessing public school education. The first-of-its-kind case and PARC's advocacy led to a settlement and consent decree that expanded free public education to children with intellectual disabilities around Pennsylvania. This was the inspiration for the federal Education for All Handicapped Children Act of 1975, which expanded opportunities for public school education for children with ID/A. The 1990 Individuals with Disabilities Education Act, or IDEA, continued the movement towards less restrictive, more person-centered education. This inclusion has shaped the current generation. Backed by federal and state law and policy, parents today expect inclusion as much as possible and individualized supports when needed. The millennial generation grew up sharing classrooms and extracurricular spaces with children with ID/A. That is the standard now, and it is what is expected for their own children.

Institutionalization is now a temporary or last-resort option for care. Pennsylvania does have a waiting list for services for people with ID/A, but this is *not* a waiting list for a state center. People are waiting specifically for home and community-based services. When a person or their family member applies for services in the ID/A system, they are provided with the choice of services in an intermediate care facility (private ICFs) or community. 13,000 people have decided to wait for community services, even though there are approximately 100 vacant beds in private intermediate care facilities.

The Department has been criticized in recent years for admission policies for our state centers, but DHS' state center admission policy is governed by interrelated statute, regulation and case law. Statutes include the Mental Health and Intellectual Disabilities Act of 1966, the Guardianship Statute, which does not allow a guardian to voluntarily admit someone to a state center, and the federal Americans with Disabilities Act. Admissions are managed through the process established in regulations at 55 Chapter 6250 following a 1976 federal court decision, which require a court determination that people with intellectual disabilities cannot be admitted to a state center unless services cannot be provided or developed in their existing home or in their community. This is also consistent with the United States Supreme Court's 1999 ruling in the Olmstead case that unnecessary institutionalization of people with disabilities constitutes discrimination under the Americans with Disabilities Act.

Today, we operate just four state centers with approximately 700 residents. Each year, this number continues to decline due to aging residents passing away or moving into the community. The following chart details admissions and discharges at the state centers since State Fiscal Year (SFY) 2014-2015:

	<b>Admissions</b>	<b>Total Discharges</b>	<b>Discharge to Community</b>	<b>Discharge to Nursing Facility</b>	<b>Deaths</b>
<b>SFY 2014-2015</b>	6	51	7	2	42
<b>SFY 2015-2016</b>	7	51	9	5	37
<b>SFY 2016-2017</b>	16	62	20	3	39
<b>SFY 2017-2018</b>	14	93	51	3	39
<b>SFY 2018-2019</b>	4	64	24	6	34
<b>SFY 2019-2020 (as of August 2019)</b>	2	9	1	1	6

Admissions happen infrequently because alternative options are available in people’s current homes or elsewhere in their community. There are far more options than what residents and families previously knew or had access to. As the census declines, the cost of care at these facilities grows, now hovering at approximately \$400,000-\$450,000 per resident each year. These costs can be verified by referring to the Governor’s Executive Budget, which includes operating costs for each state center, and dividing by the number of residents at each center. These costs continue to rise despite recent reductions to state center operating costs in the 2019-2020 budget.

The declining census and growing cost of maintenance is not lost on stakeholders on both sides of this issue. Legislation is regularly introduced in the General Assembly to close the centers, and conversely, there are advocates who view expanded admission to the state centers as a solution for the ID/A service waitlist. In May, the House Human Services Committee held a hearing on the state center system and expanding admissions. DHS was not invited to testify. In 2015, the Legislative Budget and Finance Committee conducted a study of our state center system and issued a report recommending that DHS consolidate operations and move current residents and future admissions to one or two state centers and establish a plan to transition residents out of state centers and into the community in line with the Olmstead decision. So as DHS monitors this system, we do so knowing that there is fervent interest in the centers’ future on both sides of this issue.

It would be irresponsible to make these decisions based on emotion. We have a responsibility to our residents and their families, the staff at each facility, and also to all Pennsylvanians and we need to consider the sustainability of this system as it currently stands. As the census drops, the cost of care gets higher, which means less funding to be used for families seeking services. Reinvesting savings from these centers will help support more people in need of services in the long run. The more money we spend on serving people in state centers – a level of care that is available in privately-run facilities – the longer more people will have to wait for services.

There is much more to consider than just the cost of the direct services to individuals. We are also maintaining facilities that serve increasingly fewer people. The decision to close Polk and White Haven versus Ebensburg or Selinsgrove was not arbitrary. We have to weigh the long-term costs for each

setting and be judicious about how taxpayer resources are used. Ultimately, maintaining operations at Ebsburg and Selinsgrove is more sustainable than Polk and White Haven.

As we move forward with this process, I hope all of us – members of the General Assembly, advocates, stakeholders, and families can work together as partners. I understand and am not trying to minimize the anger, sadness, confusion, and fear that this change brings, but we all want to make sure that residents are safe, cared for, and happy. Through our experience with the Hamburg closure, we know that this is possible. At the time of the closure announcement, 80 people resided at Hamburg. Families and representatives for each resident were counseled regarding options for community-based placements, nursing facility-level care, and transferring to a different state center.

Following the announcement to close Hamburg State Center, 39 community providers expressed interest in serving Hamburg residents. 28 of those providers submitted Provider Response Plans, which detailed plans of care for the residents that would be moving. Following a detailed review of these plans by ODP and residents and their families, 21 of those providers were selected based on the plan's compliance with ODP regulations, the providers' ability to meet residents' needs, and resident and family wishes. All 52 former Hamburg residents that moved into the community chose their own providers that best met their needs and wants.

ODP's home and community-based services are highly regulated services that offer the same types of health and safety protections that are provided in the state centers. Community providers are held to the same policy and procedure for incident reporting and incident management that applies in the state centers and ODP's community programs.

In terms of oversight of individual care, individuals are monitored on at least a monthly basis by supports coordinators. ODP conducts licensing inspections annually and ODP also conducts provider monitoring that runs on a three-year cycle. There is also quality-of-life and satisfaction-with-services monitoring that is conducted by individuals and family members in each county for a sample of people in residential programs.

ODP provided additional monitoring for Hamburg residents on a regular basis in the year following their move into the community. Former residents were visited by State Center staff at a minimum at the 30-day, 60-day, 90-day, six-month, and one-year marks after moving out of Hamburg State Center. These visits are in addition to regular monitoring visits in place for both licensed providers and people receiving services that continue when the post-discharge monitoring period ends.

Families who never imagined their loved one could live in the community found placements that exceeded their expectations, and for the first time in their lives, residents had homes that they truly understood to be their own. These are not just my words – this is the actual experience we heard from families who moved through the transition process. I hope you'll read the attached report that summarizes our experience with the Hamburg State Center closure, which includes these sentiments from the residents and families we worked with.

This decision is not being made to disrespect families' wishes for their loved ones. The centers may be the only home they've known, and families chose the centers because it was the best option available at that time. I need to acknowledge this because I and everyone at DHS understand the gravity of this decision. But at the same time, given the advances in developing the community infrastructure that I've discussed and the wide array of options and supports that are now available, we see very low

admissions to the remaining state centers and four centers are no longer necessary to meet this population's needs. We are confident that based on our experience with the Hamburg closure, the needs of state center residents will be served just as well if not better in the community.

This decision is also not a slight at the quality of care at each of these facilities. The 1,179 employees at Polk and White Haven State Centers provide exceptional, loving care to each of the residents they work with. They are like family to the residents and their families, and I know this decision is hard on them as well. We are committed to working closely with each employee over the next 36 months to help counsel them towards employment opportunities either with the commonwealth or with private providers who may serve state center residents moving into the community. All former Hamburg State Center employees who expressed an interest in continued state employment following the closure were offered jobs with the state.

I know that this is a difficult decision for many people affected, and this is why we are committed to counseling residents, their families, and staff through every step of this process. Meetings with residents, family and staff began immediately with the announcement of closure and will continue throughout the transition. We will work with the families and residents to have a plan in place that best meets their needs and preferences. No resident will leave the center without a destination of their choosing and a fully developed plan that meets their physical, emotional, social, and mental health needs. We will not abandon anyone.

Thank you again for the opportunity to provide testimony here today. On behalf of all of us at DHS, I look forward to working with you on this moving forward.