



The Arc[™]

Pennsylvania

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Pennsylvania Message

A CASE FOR CLOSING STATE CENTERS



President Bush signing the ADA in 1990.

July 26th, 2020 marks the 30th Anniversary of the signing of the Americans with Disabilities Act (ADA). As he signed the law on the south lawn of the White House, President George H. W. Bush, surrounded by people with disabilities and members of Congress, closed his remarks by stating, “Let the shameful wall of exclusion come tumbling down.” Despite great advances in physical access and technology that have made schools, workplaces, and neighborhoods more accessible, there continue to be barriers to equal opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities. Over 700 people continue to live in Pennsylvania’s state-operated state centers.

On August 14, 2019, the Pennsylvania Department of Human Services, announced the closure of Polk Center in Venango County and White Haven Center in Luzerne County over a period of 36 months. Both are large state-operated intermediate care facilities for people with intellectual disabilities. Closing state centers has long been the work of The Arc of Pennsylvania. This issue of the PA Message shares why!



Polk Center in Vanango County



White Haven Center in Luzerne County

President's Message

Sarah Holland



As I was sworn into my role as President of The Arc of Pennsylvania, I had no idea that this year would bring such an important milestone for our organization - but, more importantly for the individuals with intellectual and developmental disabilities across our Commonwealth. The announcement of the planned closure of White Haven and Polk State Centers was a result of years of advocacy, planning, and support from every corner of our state and beyond. As families, individuals with disabilities, and the disability community, we have known for too long that living in community should be available to every individual. The announcement of the closure of these two state centers bring us closer to that reality.

My first experience of state centers came from the lived experiences of individuals who had themselves lived in state centers. After college I took a job working in a community program that supported individuals with intellectual disabilities. The majority of the individuals that attended this program had spent many of their years in state centers. Many of my colleagues had previously worked in state centers. It was through their stories that I learned so much. I learned how much was lost; how so little of the individual's history had been able to be preserved; how individuals lost touch with family;

and how individuals were often exposed to stress, conditions that favored efficiency of daily tasks, as opposed to individualization.

I also learned of stories of reconnection and new lives when individuals lived in community. Some were now connected with siblings that they had lost touch. All lived in homes and had lives outside of those walls. I had no idea that these few months that I worked with these individuals and got to know some of their stories, would guide me in ways that I could have never imagined.

Fast forward to my own journey. My firstborn came into this world with many complications and a story that started with and continues to be complex. It is filled with unknowns and question marks. What we have learned as a family over the past 25 years, reinforces what I learned while working with the individuals. I learned that relationships happen in the context of our daily interactions. That safety is preserved when there are many who know you rather than in settings that are designed to cater to one specific group. It is the needs of the group that almost always drive the day. Mostly, I learned that everyone can contribute if we listen to each other.

As we embark on the work to dismantle a system that was designed with an intent to shelter and create efficiencies of scale - may we be reminded of the core of this work. It is about ensuring that each and every individual receives the services and supports that are in service of building relationships ... real, meaningful connection and lives beyond a location. The opportunity, presented in the planful transition into a community, cannot be underestimated. This opportunity provides not only a new path for so many individuals- it provides an opportunity to learn and grow as a field.

I know that The Arc of Pa stands ready to support the individuals and families across Pennsylvania. As a parent, I continue to be guided by the stories of those that came before me. We must do the hard work to listen, plan, and support. As The Arc of Pennsylvania, we must stand firm and clear in the belief that individuals with intellectual and developmental disabilities have gifts and value. They belong as part of our collective Everyday Lives...may we work to make this so.

- Sarah Holland



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GO GREEN

The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to:
skeithknox@thearcpa.org
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Executive Director's Message Sherri Landis



LONG HISTORY OF SUPPORTING STATE CENTER CLOSURES

At the Public Interest Law Center's 50th Anniversary Celebration, In Pursuit of Justice, The Arc of Pennsylvania was recognized as the 2019 Thaddeus Stevens Award Honoree. The Thaddeus Stevens Awards are presented each year to individuals or organization whose actions best exemplify the mission of the law center. With the law center as our legal partner, The Arc of PA - formerly known as PARC - was the plaintiff in the 1971 case PARC v. Commonwealth of Pennsylvania. This was the first case in the country that established the right of students with disabilities to receive public education.

We partnered with the law center again to join the class action lawsuit, Halderman v. Pennhurst, filed by residents challenging the horrendous conditions at Pennhurst State School and Hospital. The settlement, reached in 1986, resulted in the closure of that facility. Throughout the years, additional cases were brought to assure that the rights of people with intellectual disabilities to live in their community and attend regular schools were filed.

Particularly during these past few months, our rich history has given us a strong foundation for the work that lies ahead. On August 14, 2019, the Department of Human Services (DHS) Secretary Teresa Miller announced the closure of Polk State Center in Venango County and White Haven State Center in Luzerne County. The closure process is expected to take about three years. Both centers are intermediate care facilities for individuals with intellectual and developmental disabilities.

Having attended the Polk and White Haven Act 3 Hearings and subsequent PA Senate and House of Representative hearings on this issue, it is evident that some people are in strong opposition to these closures. While the conditions at state centers have vastly improved since the terrible human rights abuses

“This action - moving away from a segregated, state-operated institutional model of care - shows Pennsylvania's commitment to investing in the lives of people with disabilities. –SHERRI LANDIS”

brought to light in the 1970s, they remain a segregated model of service. I can only believe that the founders of The Arc of Pennsylvania never thought that over forty years later Pennsylvania would still have people in state-operated centers.

The Arc of PA knows that transitions are never easy. Closing a state center is not new to The Arc or the Department of Human Services, but it is new to the individuals with disabilities living at Polk and White Haven Centers and their families. That is why The Arc supports the 3-year, intentional plan of the department to meet with individuals, conduct the proper assessments, and talk through all the options. We know that families are integral to a successful transition and we are committed to supporting individuals and their families in whatever way we can to make this a successful move to community-based living.

This action - moving away from a segregated, state-operated institutional model of care - shows Pennsylvania's commitment to investing in the lives of people with disabilities. We've seen countless instances of people with disabilities - some of whom lived their entire life in a state center - some with very significant support needs - flourish when they moved into the community. We believe that Individuals with disabilities deserve the opportunity to experience life in their community, just like anyone else.

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MICHAEL STORM: A PENNHURST SURVIVOR

Through the Eyes of James Storm, His Younger Brother



Michael and his family

Michael was born in the 1950's and it sure seems like a lifetime ago. Harry S. Truman was President of the United States; the Korean War Conflict was underway; and Rock and Roll was born. No one had a cell phone or a computer, and the television, if you had one, had only 2 or three stations - tops. And sadly, there were few, if any, services for people with disabilities. In fact, it was a time when people didn't talk about having a child with special needs - there was shame and guilt for the hard decisions that needed to be made. At least, that's how I remember it. No one ever asked about Michael; it was as if he didn't exist. But my family always thought of him and loved him deeply.

Sixty-seven years ago, Michael was born to my parents, Joyce and Marcus Storm who lived in the Easton area. My mother was a homemaker and my dad worked two jobs to make ends meet. My mother had contracted polio as a young woman, and it effected how she walked and her internal abdominal muscles. They lost their first child during childbirth;

“THE STATE GOT IT RIGHT THIS TIME! THEY TOLD ME THE TRUTH WHEN THEY SAID EVERY ONE OF MICHAEL’S NEEDS WOULD BE MET.”

Michael was their 2nd child. His birth, a natural childbirth, resulted in damage to his brain and body. Michael has cognitive disabilities, cerebral palsy, and epilepsy. I am the 3rd son and my brother, Billy is the youngest. We were delivered by Caesarean section with no difficulties.

At some point, my mom and dad realized Michael was not developing typically; he wasn't walking or talking. I remember that he never learned not to touch the stove. In every picture I have of Michael as a young child, someone always had a hold of him. At one point, my dad borrowed money to pay a doctor who looked at Michael's brain, only to be told there was no hope for any progress. My parents were told that Mike would die before the age of 20. As Michael got older and with two additional sons, my parents were concerned they would not be able to meet the needs of Michael, as well as raise Billy and me.

Michael Moves to Pennhurst State School & Hospital

My mother always said, “It was the saddest day of my life”; the day that she and my dad left 4-year-old Michael at Pennhurst. They made this terribly difficult decision after being advised to do so by doctors and family who were concerned for the welfare of our family. I remember visiting Michael at Pennhurst. I must have been about 6 or 7. My mom,



Michael's Home

dad, and I walked into this big room where benches had been stacked either to keep people in or keep people out. I remember the sounds of people crying and the smell of urine. My parents didn't think that Michael would remember us, but he did. He came right over and held out his hand to mom. My dad couldn't take it. He left crying and could never return again.

When Pennhurst closed, Michael moved to a group home. I remember that my mother was so against this as she thought that Michael was getting what he needed at Pennhurst and believed a group home would never be able to meet his needs. While living at the group home, Mikey had some medical issues and he became hospitalized and stayed there for 6 months. The group home could not take him back because he then needed ventilator and feeding tube care. No other group home could be found to provide that level of medical care.

Good Care at Hamburg

His next home was Hamburg, where he lived for 11 years. It was a rough start at Hamburg; he had a difficult time adjusting to the change in his environment. He did not use words to communicate and it took a while for people to understand him. But, they did, and we felt that the staff at Hamburg got to know him, his needs, and most important, that they really cared about him.

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Hamburg's Closing: A Brother's Dilemma

Since my parents have passed, my wife Marta and I are the legal guardians of my brother. We make the decisions about his care and where he lives. When we got the call that Hamburg was closing I was mad. We went into "fight" mode. At a minimum, we wanted the state to keep the medical unit open. I could just hear my mom's concerns in my head - "no group home is able to meet his needs in the way that the caring staff at Hamburg do". This was like dynamite with a fuse - people were scared, and people didn't know where their loved ones were going.

When it became evident that saving Hamburg was not possible, we decided to be actively engaged in the process. And the process to move my brother from Hamburg was very deliberate. We participated in a series of planning meetings that included state officials and Mike's Supports Coordinator - this was to identify the specific services and supports he would need. Then Hamburg staff arranged for us to meet with a variety of providers and we were encouraged to visit their homes. We felt that we were the decision-makers and that we had choices as to where Michael would live. And we were assured that all of Michael's needs would be met.

Michael moved to a home operated by KenCrest in 2018. The home is situated in Montgomery County on a quiet lane, and the house is surrounded by trees,

flowers, and nature. There are floor to ceiling windows in each room which give a view of the birds and deer who regularly visit. The house was renovated specifically for the new occupants who all need medical care. There are four people that live in the house; three of the folks moved from Hamburg Center close to the same time that Michael moved there.

The State Got It Right This Time!

"The state got it right this time!" They told me the truth when they said every one of Michael's needs would be met. In his home, Mike receives 'round the clock' nursing care (there are 2 Registered Nurses on staff at all times). The people supporting Michael know his needs and have figured out his likes and dislikes and how he is feeling by watching his facial expressions and how he moves his body. I am in regular contact with the staff at Michael's home, by phone, and text. And they always take the time to answer all my questions. I am encouraged to visit as often as I can. I especially love visiting during one of the seasonal parties that they sponsor for families and other visitors!

I have no doubt that Michael is safe and that he is loved. He is getting all his needs met - his medical needs, his social, and emotional needs. That is what my mother wanted for him! My younger brother Billy has little memory

of Michael and while he lives hundreds of miles away, we still keep him updated on Michael's life and his progress.

This is the first time Michael has lived in a "home", a place that he is truly loved and surrounded by people that know and respect him. While he received excellent care at Hamburg, it was not a home setting. We tried to keep Hamburg open out of fear, believing that the services he received there could not be replicated anywhere else. But, now Michael has found what he needs in his home.

Michael loves women - you can see that extra smile in his face when someone gives him extra attention. And he loves Elvis. My mother always played records for us when we were little and maybe this is Michael's way of remembering my mom. At a recent birthday party, the staff arranged for an Elvis impersonator to perform and Michael grabbed the purple scarf from around his neck. I know that the staff at this home get Michael!

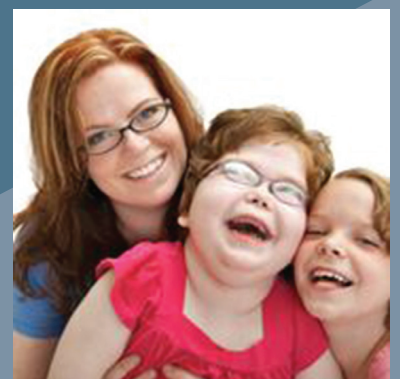
We always thought that Michael would die young, but he sure proved us wrong. We have nicknamed him the 'Snapping Turtle' because he keeps surviving all that life puts before him. I know that someday my mom is going to come back, grab him by the ear, and take him to heaven with her and dad. My faith says that will be so!

Thank you to James Storm for sharing his and Michael's story. James Storm is a retired Educator from the Pocono area.

In Memory of Michael Storm. Michael Passed Away on October 10, 2019



Visit the Arc
of PA online
thearcpa.org



A HOME FOR JANET

Janet can't tell you what kind of home she wants to live in. She can't tell you the kind of staff that she wants to support her. But Janet does communicate. She communicates using gestures, grimaces, and by the way she moves her body and stomps her feet. If you know Janet, you know what she is thinking just by watching and interacting with her.

When Mr. Sodl (Janet's father) learned that Hamburg was closing, he was not happy. He (now in his 80s) and his wife, now deceased, thought that they had found a forever home for Janet at the Hamburg Center, an Intermediate Care Facility for Persons with Intellectual Disabilities. It was a place where she was safe and well cared for by professional and caring staff. Mr. Sodl had been aware of community services for many years and had been reluctant to investigate further. The anticipated closing of Hamburg Center gave him the jolt he needed to learn more.



Janet Sodl with her father

table waiting for her father to share a cupcake, or two. Janet is her dad's best taste tester - although she is known to love anything he bakes. Mr. Sodl can tell by her actions and interactions with the staff that care for her - his daughter is happy, and this is the right place for her.

Janet likes to be on the move. She is usually found walking around her house. Staff understands that Janet likes her space; she likes to be outside on the deck and have the sunshine warm her body. In fact, if she had her choice, she would forego the clothes. Yet, going shoeless and sockless are the furthest she is able to disrobe! Janet loves water, taking showers, and riding in the car. Her favorite activity is untying a pink shoe that dad and staff regularly re-tie for her. She has amazing dexterity and she loves music. Safety considerations are very important. Janet's house has no steps, and there are safety locks on cabinets and bathroom doors. All supplies are stored out of her reach and there are alarms on doors and refrigerators.

Fitzmaurice Community Services is a large service organization in Carbon, Monroe,

and Pike counties. Staff are well trained and focus on empowering individuals with disabilities to achieve independence, individuality, productivity, and inclusion within the community, as they are able. Mr. Sodl will tell you that one of the most impressive aspects of Janet's home is the staff. Many have worked at the home since the house opened over a year ago. Colleen interacts with Janet on a daily basis. "I love to see Janet each day. She smiles and laughs with staff as we spend the day together," she says. Colleen finds her job rewarding and likes the entire staff team. Hats off to all staff that support Janet - Florence, Daelynn, Coleen, Janessa, Danairy, Dawn, Beth and Liz.

I CAN REST IN PEACE!

Putting the Past Behind

Mr. Sodl is the father of Janet Sodl, a 59-year-old woman. Janet was born in Sacred Heart Hospital in Allentown, PA. She was born to Mr. Sodl and his wife in 1959 during a time when community services for people with intellectual and developmental disabilities were almost non-existent. She is the oldest of three, having 2 younger brothers, Matthew and Jeffrey. As she grew, she had a harder time communicating her needs. She would bang her head and pull her hair. Shifts at home were needed for her care to make sure she did not hurt herself. When medication changes did not help, the family's doctor advised the Sodl's to find professional care at Hamburg School and Hospital.

When her parents decided on Hamburg, they thought their decision was final. It was a desperate decision and one that caused great agony. Since Janet moved to the Fitzmaurice home, Mr. Sodl's idea of a home for his daughter has changed. While Hamburg was safe and Janet liked living there, "Janet lives in a real home now," he says, "and, I can rest in peace!" Another factor in considering this move is that Janet now lives closer to her younger

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JANET LIVES IN A REAL HOME NOW

Finding Janet's Home

In his search, Mr. Sodl found Fitzmaurice Community Services and agreed to visit one of their homes. What he saw was impressive - the house was beautiful, but most importantly, "The people were beautiful", says Mr. Sodl. He observed staff interacting and caring for people in the same way that he would want his daughter to be cared for. The decision was made, and he agreed to give this a shot.

Mr. Sodl now knows this is Janet's forever home! Janet lives in a beautiful home in Monroe County. How does he know she is happy? As soon as Janet sees her father walk in the door, her eyes light up. A smile starts to form at the corners of her mouth, and she reaches out to learn what he has hidden in the plastic bag. To her delight, he has baked chocolate cupcakes! With little time for a hug, Janet's at the

brother. Her brother has assumed some of the decision-making responsibilities now that her father is older. Most importantly, "I know my wife would be pleased," says Mr. Sodl.

Fitzmaurice Community Services, Inc. (FCS) is a not-for-profit

organization that has been Building Brighter Futures for over 50 years for Adults with Behavioral Health and Developmental Disabilities and their families. Check out their website at: <https://www.fitzmaurice.org/>.

Q & A WITH ODP DEPUTY SECRETARY, KRISTIN AHRENS

1. What is the current census at Polk and White Haven Center and who lives there?



Ms. Ahrens: The number of people living at Polk and White Haven Centers changes regularly due to people moving in and out of the center and individuals passing away due to age and illness. At Polk, there are currently 194 people living there; their ages range from 20-90. At White Haven, there are currently 111 people living there; the average age of the residents is 62 and the age range is 23 years of age to 92 years of age. The people that live at White Haven and Polk Centers have largely lived there for decades and have complex needs - medical and/or behavioral in addition to their intellectual disability. The total number of residents in all four state centers is 714 (July 2019 data) individuals; (Polk, White Haven, Ebensburg, & Selinsgrove). Overall, people living in our state centers have lived there an average of 48 years.



2. Why, at this time, is DHS and the Governor supporting the closing of both Polk and White Haven? Why were these centers chosen?



Ms. Ahrens: The Office of Developmental Programs constantly monitors the entire system of supports for people living with intellectually disabilities and autism and we have an intense system of oversight. As part of this administration and any administration, improving Pennsylvania's service to people with disabilities and their families is a constant conversation and action driven discussion. With our state centers, the physical plant of each center is an ongoing concern. Polk was built in 1897 and White Haven in 1956. Due to the age of the buildings on the grounds of these centers, the necessary updates needed to the structures (water, grounds, heating, lighting, etc.) must be addressed on an ongoing basis. Upgrades are necessary and costly. At the same time, we have a declining census at each of Pennsylvania's centers.

Most people talk about the challenges of staffing in our community programs, but each center also has challenges in staffing as well. There is turnover and keeping direct support professionals is an ongoing concern. It is harder and harder

to find clinical support staff such as nurses and psychologists. Because of the age of the structure and associated upgrade costs, the decreasing census, and the overall success of our home and community based system, the decision was made to close these two centers. The closing will occur over a period of 36-months. We attempted to close Hamburg in 18 months, the last person moving within 19 months. We believe that 36-months will be adequate time for residents and families to gather information about their needs, identify qualified providers, and for people to find their new home.

3. What made the closing of the Hamburg Center successful? What aspects of that experience will be utilized in the closing of Polk and White Haven and how will the process ensure that people's needs, and preferences will be honored?



Ms. Ahrens: The process used for the closing of Polk and White Haven Centers and moving people into the community will follow the process that we used when Hamburg Center was closed. Each individual living at Hamburg had an Essential Lifestyle Plan.

Wellness checks are conducted once the person moves. They are conducted by someone from the Center that knows the person. These checks are in addition to the routine monitoring done by program specialists and supports coordinators in the community.

We have a number of professionals directly involved with the closure of Hamburg Center who will be assisting with the closure of Polk and White Haven Centers. Throughout the next 36-months, individuals and families will receive the support they need to identify the resident's needs and to identify qualified providers.

4. Is there growth in the census at PA's large private ICF's and is DHS concerned that the closings at Polk and White Haven will increase those numbers?



Ms. Ahrens: There is not growth in the number of residents living in Pennsylvania's large private ICF's. In fact, there are vacant beds and the numbers are declining. Also, at each of our state-operated centers, we

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have vacant beds. There is no wait list for services at a state center, but admissions are allowable only with a court order.

While there is a waiting list, the waiting list is for home and community based services. When people apply for intellectual disability/autism services, as part of the waiver enrollment process, people “waive” access to institutional services. They prefer to wait until community services are available. We also know that many people on the waiting list are not seeking residential services, but other services such as employment supports, transportation, respite, etc.

5. What do you need from The Arc of PA and our local chapters to assure the success of closing Polk and White Haven Centers?



Ms. Ahrens: Three things are critical for The Arc of Pennsylvania as we move to the successful closing of Polk and White Haven Centers.

First, we need to spread the word about the benefits of living, working, and being part of the community - having an EveryDay Life! This message needs to get to general community members, as well as to our legislative delegation. They need to know that each person leaving Polk and White Haven Centers will receive all the services that they need by qualified staff and providers. There are many people unfamiliar with the community service system - the size, scope and how it is managed and regulated. No one leaving the state center will be placed on a waiting list. All

those that need a waiver opportunity will receive the waiver and the services they need. There is no waiting list for them to get community services.

Second, local Arc chapters need to step up in terms of offering services. People leaving state centers for community services need residential services and the people living there have complex needs. Some local Arc chapters have the infrastructure and expertise to successfully serve these individuals in the community. We need all providers to consider if they are able to meet the needs of the people leaving Polk and White Haven. Please stay tuned for the posting of individual profiles on the DHS website. Consider if your chapter has services that are needed by these individuals.

Third, we need to be compassionate and respectful of the individuals and families as they proceed through this process. Before coming to Pennsylvania, I worked in community programs in the state of Oregon and was involved in transition planning for individuals leaving a large state center while there. We used the Essential Lifestyle Planning tool and individual planning throughout that process. Families talked about how heart-wrenching it was when they decided decades prior that their family member could not be supported at home and would be moving to the state center. There was no other option at the time. We must take the time, be respectful, and do the best that we can to assure each person’s plan is successful.

Ms. Kristin Ahrens is the Deputy Secretary, Office of Developmental Programs in the Pennsylvania Department of Human Services.

SECRETARY TERESA MILLER

Teresa Miller, Secretary, PA Department of Human Services

The 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 people with intellectual disabilities to live more freely in their community and still maintain access to necessary supportive services.

New Models of Service Delivery

One of the challenges of the Intellectual Disabilities/Autism system is that we are constantly pushing forward with new models of service, but continue to manage legacy systems as well. 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.



But the world has changed dramatically since the 1960s. Sustainable funding for community-based services allowed states to invest in establishing a strong infrastructure of community-based services for people with intellectual and developmental disabilities. The Office of Developmental Programs 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.

Parents Expect Inclusion

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

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sharing classrooms and extracurricular spaces with children with disabilities. 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 intellectual and developmental disabilities, 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 (ICF/ID) or community. Over 13,000 people have decided to wait for community services, even though there are approximately 100 vacant beds in private intermediate care facilities.

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.

Pennsylvania's State-Operated Centers

Today, Pennsylvania operates 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. As the census declines, the cost of care at these facilities grows, now hovering at approximately \$400,000 - \$450,000 per resident each year. 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.

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.

Hamburg Center Experience - This is Possible

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. All 52 former Hamburg residents that moved into the community chose their own providers that best met their needs and wants.

Families who never imagined their loved one could live in the community found placements that exceeded their expectations, and for the first time, residents had homes that they truly understood to be their own.

The decision to close Polk and White Haven 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 understands the gravity of this decision. But at the same time, given the advances in developing the community infrastructure 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.

Source: (Approved excerpts from Secretary Miller's Testimony to the Senate Health and Human Services Committee, September 24, 2019)

LEARN MORE, DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at pie@thearcpcpa.org to receive electronic alerts and the quarterly newsletter.

THE HAMBURG STATE CENTER CLOSURE

On January 11, 2017, the Department of Human Services announced the planned closure of Hamburg State Center, an intermediate care facility for people with intellectual disabilities in Hamburg, Berks County. At the time of the closure announcement, Hamburg Center served 80 residents. At the time of the Hamburg Closure announcement, 888 people lived in Pennsylvania's five state centers.

The Office of Developmental Programs serves more than 40,000 people in home and community-based services. Approximately 20% of the people receiving services in ODP's community residential program have the same level of need as people currently receiving services in the state centers. ODP's community program serves over 2500 people with highly complex medical needs and/or behavioral support needs.

Transitioning Hamburg Residents to the Community

At the time of the closure announcement, 80 people resided at Hamburg. As of August 30, 2019:

- 53 people moved to community placements;
- 18 people transferred to another state center;
- Three people transferred to a nursing facility;
- Six residents passed away before moving out of Hamburg State Center.

Hamburg Center primarily served people who were older with higher acuity involving primarily medical needs. The center averaged five deaths per year in the years preceding the closure announcement. These deaths occurred from natural causes related to age and co-occurring medical conditions. Of the 74 people who transitioned from Hamburg, 13 have died in the 32 months since the closure announcement. Eleven of these individuals transitioned to the community, one to a state center, and one to a nursing home. NOTE: All deaths of people receiving services through the Office of Developmental Programs are subject to a mortality review conducted by the department. Of the former Hamburg Center residents who have died, one of those deaths was found to be the result of negligence from a community provider. The Department took immediate action with the provider as a result of this finding.

Moving Residents Out of Hamburg Center

Thirty-two of the 83 people who chose to move to the community now live closer to their families. Seven of the 18 people who moved to another state center are closer to their families.

Hamburg State Center Employees

At the time of the closure announcement, 351 employees worked at Hamburg State Center. All Hamburg State Center staff working at the time of the announcement or on-boarded following the closure announcement were counseled on employment options throughout the closure process. Staff were given support to pursue continued state employment or continue with a similar line of work with a community-based provider.

As of September 2019:

- 189 former Hamburg Center employees transferred to other positions within the state;
- 70 employees retired;
- 58 employees left state employment;
- 18 did not enter a contractual placement;
- 5 rejected offers for other employment;
- 1 entered a contractual placement but was not placed
- 17 remain on-site.

Plans for Hamburg State Center Property

The Hamburg State Center property will be turned over to the Department of Human Services by the end of 2019. The Department of General Services is subdividing the property. Portions of the property will be conveyed to the departments of Agriculture and Military and Veterans Affairs and the Pennsylvania State Police. The Berks County Intermediate Unit will also assume part of the property. The cemetery will be conveyed to the Berks County Association for Graveyard Preservation.

Source: Hamburg State Center Closure Report, September 2019, Office of Developmental Programs. (excerpts)

PENNSYLVANIA COALITION FOR INCLUSIVE COMMUNITY

For more information about the closure of state centers, please visit the Arc of PA's website at www.thearca.org

ARE PEOPLE BETTER OFF HAVING MOVED TO THE COMMUNITY?

When I first came to the Institute on Disabilities at Temple University 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. 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.

A Longitudinal Study Commissioned

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. 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.

Changing Attitudes of Families

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.

Efforts to Measure Satisfaction Continue

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.

Celia Feinstein is the Executive Director of the Institute on Disabilities (IOD) at Temple University. The IOD is Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research and Service. The IOD is 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. Ms. Feinstein has had the pleasure of being associated with the Institute on Disabilities for 40 years. Ms. Feinstein can be reached at shoes100@temple.edu .



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MISSION STATEMENT

The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.