

## **Hamburg State Center Closure Report September 2019**

### **Introduction**

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 State Center served 80 residents. The closure of Hamburg State Center continues the nationwide trend towards serving people with intellectual disabilities in less restrictive, community-based placement.

This report will summarize experiences and outcomes from the Hamburg State Center closure, including relocation and placement updates on former residents and employees.

### **History of State Centers and the Shift to Community Placement**

Pennsylvania's state center system was designed at the turn of the 20<sup>th</sup> Century, when institutionalization of individuals with intellectual disabilities was considered best practice. Up until the last few decades, state centers were not necessarily the places of compassionate, person-centered care that they are today, but were more focused on basic custodial care. Many of the state centers were over-crowded, underfunded, and, in some cases, inhumane due to poor conditions and standards of treatment.

Until 1966 in Pennsylvania, if you were a person with an intellectual or developmental disability (I/DD) and you needed support beyond what your family could provide, the only option for you was a state center. At its height, 228,500 people nationwide and 13,000 people in Pennsylvania lived in large, state-run institutions.

The Pennsylvania General Assembly passed the Mental Health and Intellectual Disability (MH/ID) Act of 1966, creating Pennsylvania's system of community-based options for people with I/DD. Individuals and their families were no longer forced to decide to remove a loved one from their community. In the early days of the community system, services primarily consisted of group homes and day programs. People with disabilities and their families clearly voiced what they wanted from a community system and, as a result, that system continued to grow and expand to respond to the needs expressed. Individuals and families demanded: family support, respite, counseling, and therapies delivered in community settings; assistance to find and maintain employment; alternatives to group homes including in-home and community support, self-directed supports, life sharing and supported living. With this array of alternatives, the state centers census has continued to decline.

In 1982, the federal adoption of the Medicaid Home and Community Based-Services (HCBS) Waivers made that assistance available. Allowing funds that were previously reserved for institutional services to be used for community services enabled state I/DD departments to build systems of community services that initially supported people leaving institutions and soon expanded to those at risk of institutionalization. For the next two decades, the institutional census continued to drop by 4,000 to 5,000 people annually.

## Federal and State Laws and Policies Affecting Institutionalization

Admissions to state centers are 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 (ADA).

Nationally, the primary legal basis for deinstitutionalization is the ADA, which Congress enacted in 1990 "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." In passing this groundbreaking law, Congress recognized that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."

In 1995, two residents of institutions in Georgia sued the state, claiming that they had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA. Eventually, the case made it to the U.S. Supreme Court which ruled in the case of *Olmstead v. L.C.*, 527 U.S. 581 (1999), that unnecessary institutionalization of people with disabilities constitutes discrimination under the ADA.

The decision requires community placement when the following three conditions are met:

1. The individual can handle or benefit from community placement;
2. The transfer is not opposed by the affected individual; and
3. Community placement can be reasonably accommodated (i.e., would not impose a fundamental alteration, which the state must prove).

## Systems of Care Today

In the five decades since the Pennsylvania General Assembly established community systems of care for people with intellectual disabilities, the census in state-run institutions serving this population has declined significantly both in Pennsylvania and nationwide. This shift has led Pennsylvania to close 19 state centers or intellectual disability units.

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 percent 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 currently serves over 2500 people with highly complex medical needs and/or behavioral support needs.

## Transitioning Hamburg Residents to the Community

### Census

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.

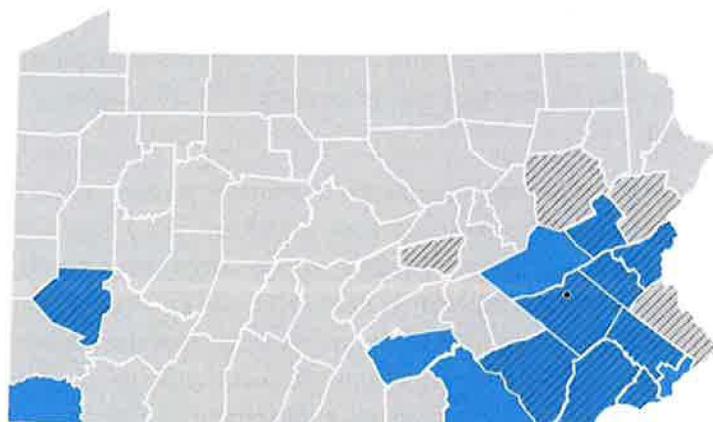
Hamburg Center primarily served people who were older with higher acuity involving primarily medical needs. The center averaged five deaths per year in the years preceding the closure announcement. These deaths occurred from natural causes related to age and co-occurring medical conditions. Of the 74 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.

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 in the past 32 months, one of those deaths was found to be the result of negligence from a community provider. Following this instance, the provider received a licensing citation and was required to submit a Corrective Action Plan to the department, which the department approved. The department verified that steps required in the Corrective Action Plan were completed promptly. The department also sent an Act 28 Neglect of a Care Dependent Person referral to the Lehigh County District Attorney and the State Office of the Attorney General.

### Moving Residents out of Hamburg Center

Thirty-two of the 53 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.



- County where residents only originated from
- ▨ County where residents have originating from and moved to
- ▨ County where residents only moved to

### Regulatory Oversight of Community Providers

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.

ODP's home and community-based services are highly regulated services offering the same types of health and safety protections that are provided in the state centers. For example, the same policy and procedure for incident reporting and incident management 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 3-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.

### **Post-Discharge Monitoring**

ODP provided additional monitoring for Hamburg residents on a regular basis in the year following their move. 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.

Post-discharge monitoring visits are conducted by ODP staff and focus on former residents' health and well-being. Staff looks for progress and concerns around former residents' quality of life, community integration, and progress on each person's essential lifestyle plan and other transition plans. Specifically, staff are monitoring for potential environmental, medical, health and safety, and program service concerns in addition to a discharged individual's overall wellness.

### Experience During Monitoring

Between February 2018 and July 2019, more than 300 monitoring visits were completed. All 74 individuals were monitored, regardless of post-discharge placement. The following summarizes experiences from this period:

- **Environmental:** ODP staff evaluated cleanliness of a former resident's new environment, potential safety concerns, and its personalization to the person's wants, needs, and interests.
  - No areas of concern were found in 94.8 percent of monitoring visits.
- **Discharged Individual's Status:** ODP staff evaluated the person's interactions and response based on their typical baseline prior to discharge, his or her feeling of happiness and safety in their home (depending on their ability to communicate, this may be assessed by ODP staff), the person's cleanliness, and their access to adaptive equipment and devices.
  - No areas of concern were noted in 87.9 percent of monitoring visits.

- **Medical:** ODP staff assessed resident health and wellbeing through a person’s medical functioning, access to necessary medical supports, weight, and emergency room visits or hospital admittances since previous monitoring visits.
  - No areas of concern were noted in 70.2 percent of monitoring visits.
  - Because of the aging and medically complex and fragile nature of former Hamburg residents, medical concerns and need for follow-up and intensive monitoring are expected.
- **Program Services:** ODP staff assessed support staff’s awareness of and involvement in the person’s needs, how staff work with former residents during visits, availability of and involvement in activities in the community, whether the person is employed or attending a day program, and if behavioral concerns have occurred since the previous monitoring visit.
  - No areas of concern were noted in 83.6 percent of monitoring visits.
- **Immediate Health and Safety Concerns:** ODP staff looked for immediate concerns so they could be addressed quickly by provider staff with support of ODP and the county administrative entity as necessary.
  - No immediate health or safety concerns were identified in 98.4 percent of monitoring visits.

ODP, the county/administrative entity, supports coordinator, and the person’s family or legal guardian are all aware of scheduled monitoring visits. If an area of concern is identified during the post-discharge monitoring process, this would be communicated to all necessary partners. Issues identified are remediated using ODP’s normal individual support planning processes, which involves the provider, ODP, county/administrative entity, and the person’s family or guardian to work together to reach a solution to the identified problem. This is the same process used for all individuals in community settings. Once a solution is identified and implemented, ODP regional staff, the county/administrative entity, and the person’s supports coordinator will monitor to ensure the solution’s effectiveness and, if necessary, will adjust as needed.

#### Resident and Family Experiences

DHS keeps in close contact with families and former residents throughout the transition process and post-discharge. Below are testimonials from both former residents and family members about their experience moving out of Hamburg State Center.

##### *From Former Residents*

“I love my house. Can I stay here?”

“I like everybody, but I don’t want to go back to Hamburg Center. I love, love my house.”

“Welcome to my home.”

“This is my house and I picked out the furniture. “

“Is this really my house? It is beautiful. Can I stay here?”

### *From Families*

“Myself and the rest of my family were so upset when the announcement to close Hamburg Center was made, but I can’t believe how good everything has turned out. My sister has a beautiful home and both she and the rest of my family are very happy. We loved Hamburg Center, but there is nothing like living in a home. “

“I originally planned for my brother to move to another State Center. There was no way that I was ever going to consider a move into the community for him. I was encouraged to look at all of my options before making that decision. After looking at community homes and meeting providers I decided to make the decision for my brother to move into a community home closer to where we live. That was one of the best decisions I ever made. My brother loves being in his home! I only wish I would have explored this possibility for him years ago so that he could have had the opportunity to enjoy life in his own home before the Center closed.”

“I never knew services like this existed in the community setting. My brother receives excellent medical care and lives in a beautiful home. When the announcement was made that Hamburg Center was closing, I was sure that I wanted my brother to move to another state center or an ICF. I was asked to meet with providers and look at homes in the community before making my decision. I did do that and now my brother no longer has to live in an institution and is very happy in his home. “

“This home is beautiful. The provider found the right home for my daughter. I knew when I met the director of this agency, that this was the agency I would select to support my daughter. I loved Hamburg Center, but to see my daughter so happy in her home is something I could not believe could ever have happened for her.”

“From the time the closure announcement was made to where we are today is amazing. I never knew my daughter could live so close to me in a lovely home. I visit her often and work through issues that come up as nothing is perfect....but I am so happy my daughter is now living in a home.”

“I absolutely love the home that my brother moved to. My brother has so many medical problems, that I never thought this could be a possibility for him. He seems so much happier in his bright, cheery home. My wife and I are still amazed that this was able to happen for my brother.”

### **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 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 State Center employees transferred to other positions with 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.

After the closure in July 2018, 22 staff remained on property to maintain grounds, utilities, and properties and transition supplies and equipment to surplus. At of September 2019, 17 staff remain. Four stay behind staff have retired, and one has transferred to other employment.

**Plans for Hamburg State Center Property**

The Hamburg State Center property will be turned over to the Department of General Services (DGS) by the end of 2019. DGS 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.

## 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.

### 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 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, 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.

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.

### **Putting the Past Behind**

Mr. Sodl is the father of Janet Sodl, a 59 year 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 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/>*