

October 22, 2019



Budget Primer

Department of Human Services

Intellectual Disabilities and

Autism Spectrum Disorder

Pat Shaughnessy, Senior Budget Analyst

The Department of Human Services provides a wide array of services to Pennsylvanians with intellectual disabilities and Autism Spectrum Disorder through its Office of Developmental Programs. Intellectual disabilities are permanent conditions that affect an individual's ability to learn and function unassisted in daily life. Eligibility for intellectual disability treatment services requires a diagnosis that a person's general intelligence and ability to function in daily life are significantly below average.

Autism Spectrum Disorder (ASD) is a developmental disability that can cause social, communication, and behavioral challenges for affected individuals. In many instances, ASD coexists with intellectual disabilities, physical disabilities, or mental health challenges.

Services to individuals with intellectual disabilities or ASD range from 24-hour institutional care to support services for individuals living within their communities. The majority of spending on these programs pay for services for Medicaid recipients, for which the state receives federal Medicaid matching funds.

Pennsylvania's Mental Health and Intellectual Disability Act of 1966 established responsibilities for state and county government, identified mandated services, defined eligibility, and created procedures for commitment to state facilities. At that time, all services were provided through state institution. However, the vast majority of individuals receiving services now do so in community-based settings.

Act 1A of 2019 (amounts in thousands)	State Funds	Federal Funds	Other Funds	TOTAL FUNDS
State Centers	\$115,646	\$166,564	\$25,840	\$308,050
Community Base Program	\$149,653	\$66,489	\$0	\$216,142
Intermediate Care Facilities	\$148,148	\$183,099	\$18,519	\$349,766
Community Waiver Program	\$1,728,641	\$1,773,989	\$0	\$3,502,630
Lansdowne Residential Services	\$340	\$0	\$0	\$340
Autism Intervention and Services	\$30,925	\$33,839	\$0	\$64,764
TOTAL	\$2,173,353	\$2,223,980	\$44,359	\$4,441,692

Institutional Care

Some individuals with intellectual disabilities – particularly those who may have coexisting mental or physical disabilities that make it difficult to deliver appropriate care in a community-based setting – require 24-hour residential care and monitoring. For these individuals, Pennsylvania provides care through state-operated centers or privately run facilities. Public and private facilities are both required to meet federal Medicaid standards, allowing Pennsylvania to access federal matching funds for the cost of care.

Since 2004/05, an assessment of 6 percent of operating revenue has been in place for public and private providers to reduce the state's cost for delivering these services. Act 19 of 2019 extended this assessment, which had been set to expire June 30, 2019, and will now expire June 30, 2024, unless extended by the General Assembly.

State Centers

Pennsylvania operates a system of four state centers for individuals with intellectual disabilities that provide 24-hour residential services. Over time, however, the choices of individuals and their families and best practices have turned to serving more people in smaller, less institutional settings or in their communities. As a result, the capacity utilization at Pennsylvania's state centers has precipitously fallen.

With utilization falling but operating and maintenance costs largely fixed, the per capita cost for serving individuals at the state centers has dramatically risen. In 2019/20, the commonwealth will spend approximately \$419,000 for each resident at a state center.



State Centers	July 2009			July 2019		
	Population	Capacity	Filled Capacity	Population	Capacity	Filled Capacity
Ebensburg	286	402	71.1%	196	402	48.8%
Hamburg	126	237	53.2%	0	0	0.0%
Polk	313	521	60.1%	195	521	37.4%
Selinsgrove	335	579	57.9%	210	564	37.2%
White Haven	169	275	61.5%	115	275	41.8%

In August 2018, the Hamburg Center became the most recent facility to permanently close. A year later, Gov. Wolf announced that two of the four remaining facilities – the Polk State Center in Venango County and the White Haven State Center in Luzerne County – would close. Upon the closure of those facilities, the commonwealth’s remaining two state centers will operate in Cambria and Snyder counties.

Intermediate Care Facilities

In addition to the state centers, Pennsylvania contracts with private intermediate care facilities for the intellectually disabled (ICF/IDs) who require residential care. There are 166 certified facilities throughout the commonwealth and they vary in size. The majority (144 facilities) serve four to eight individuals because department policy encourages smaller facilities, but the largest serves 167 people. Approximately 2,000 individuals receive services in these facilities.

In furtherance of its goal of serving individuals in the least restrictive and most community-integrated settings that meet their needs, DHS has shifted more resources towards its community waiver program. The resulting “bed conversions” cause funding under the ICF/ID appropriation to fall and funding for the community waiver to rise as more intermediate care facilities shift to community-based services.

The Olmstead Supreme Court Decision and the Benjamin Settlement Agreement

In 1999, the U.S. Supreme Court’s landmark decision in Olmstead v L.C. found that the unjustified institutionalization of people with disabilities is a form of discrimination under the Americans with Disabilities Act. The Olmstead ruling confirmed that states must ensure Medicaid-eligible people do not experience discrimination by being institutionalized when they could be served in a more integrated, community-based setting.

The court said states must provide community-based services when:

- a) The state’s treatment professionals reasonably determine community placement is appropriate;*
- b) The person does not oppose such placement; and,*
- c) The state has the available resources to provide the placement.*

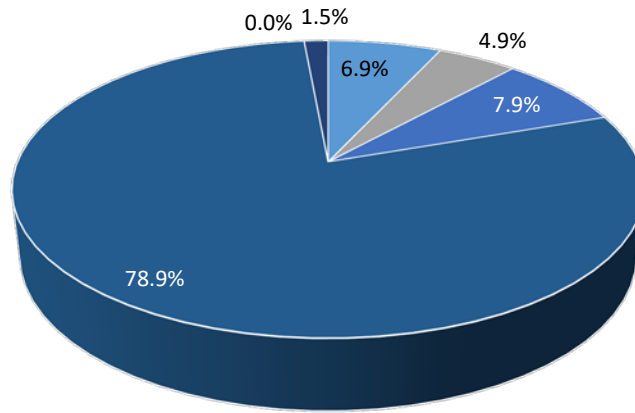
Additionally, the court indicated that each state should develop an Olmstead plan to demonstrate their efforts to comply with its ruling.

The Olmstead decision applies to people currently in institutions and those who are risk of institutionalization. As a result, advocates can use the Olmstead decision to argue not only that people in institutions should receive services in the community, but also that cuts in community services that would force an individual into an institution violate the ADA.

In September 2014, a settlement reached between DHS and the Disability Rights Network of Pennsylvania (the Benjamin Settlement Agreement) required the department to enable hundreds of residents to remain in their current state facility or transition to community-based care based on the individual’s choice. This settlement, approved by the U.S. District Court, serves as Pennsylvania’s Olmstead plan.



2019/20 Intellectual Disability and Autism Budget



- State Centers
- Intermediate Care Facilities
- Lansdowne Residential Services
- Community Base Program
- Community Waiver Program
- Autism Intervention and Services

Community Programs

When possible, services to individuals with intellectual disabilities are provided in a community rather than institutional settings. In Pennsylvania, these services are administered through county mental health or intellectual disability (MH/ID) offices; there are 48 county or multi-county MH/ID offices throughout the commonwealth, and they are responsible for eligibility determinations and support coordination. Community-based services include residential and non-residential programs, depending on the needs of the individual.

- Residential options include small group homes, family settings, or support for individuals living in their own homes or apartments.
- Non-residential programs include day services, adult day care, and family support, as well as employment, training, socialization, and recreational activities.

There are two separate appropriations that fund community-based services: the ID community base and ID community waiver programs.

Community Base Program

The community base appropriation funds services for individuals of all ages who are ineligible for Pennsylvania's community waiver programs or those who are eligible for waiver programs but are not yet enrolled due to a lack of funding for new waiver spots. Approximately 24,000 individuals receive services through the community base program.

Community base program services are delivered by counties and include a menu of non-residential services that include support coordination, family aid, family respite care, education training, recreational therapy, recreational/leisure time activities, vocational therapy, dental hygienic services, employment training, and home modifications. Counties are required to contribute a 10 percent match.

The community base appropriation pays for the administrative costs of all community-based programs including the waiver programs. Additionally, it funds the operations of the commonwealth's eight health care quality units (HCQUs), which provide technical assistance to ensure the highest quality of behavioral and physical care for all individuals receiving community-based services.



Act 80 of 2012 established the Human Services Block Grant (HSBG) Program to allow participating counties more flexibility to use funds appropriated under the community base program for other human services expenditures to meet local needs. To date, 38 counties have opted to participate in the HSBG program.

Waiver Programs

The largest share of Pennsylvania's budget for intellectual disability services – 78.9 percent of total spending – is directed to the community waiver appropriation. The state's waiver programs serve Medicaid eligible individuals who require the level of care provided in an institution, which leads to a high per recipient cost and significant total budget. Medicaid waiver programs are subject to approval from the federal Centers for Medicare and Medicaid Services (CMS) since they must comply with certain federal requirements regarding cost effectiveness and the welfare of the participant. Waiver programs must be approved no less frequently than every five years.

This appropriation supports three different Medicaid waiver programs: consolidated, person/family directed support, and community living. These waiver programs support a wide range of services, including in-home and community support, transportation, accessibility adaptations, assistive technology, specialized therapy, shift nursing, education support, supported employment, and behavioral support.

Consolidated Waiver

The consolidated waiver delivers comprehensive residential or non-residential services to individuals requiring high levels of support. The average cost per consolidated waiver enrollee is \$132,000. Approximately 17,600 individuals are enrolled in the consolidated waiver.

Person/Family Directed Support Waiver

The person/family directed support (P/FDS) waiver targets individuals who live in their own homes or with family. Approximately 13,000 individuals are enrolled in the P/FDS waiver. Services under this waiver are capped at \$33,000 per person per year, though the average is around \$20,000 per enrollee per year.

Community Living Waiver

The community living waiver is the smallest and newest of the three community waiver programs, having been established in January 2018. It is targeted to individuals on the emergency or critical waiting lists who have aging caregivers but who would like to remain in their homes. The community living waiver serves just 1,000 individuals. Non-residential services under the community living waiver are capped at \$70,000 per person per year.

Because funding falls short of demand for waiver programs, there is a waiting list of eligible individuals in need of services. Act 1A of 2019 included \$30.4 million in funding – \$15 million of which came from state funds – to remove 865 individuals from the waiting list for waiver services. Those funds were allocated to open 100 spots in the consolidated waiver and 765 spots in the community living waiver.

Autism Intervention and Services

Autism Spectrum Disorder (ASD) is a developmental disability that may cause significant social, communication, and behavioral challenges. The Pennsylvania Autism Census indicates there are more than 55,000 individuals around the commonwealth with ASD. Pennsylvania has become a leader in policies and services directed to individuals with ASD.

Many adults with Autism Spectrum Disorder receive services through the community waiver program. In 2018/19, a new initiative funded immediate services for individuals graduating from special education programs to ensure that there was no gap between when they graduated and received home and community-based services. Pennsylvania has developed two specific programs for adults with ASD:

- The Adult Autism Waiver (AAW) is a home- and community-based services program that serves 718 individuals throughout the commonwealth.



- The Adult Community Autism Program (ACAP) utilizes a managed care approach rather than a fee-for-service model and it serves 200 individuals in Lancaster, Cumberland, Dauphin, and Chester counties.

Waiting List

Due to limited funding, there are fewer waiver spots than eligible enrollees. As a result, there is a waiting list for the commonwealth's waiver programs for individuals with intellectual disabilities. Because counties are responsible for making eligibility determinations and administering the waiver programs, the waiting list is divided between counties since spots are allocated on a county basis. Counties use the Prioritization of Urgency of Need for Services (PUNS) system to determine the urgency of need for all individuals.

There are three categories of need on the waiting list, which combined held 13,015 individuals as of May 2019:

- *There are 5,331 individuals in immediate need of services on the **emergency waiting list**.*
- *There are 4,690 individuals who need services within two years on the **critical waiting list**.*
- *There are 2,994 individuals who will need services within five years on the **planning waiting list**.*

Further information on the waiting list can be found at <https://pawaitinglistcampaign.org/>.

Finally, the commonwealth supports a series of programs through its Autism Services, Education, Resources, and Training (ASERT) collaboratives, which are designed to:

- Improve access to services for individuals with ASD,
- Train professionals in best practices,
- Provide information and support to families, and,
- Facilitate program development.

