Primer
House Appropriations Committee (D)
JOE MARKOSEK, DEMOCRATIC CHAIRMAN
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Department of Human Services Intellectual Disabilities

The Department of Human Services supervises and funds Pennsylvania's system of programs and services for individuals with intellectual disabilities. An intellectual disability, often called ID, is a permanent condition that affects an individual's ability to learn and function in daily life. Eligibility for intellectual disability services requires a diagnosis that a person's general intelligence and ability to function in daily life (such as self-care and communicating) are significantly below average.

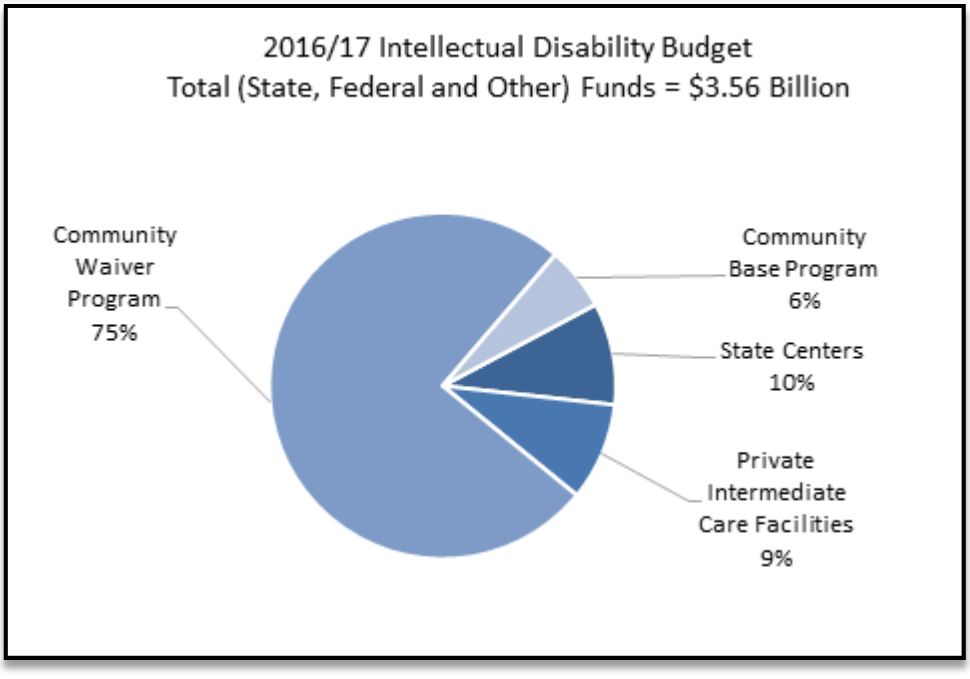
Pennsylvania's ID system includes institutional care and community services. Institutional care is provided by DHS-operated state centers and private intermediate care facilities under contract with the department. Counties administer community services. DHS's Office of Developmental Programs sets policy and guidelines for counties to administer community ID programs, which include two waiver programs for Medicaid recipients and the base program for all other individuals not in a waiver.

The 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.

In 1966, all intellectual disability services were provided in state institutions, which cared for more than 13,000 individuals. Pennsylvania's ID system has since evolved from an institutional system into one that is predominantly community-based. During 2016/17, approximately 3,200 individuals received institutional care while 52,000 individuals received services in the community.

Budget Trends

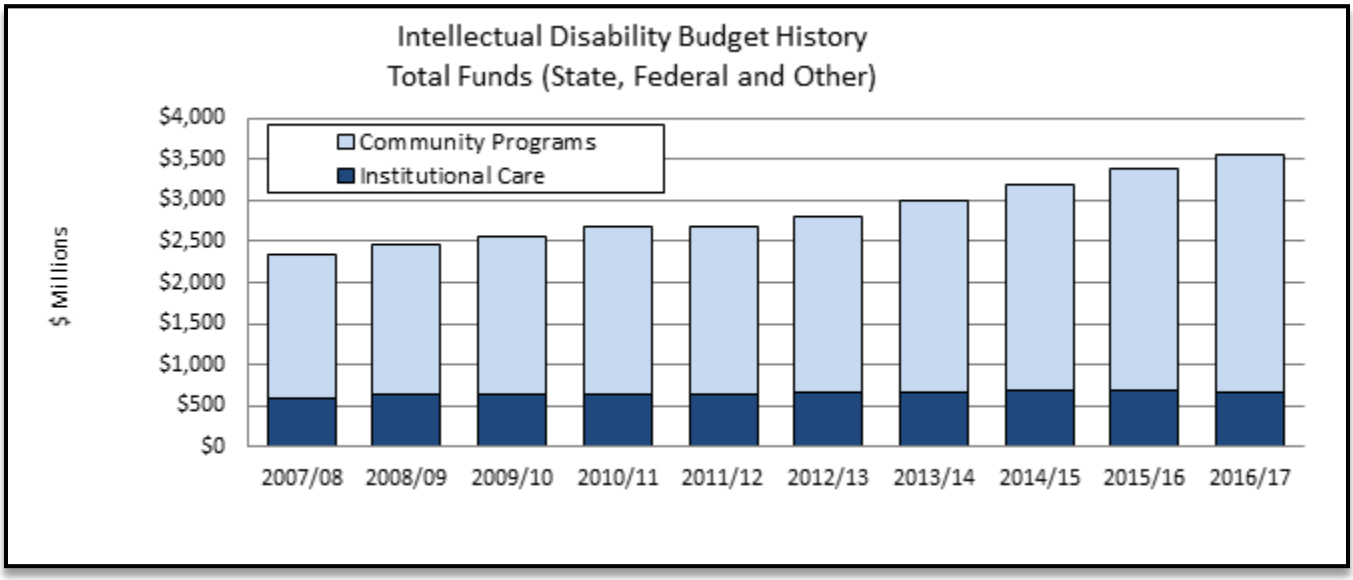
Most of the ID budget is used to pay for services provided to Medicaid recipients, including all people participating in a community waiver program and virtually all individuals receiving institutional care. Medicaid expenditures for the state centers, private intermediate care facilities, and community waiver programs accounted for 94 percent (or $3.3 billion) of total spending in the commonwealth's 2016/16 ID budget.



Federal Medicaid funds constitute more than half of Pennsylvania's intellectual disability budget. The federal government reimburses states for the cost of Medicaid services provided to Medicaid recipients based on the federal medical assistance percentage, or FMAP, for that state. Pennsylvania's federal medical assistance percentage has averaged roughly 52 percent in recent years.

The graph below shows ID funding trends from 2007/08 through 2016/17. Total funding has increased nearly $1.2 billion during this period, of which more than $1.1 billion was for community programs. During the same period, spending for community programs increased 66 percent from $1.75 billion to nearly $2.9 billion, while spending for individuals in institutional care increased 12 percent from $591 million to $665 million.

Growth in community programs reflects the expansion of Medicaid waiver programs over the past decade so that more individuals may receive services in their homes and communities instead of an institution.



Institutional Care

People receiving institutional care have a wide range of disabilities and needs. Most have a severe or profound level of intellectual disability. Many have a co-existing mental health diagnosis or seizure disorder, and many have a visual or hearing impairment.

DHS provides institutional care through state-operated centers and private intermediate care facilities. Both types of institutions provide 24-hour residential care and specialized health and habilitation services.

Each state center and private intermediate care facility must meet federal Medicaid standards related to program services, physical environment, and client health and safety. Because the state centers and private facilities meet federal Medicaid certification requirements, the federal government provides Medicaid matching funds for the cost of institutional care provided to Medicaid recipients.

Institutional care is funded through two separate appropriations in the department's budget: **ID State Centers** and **ID Intermediate Care Facilities.** The primary revenue sources are state General Funds and federal Medicaid funds.

Beginning in 2004/05, Pennsylvania instituted a provider assessment (i.e., tax) to generate additional revenue to support the cost of institutional care. The assessment reduces the need to spend state General Fund dollars while drawing down federal matching funds. Currently, each state center and private intermediate care facility pays the department a 6 percent assessment on its net operating revenue. The assessment will expire after June 30, 2019, unless extended by the General Assembly.

State Centers

DHS currently operates five regional state centers: Ebensburg, Cambria County; Hamburg, Berks County; Polk, Venango County; Selinsgrove, Snyder County; and White Haven, Luzerne County.

The state centers have been operating at half their capacity, according to the July 2016 census that counted 905 individuals and a projected capacity of 1,795.

The table below compares the population and staffing census for each of the state centers in 2014 and 2016. During this two-year period, the total number of residents declined 9 percent while staffing levels declined 4.5 percent. DHS expects the state center population to drop below 700 residents by June 30, 2018.

State Center Population and Staffing Census

State ID	Population			Staffing		
Center	July 2014	July 2016	% Change	July 2014	July 2016	% Change
Ebensburg	246	230	-6.5%	767	753	-1.9%
Hamburg *	100	84	-16.0%	395	362	-8.2%
Polk	257	234	-8.9%	840	803	-4.4%
Selinsgrove	257	233	-9.3%	858	812	-5.3%
White Haven	135	124	-8.1%	491	469	-4.6%
TOTAL	**995**	**905**	**-9.0%**	**3,350**	**3,198**	**-4.5%**

** On Jan. 11, 2017, the department announced it will close Hamburg State Center in the next 18 to 24 months. The last center to close was Altoona State Center in 2006.*

The reduction in state center residents reflects the movement of people from the centers to the community waiver program in compliance with what is known as the *Benjamin Settlement Agreement* between DHS and the Disability Rights Network of Pennsylvania. The settlement, approved by the U.S. District Court in September 2014, requires the department to enable hundreds of residents to remain in their current state facility or transition into community-based care, according to their individual choice. It also provides for placing 230 state center residents in the community by June 30, 2018.

The Benjamin Settlement serves as the department's Olmstead plan for individuals with an intellectual disability (see blue box on page 4 regarding the Olmstead Supreme Court Decision).

The appropriation for ID state centers funds the staff, operating expenses, and fixed assets (i.e., maintenance equipment and office equipment) needed by the department to effectively run the centers. Annual funding is primarily driven by personnel costs, which accounts for 80 percent of total expenditures because the staffing levels for each center must meet minimum staff-to-client ratios required to maintain federal certification and avoid the loss of federal Medicaid funding.

The 2016/17 budget included $340 million in total funding for the state centers, with the cost-per-resident averaging approximately $386,000.

Because state centers are operating at less than half their capacity, per capita costs are higher. Until a center is closed, the department must continue to pay for maintenance and repairs of the facility and maintain appropriate staffing ratios.

The Olmstead Supreme Court Decision

In July 1999, the U.S. Supreme Court issued a landmark decision in *Olmstead v L.C.*, which 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 that Medicaid-eligible people do not experience discrimination by being institutionalized when they could be served in a more integrated (community) setting.

The court held that states must provide community-based services when (a) the state's treatment professionals reasonably determine that 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 its efforts to comply with the ruling.

The Olmstead decision applies to people currently in institutions and those who are at 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.

Private Intermediate Care Facilities

Private intermediate care facilities for individuals with intellectual disabilities, or ICFs/ID, vary in size from large facilities on campus-like settings to small facilities in a community. DHS contracts with 176 private intermediate care facilities; 156 of these serve 4 to 8 people and 20 facilities serve more than 8 people. The largest facility serves 184 people.

The "ID Intermediate Care Facilities" appropriation funds the per diem rates paid by DHS to these contracted providers. In 2016/17, the average cost for an individual in a private facility was roughly $174,000.

To be more efficient with its funding, DHS encourages the private intermediate care facilities for individuals with intellectual disabilities providers to convert to the waiver program in the community system. These conversions shift funding from ICF/ID to the community waiver program, which gives the state flexibility in using federal Medicaid funds to meet individuals' needs and preferences.

Community Programs

Community intellectual disabilities services are administered through county mental health/intellectual disabilities, or MH/ID, offices. Pennsylvania has 48 single- and multi-county MH/ID offices.

The county MH/ID office verifies a person's eligibility for services and assigns a supports coordinator to help approved individuals plan, choose, locate, coordinate and monitor their assistance.

Community services include residential and non-residential programs.

- Residential programs help individuals become independent and encourage active participation in the community. Residential options include licensed group homes for three or four people; supports to individuals renting an apartment or owning their own home; and family living settings, in which one or two people receive services in the licensed family home of an unrelated adult.
- Non-residential programs provide services to individuals and their families. Day services help individuals develop their personal and vocational skills. Services include adaptive equipment, employment and training programs, and socialization and recreation activities. Family support services help families who care for a family member with intellectual disabilities, and those services include respite and adult day care.

Community services are funded through two separate appropriations in the DHS budget: "ID Community Waiver Programs" and "ID Community Base Program." The waiver programs provide home and community-based services to individuals who are eligible for Medicaid. The base program serves individuals of all ages who are not eligible for the waiver program, as well as those Medicaid-eligible individuals who are not yet enrolled in the waiver.

Of the 52,000 individuals with ID who received community services in 2016/17, about 32,000 received services through a Medicaid waiver program and 20,000 received base services through counties. Waiver programs account for a large part of all community expenditures and consume the lion's share of funds appropriated for community programs. For 2016/17, expenditures for community programs totaled nearly $2.9 billion, of which nearly $2.7 billion covered waiver program expenditures and $211 million were expenditures for the base program.

Waiver Programs

Pennsylvania operates two home- and community-based services waiver programs that serve people with different types and levels of need: the "Consolidated Waiver" and the "Person/Family Directed Support Waiver." Both programs are available to individuals who are at least 3 years old and meet financial requirements for Medicaid. Additionally, they must be diagnosed as needing the level of care provided in an intermediate care facility for persons with intellectual disabilities.

The **Consolidated Waiver** provides residential and non-residential services for individuals who require high levels of support and monitoring. Most participants receive residential services, often in small group homes. For 2016/17, an estimated 18,150 individuals received Consolidated Waiver services at an average cost of $132,000 per person.

The **Person/Family Directed Support Waiver** serves individuals who live in their own homes or with family members. The waiver provides non-residential services and caps individual expenditures at $33,000 per year. For 2016/17, an estimated 13,650 individuals received Person/Family Directed Support Waiver services at an average cost of $20,200 per person.

Non-residential services available under these waiver programs include: specialized therapy services (i.e., physical, speech, hearing, and behavioral), home and community habilitation, education support services, supported employment services, assistive technology, home accessibility adaptations (i.e., ramps, widening of doorways, and bathroom modifications), homemaker/chore services, nursing services, respite, and transportation.

Medicaid Home and Community-Based Service Waivers

Home and community-based service waiver programs are also known as "1915(c) waivers" after the section in the Social Security Act that authorizes federal Medicaid matching funds for home and community based services for individuals at risk of institutionalization. "Waiver" comes from the fact that the federal government waives or sets aside its Medicaid rules (that tend to favor institutional care) so states can receive federal Medicaid matching funds for expenditures that, normally, would not qualify for federal participation.

Section 1915(c) of the Social Security Act gives states the flexibility to design programs with a unique set of benefits targeting particular groups. It also allows states to limit the amount of services and spending for each waiver participant. Also, states may cap the number of people enrolled in a waiver program by creating "waiver slots."

States use service/spending limitations and enrollment caps as tools to contain the cost of waiver programs. The ability to set enrollment caps is a powerful tool that differentiates wavier programs from the open-ended entitlement in the traditional Medicaid program which obligates states to serve everyone who qualifies. By opting to create waiver slots, states protect themselves financially from growing demand for waiver services.

The federal Centers for Medicare and Medicaid Services (CMS) must approve each waiver program. Initial approval is for three years and waivers can be renewed thereafter for five years at a time. For each waiver program it wants to operate, a state must submit to CMS an application that describes the program, including the target population to be served and the home and community-based services furnished through the waiver. To obtain approval, the state must ensure that the waiver services are cost effective compared to the cost of institutional care and demonstrate that it has safeguards to protect the health and welfare of persons served in the waiver program.

States must specify in their application the maximum number of participants to be served in each year that the waiver is in effect. Once approved by CMS, a state is held to the number of estimated individuals in its application. However, states have the flexibility to modify the number of participants specified for any year by submitting a waiver amendment to CMS for approval. Consistent with the maximum number of specified participants, states have the option to create waiver slots, limiting the number of persons served at any point during the year.

The state is permitted to offer various services to waiver participants provided that these services are specified in an individualized, written plan of care and are necessary to keep a person from being institutionalized. An Individualized Service Plan must be developed for each waiver participant, addressing their preferences, goals and needs. The plan describes the waiver services furnished to the participant as well as the justification for the services and the type of provider for each service.

Waiver services are an entitlement for participants. Consequently, DHS must allocate sufficient funds to fully serve waiver participants in order to comply with federal Medicaid requirements and avoid the loss of matching federal Medicaid funds. Pennsylvania receives federal Medicaid matching funds for waiver services based on its federal medical assistance percentage. While Medicaid reimburses states for room and board (i.e., food) in a state facility or private intermediate care facility, federal regulations prohibit Medicaid reimbursement for room and board under a home and community-based waiver; consequently, these costs in the Consolidated Waiver are paid entirely with state funds.

Individuals who are eligible for the waiver programs receive services, provided there is sufficient funding and capacity. Otherwise, they are placed on a county waiting list. Counties use the Prioritization of Urgency of Need for Services (PUNS) process to collect information on individuals who are waiting for services, including the types of services they need and the urgency of their need. Information on the PUNS form is updated at least annually for each individual, to reflect changing needs.

May 2017 PUNS data indicated 13,513 Pennsylvanians were on county waiting lists. This included:

- 4,905 individuals on the **Emergency Waiting List** who are in need of services immediately. For example, there is a death in the family and no other family is available to provide support.
- 5,321 individuals on the **Critical Waiting List** who will be in need of services within two years. For example, a person has an aging or ill caregiver who soon will be unable to provide support.
- 3,287 individuals on the **Planning Waiting List** who will be in need of services within the next five years. For example, a person would like to move to another place or needs increased supports.

Initiatives to reduce the waiting list have been included in recent budgets, as funding permits. Recent initiatives often focused on serving adult children of aging parents (or other family caregivers) and graduates from special education programs. The first year costs for these initiatives are relatively low because individuals are removed from the list on a monthly basis and provided less than a full year of services. However, costs in year two and thereafter increase dramatically when the state must pay for a full twelve months of services for each individual and make additional investments to account for individuals' changing needs.

Base Program

The base program provides services to individuals of all ages who are not eligible for the waiver program (i.e., they do not require the level of care provided in an institution) and to those Medicaid eligible individuals who are not yet enrolled in the waiver program. Base program services include: recreational therapy and recreation/leisure time activities; employment training; home modification; family aide; family education training and supports coordination to assist individuals in accessing services.

The base program also covers the administrative costs associated with the community programs (both waiver

and non-waiver), including funding for the local independent monitoring teams and the Health Care Quality Units that serve the counties. Local independent monitoring teams assist the counties in improving the quality of community services while the eight Regional Health Care Quality Units assist with improving the physical and behavioral health of individuals receiving community services.

The base program is a relatively small part of the overall intellectual disabilities budget. Ii is funded primarily with state and federal funds, with counties required to contribute a 10 percent county match for the cost of non -residential services.

- State General Funds account for approximately 70 percent of funds allocated to counties.
- Federal Medicaid funds account for approximately 25 percent of county allocations.
- Federal Social Services Block Grant funds account for 5 percent of county allocations.

Beginning in 2012/13, most of the funds allocated to counties for community base programs are eligible for inclusion in the Human Services Block Grant Program established by Act 80 of 2012. Excluded from block granting are those funds distributed to counties for support services provided to Medicaid eligible persons not yet enrolled in the waiver program.

Counties that participate in the block grant program have flexibility to spend block granted funds for human services other than those that are supported under the categorical appropriation. That is, a county could (subject to the requirements and restrictions established in Act 80) use a portion of its allocation for the community base program to support the following human services: community mental health programs, child welfare services, behavioral health services, homeless assistance, and drug and alcohol treatment and prevention services.