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Department of Human Services' Implementation of the *Olmstead* Decision As It Pertains to State Centers

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Report Summary and Recommendations

House Resolution 2014-903 directs the Legislative Budget and Finance Committee to conduct a comprehensive review of the Department of Public Welfare (now Department of Human Services), Office of Developmental Programs' implementation of the 1999 ruling by the U.S. Supreme Court in *Olmstead v. L.C.*, relating to the Commonwealth's five centers for people with intellectual disabilities (ID) and the provision of home-based and community-based services. The resolution also calls for a report on the economic impact of the closure of the state centers, the potential for economic development of the five properties, opportunities for employees in the post-closure environment, and the potential to reinvest post-closure financial savings in community-based supports for people on the waiting list for intellectual disabilities services. See Appendix A for a copy of House Resolution 2014-903.

The *Olmstead* Decision Held That Individuals With Disabilities Have a Right to Receive Care in the Most Integrated Setting Appropriate

In its 1999 decision, the U.S. Supreme Court held that Title II of the Americans with Disabilities Act (ADA) requires public entities to provide community-based services to persons with disabilities¹ when:

- such services are appropriate;
- the affected persons do not oppose community-based treatment; and
- community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity.

To comply with the ADA's integration mandate, public entities must reasonably modify their policies, procedures, or practices when necessary to avoid discrimination. The obligation to make reasonable modifications may be excused only where the public entity demonstrates that the requested modifications would fundamentally alter its service system.

An *Olmstead* Plan is a public entity's plan for implementing its obligation to provide individuals with disabilities opportunities to live, work, and be served in integrated settings. The Plan is to have specific and reasonable time frames and measurable goals for which the public entity may be held accountable, and there must be funding to support the plan, which may come from reallocating existing service dollars. Although an *Olmstead* Plan is not required, the "fundamental

¹ Although the decision is applicable to all disabilities, the scope of our report is limited to individuals with intellectual disabilities.

alteration” defense is not available to a state without such a plan.² Additionally, any significant shift from institutional to community placements could likely benefit from a plan that would clearly state the objectives and detail the actions necessary to meet them.

The *Benjamin* Settlement Agreement Provides a Temporary Plan for Transitioning Residents of State Centers to Community Placements

The *Benjamin* lawsuit involved five people institutionalized in Pennsylvania state centers seeking community placements for themselves and others similarly situated. They alleged that, in violation of §504 of the Rehabilitation Act and Title II of the ADA, Pennsylvania failed to offer community placements to state center residents who did not oppose community placement and for whom such placement was appropriate. The resulting settlement agreement requires the Department to move up to 230 residents of the state centers into community placements through the development of a viable integration plan by the expiration of the agreement in June 2018. It also includes protections for class members who choose to remain in a state ICF/IID. The first quarterly status report, issued in November 2014, showed that 40 class members on the planning list had been discharged to community placements. Most of these community placements, however, occurred prior to the actual signing of the settlement agreement (as allowed by the agreement). The next three status reports showed six additional discharges; however, DHS reports expecting an additional six to 22 discharges by the end of August 2015.

As of May 2015, the Department of Human Services (DHS) Does Not Have a Formal Olmstead Plan (Beyond the *Benjamin* Settlement Agreement) for Individuals With Intellectual Disabilities

Some advocates consider the *Benjamin* agreement to serve as an Olmstead Plan for those covered under the agreement; however, others point out that it does not provide for the ongoing movement of residents into community placements in a structured manner as delineated by the *Olmstead* decision. The Department considers the settlement agreement to be its Olmstead Plan, but does not otherwise have a plan for the continued discharge of state center residents to community placements. In addition, the *Benjamin* Agreement is silent on admissions to the state centers.³ From July 2012 through March 2015, 23 individuals were admitted to state centers. The majority of these admissions were from psychiatric facilities, hospitals, and prisons. As of 2013, 27 states had Olmstead Plans.

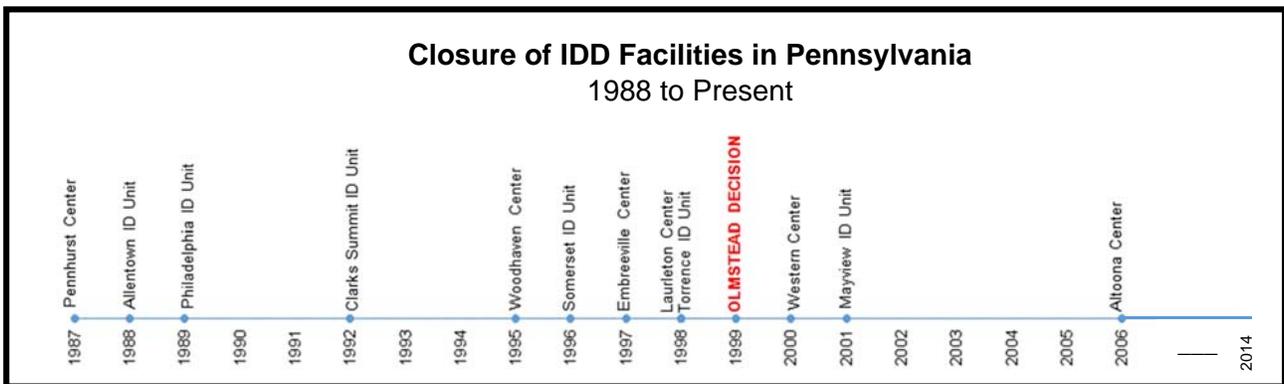
² DHS notes that the United States Court of Appeals for the Third Circuit, which oversees the Federal District Courts of PA, NJ, DE, and the U.S. Virgin Islands, is the only federal court of appeals that explicitly requires that a state have an Olmstead plan in order to raise the fundamental alteration defense. See Disability Advocates, Inc. v. Paterson, 598 F. Supp. 2d 289, 335 (E.D.N.Y. 2009).

³ Admissions to state centers occur only through a court order.

The DHS does have an Olmstead Plan for individuals receiving mental health treatment. This plan requires at least 90 patients to be discharged, with their beds closed to future admissions, each fiscal year with the resultant savings to be provided to the counties to develop and support necessary community services and infrastructure. The plan further calls for the Office of Mental Health and Substance Abuse Services (OMHSAS) to provide necessary supports and assistance to counties to create a variety of residential housing options for persons with mental illness and to review the implementation of the plan annually to assess and determine the need for revisions and updates. Stakeholders, including individuals who have a mental illness, family members, advocates, service providers, county mental health officials, state officials, and others, are to be involved at all levels in the planning and implementation of the plan.

DHS Had Already Begun Transitioning ID Services From Institutional to Community Placements Prior to the *Olmstead* Decision

By the time *Olmstead* was decided, Pennsylvania, like many other states, had increasingly begun to serve those individuals with intellectual disabilities in home and community-based services (HCBS). Prior to *Olmstead*, the state operated 20 ICFs/IID, known as state centers. As shown below, between the mid-1980s and 1999, nine state centers for individuals with intellectual disabilities (or ID units associated with state mental health facilities) were closed. Since the decision, Pennsylvania has closed two state centers and one ID unit, although the closure of the Western Center was initiated prior to the 1999 decision. Pennsylvania currently operates five state centers for individuals with disabilities. See the map on page 52 for the locations of the state centers.



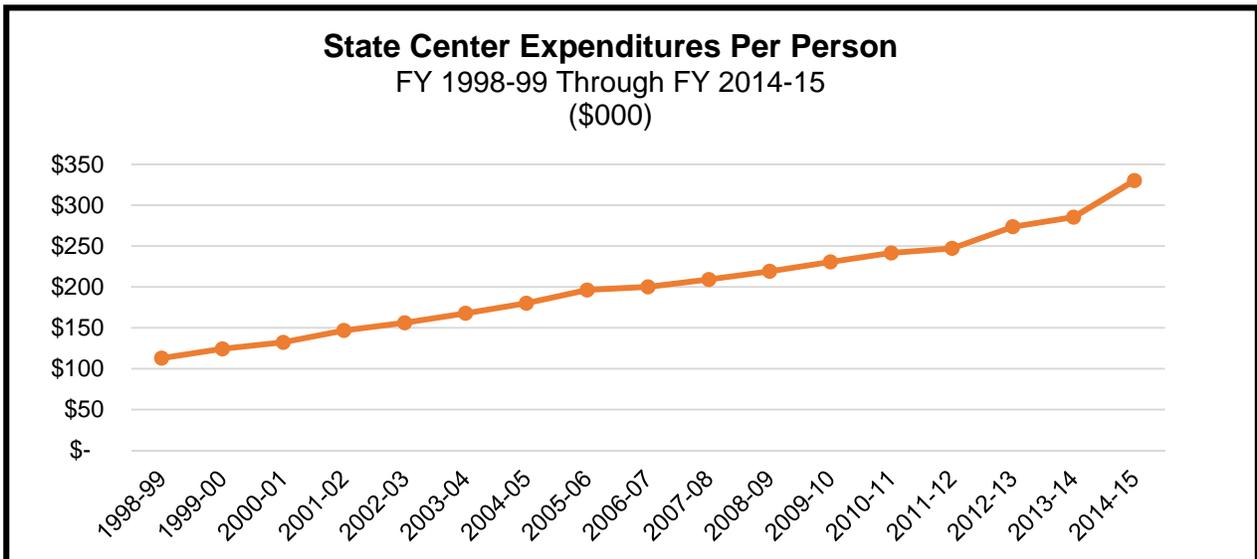
In addition to closing state centers, the Department had plans to address a shift to community services. In 1997, the Department adopted *A Multi-Year Plan for Pennsylvania's Mental Retardation Service System*, which covers a five year period beginning with state FY 1997-98 and ending with FY 2001-02. The plan called for a shift from facility-based programs to services that build on natural supports and provided choices for people with ID in the area of housing, transportation, and

jobs. In addition, the plan included moving a total of 1,500 residents from state centers to community placements over the course of five years. The total number of residents in state facilities actually declined by 1,284 during that period, although we could not determine whether that decline was due solely to resident placement in the community.

In 1999, the Department adopted *A Long-Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*. This plan was created to address the needs of people with intellectual disabilities and their families who were waiting for community services. Neither the *Multi-Year Plan* nor this plan have been updated. To continue to encourage movement from state centers to community placements, however, DHS funds Self Advocates United as One (SAU1) to speak with state center residents and their families about living in the community. Department officials have indicated that the state centers will close at some point, primarily due to the shift from institutional to community placements, but that there is no specific plan for closings at this time.

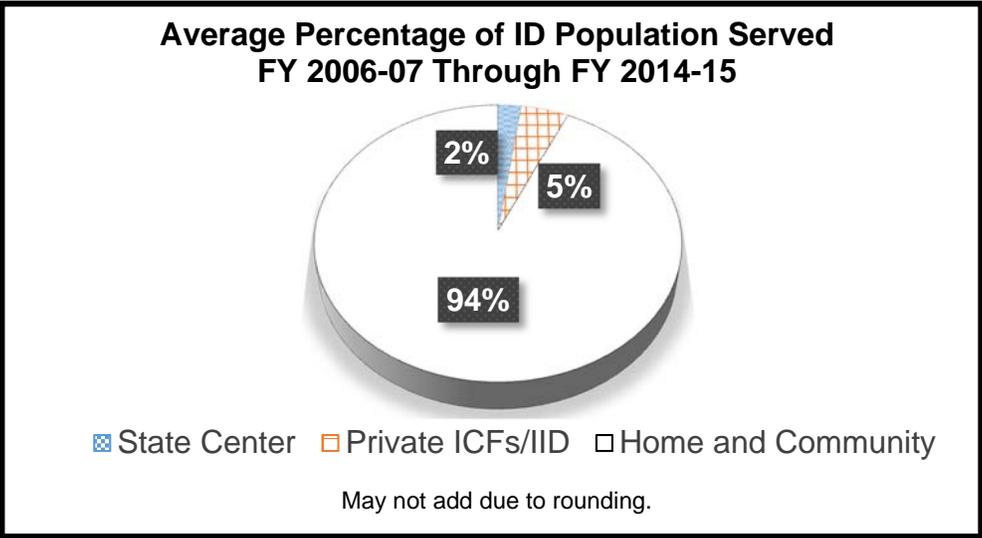
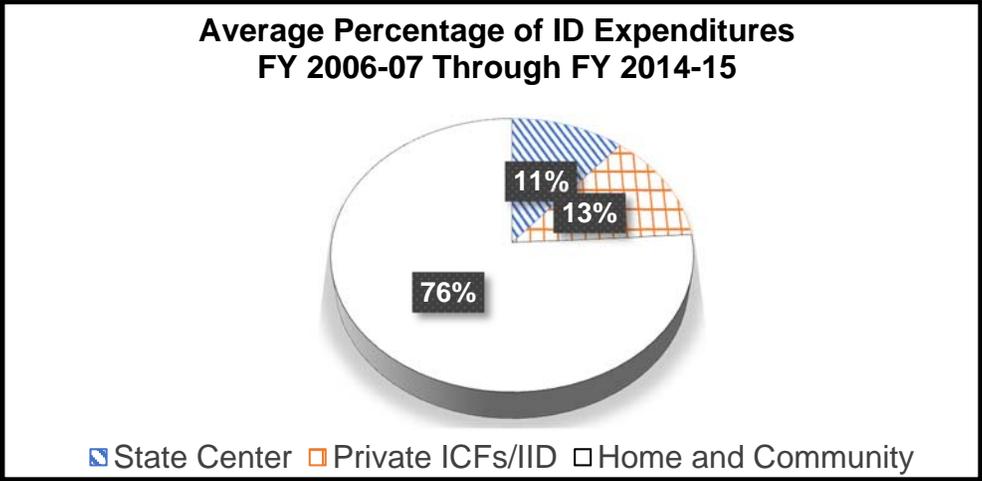
State Centers Comprise 11 Percent of ID Expenditures but Only Serve 2 Percent of the Individuals Receiving ID Services; Almost All of These Individuals, However, Are Severely or Profoundly Disabled

Since the *Olmstead* decision in 1999, overall expenditures for ID in Pennsylvania have increased by 122 percent, from \$1.36 billion to \$3.0 billion. (See below for distribution of these funds and the percentage of population served in each setting.) Expenditures by the state centers increased slightly during this time period; however, the resident population at the state centers declined 63 percent, from 2,533 in 1998 to 948 as of July 2015. The state centers provide services to about 2 percent of the total number of clients receiving ID services in Pennsylvania. State center expenditures per individual are shown below.



Expenditures by private ICFs/IID grew 20 percent from 1999 to the present, while the number of clients served decreased 36 percent, from 3,109 in FY 1998-99 to 1,982 in FY 2014-15. Community-based services showed the largest increase in expenditures, growing by 191 percent since 1999, with waiver expenditures increasing by 51 percent since FY 2007-08. The number of individuals served in HCBS grew by 15 percent since FY 2006-07, and now represent 94 percent of individuals receiving ID services.

In FY 2014-15, expenditures per resident at state centers were \$330,200, at private ICFs/IID were \$145,170, and for individuals receiving Home and Community-Based Services (HCBS) were \$47,000. Funds expended per individual at a state center averaged seven times the funds expended for an individual being served in the community; however, approximately 88 percent of the current residents of state centers are diagnosed as severely or profoundly disabled, compared to 16 percent of individuals similarly diagnosed who are receiving HCBS.



From FY 2006-07 through FY 2014-15, institutional placements served 7 percent of the ID population, but expended one-quarter of the funds. State centers accounted for, on average, 11 percent of total ID expenditures while serving 2 percent of the ID population, and private ICFs/IID accounted for 13 percent of the total expenditures and served, on average, 5 percent of the ID population over this time period. The majority of the expenditures, 76 percent, and the majority of the population served, 94 percent, were by home and community-based services.

Funding and Restrictive Regulations Reportedly Have Slowed Growth in Community Services

Additional growth in community placements, and the services needed to support those placements, is needed to serve both individuals new to the service system, as well as those in institutional placements who are transitioning, or who want to transition, to community placements. Many of the current residents of the state centers have highly complex conditions, and, therefore, will need significant supports to live in the community. It is anticipated that costs for the support services for residents now living in state centers will be higher than the average costs for individuals currently receiving home and community-based services, as most current state center residents have a severe or profound level of disability, over a quarter are 65 years of age or older, and about 90 percent have been residents of a state center for over 16 years.

According to representatives of the intellectual disability service providers, funding issues related to the Chapter 51⁴ regulations, delays in processing PROM-ISE applications, limited funding for start-up costs, restrictive service definitions, and restrictive exceptions processes have slowed the growth in community services in the last four years. These delays and policies are reportedly having the effect of discouraging providers from accepting more involved cases or offering new services. In addition, the service providers report concerns related to the Individual Support Plans (ISP) developed for individuals transitioning from state centers to community placements. Reportedly, the ISPs are based on assessments of the residents in the context of the state center supports, and as a result, call for a level of service that at least some providers believe is not appropriate to address the actual needs of the person leaving the state center.

Due to concerns related to the Chapter 51 regulations, several provider associations negotiated a settlement agreement with the Department to avoid the costs and uncertainty of litigation. As part of this agreement, the Department adjusted the vacancy factor that is applied to residential habilitation payment rates, revised the process for exceptions to the vacancy adjustment, and implemented a retention factor for certain earnings. The settlement agreement was amended in February 2015 to further adjust the exception process and to provide for partial recoupment of

⁴ 55 Pa. Code Ch. 51.

certain payments when the payments are not eligible for federal participation. As part of the initial settlement agreement, ODP's stakeholder workgroup was reconvened to continue the review of the regulations and to make further recommendations for amendments to Chapter 51 to the Department by December 15, 2015. DHS has recently made changes to the PROMISE application process to address provider concerns.

DHS Is in the Process of Evaluating the Current System of HCBS to Ensure Compliance With the Center for Medicare and Medicaid Services' (CMS) Integration Rule

The CMS Final Rule that requires increased integration in providing services will require changes to current community service options. This includes new definitions of community placements that are acceptable to meet the integration standard. For example, group homes located on facility campuses are likely not to be considered to meet the integration standard. In order to comply with the rule, the Department is in the process of assessing its regulations and policies, to identify revisions that may be needed to meet the new standard. Meeting this standard will also require providers to adjust their services to ensure that individuals are served in appropriate settings. Compliance is required by 2019.

The Closure of State Centers May Only Result in Modest Economic Development Activity, but Should Result in Significant Operational Savings Over the Long Term That Could Be Used to Provide Funding for Community Services

The Commonwealth has closed state centers in furtherance of its policy to support community living, whether or not as a result of litigation. As has happened in other states that have closed similar facilities, the facilities have been sold to private concerns, repurposed for state use, or remain unused awaiting sale or other use. The biggest challenges in closing a state center are the transition of residents to other placements, the effect on state center staff, and the disposal of the property given the mostly rural locations of the remaining centers.

In the case of the Western Center in Washington County that closed in 2000, the majority of the residents were transitioned to community placements and the property was sold in 2003 for \$2 million to the Washington County Authority for development. A portion of the property has been developed into a business park with an estimated \$412 million of private investment funds. Not all closed state centers, however, are sold that quickly, and in the interim, must be maintained even though not in use. For example, the Embreeville Center closed in 1997 but was not sold until 2012. In the interim, about half the property was leased to several tenants. None of the economic development agencies we spoke with had plans for the use of

the remaining state center properties, several of which are in the state's more rural areas and therefore may have limited economic development potential.

When the state centers closed, staffs have transferred to other similar positions in other state centers or agencies, retired, or accepted furloughs. Although the private service providers may have positions available, the salaries paid are significantly lower than those in the state centers for similar positions. Approximately 7 percent of state center staff are either 60 years of age or have 30 years of service and, therefore, may be close to retirement.

The resident care and facility maintenance funds saved as the result of a state center closing could be used to support additional services in community placements. We estimate such savings at approximately \$175.4 million annually, once all properties are closed and owned by another party (i.e., DHS has no ongoing maintenance costs).⁵ The OMHSAS Olmstead Plan, for example, states that funding will be redirected to community services as state mental health facilities close. In Maryland, a fund was established to ensure that funds equal to the average cost of serving an individual in a state center follow anyone moving into the community and any funds beyond these be used to provide community-based services to eligible individuals not currently receiving such services. In Pennsylvania, a similar approach was taken when the Pennsylvania Justice Reinvestment Fund was created to provide grants for the delivery of criminal justice services from the savings generated by the Department of Corrections through program efficiencies and reductions to the inmate population.

Recommendations

We recommend the following:

- 1. The General Assembly consider ensuring that monies saved due to the transitioning of residents of state centers to community services, or from the future closure of state centers, be used to provide additional community based services for individuals with intellectual disabilities.** These funds should supplement, and not supplant, ongoing funding for these services, and could be used specifically to reduce the waiting list for services. One approach would be to create a special fund, similar to the Pennsylvania Justice Reinvestment Fund (see page 57), for these funds. Such a fund would provide transparency regarding the use of the funds to the stakeholders and public.
- 2. DHS create an Olmstead Plan for the continued transition to community placements of state center residents who do not object to community placements using the *Benjamin* Settlement Agreement and the MH**

⁵ See page 52 for how we calculated this estimate.

Olmstead Plan as guides. The plan should be adopted on or before the expiration of the *Benjamin Settlement Agreement* in June 2018. This plan should be developed with the input of the ODP Advisory Committee for Mental Health and Intellectual Disabilities, IDD service providers, county IDD staff, and other stakeholders. The plan should address fostering the availability of the supports necessary to ensure successful transitions through the identification of appropriate services and meet the DOJ guidelines regarding time frames and management goals (see page 14).

- 3. DHS conduct a review of the current operation of state centers to identify whether center operations could be consolidated.** This would continue a past unofficial practice of the Department to review these centers when their census falls below 100 residents. At this time, one center has a census of fewer than 100 residents and another has fewer than 150 residents.
- 4. DHS consider, with the input of the ODP Advisory Committee for Mental Health and Intellectual Disabilities, restricting new admissions to designated state centers.** Although this may be difficult for families due to the locations of the state centers, as long as new residents continue to be admitted to all centers, fixed costs and staffing will remain high at all the centers, and closing due primarily to attrition will be less likely.
- 5. DHS should review the revised PROMISE approval process within 6 months to determine whether it has reduced the length of time it takes for an application to be approved.** Since this delay has been cited as causing significant problems for providers in being able to offer services, it is important that the new process is timely.⁶

⁶ The Department reports that since July 2015, ODP has successfully reduced the time needed to qualify and enroll new providers to an average of 18 days.

I. Introduction

House Resolution 2014-903 directs the Legislative Budget and Finance Committee to conduct a comprehensive review of the Department of Public Welfare, Office of Developmental Programs' implementation of the 1999 ruling by the U.S. Supreme Court in *Olmstead v. L.C.*, relating to the five state centers for people with intellectual disabilities and the provision of home-based and community-based services. The resolution specifically calls for a report on the economic impact of the closure of the state centers, the potential for economic development of the five properties, opportunities for employees in the post-closure environment, and the potential to reinvest post-closure financial savings in community-based supports for people on the waiting list for intellectual disabilities services.

Scope and Objectives Statement

1. Report on the Department of Public Welfare, Office of Developmental Programs' implementation of the *Olmstead* decision as it relates to the status of the five state centers for people with intellectual disabilities.
2. Report on the Department of Public Welfare, Office of Developmental Programs' implementation of the *Olmstead* decision as it relates to the provision of home-based and community-based services for people with intellectual disabilities.
3. Identify the economic impact of the closure of the state centers, including the potential for economic development of the five properties, opportunities for employees of the state centers in the post-closure environment, and the potential to reinvest post-closure financial savings in the community-based supports for people on the waiting list for intellectual disabilities services.

Methodology

To determine the Department of Human Services (DHS)¹ Office of Developmental Programs' implementation of the *Olmstead* decision as it related to the status of the five state centers for individuals with intellectual disabilities, we reviewed the history of the state centers beginning with the Pennhurst closure in 1987. We examined the Governor's Budget documents for FYs 1999-00 through 2015-16 to identify funding trends for the remaining state centers as well as the costs to maintain closed state centers. We requested information from DHS regarding staffing at the state centers as well as the number of residents at each state

¹ The Department's name was changed to the Department of Human Services by Act 2014-132, with an effective date of November 23, 2014.

center. For the five state centers currently operating, we reviewed the types of staff positions at each facility, the age of the residents at each facility, the length of time the current residents have been in the facility, and the level of intellectual disability of the residents at each facility. We toured the White Haven State Center and visited with individuals who were, and had been, residents of a state center.

Regarding the implementation of the *Olmstead* decision by the Department as it relates to home and community-based services, we reviewed testimony from a series of hearings the House Resolution 187 Task force held in 1997 concerning DHS' multi-year plan to redesign intellectual disability services in Pennsylvania, including closing state facilities. We also reviewed the transcripts from the House Human Services Committee hearing that was held in March 2014 regarding the effect of *Olmstead*. We contacted many of the stakeholders who were involved in the hearings, as well as other interested parties and advocates to solicit their input regarding our study.

To provide trend information regarding the number of people served in community placements compared to state centers, as well as the cost of providing the different services, we analyzed the Governor's Budget documents for FYs 1999-00 through 2015-16.

We reviewed court cases and spoke with agency staff regarding the implementation of settlement agreements. We additionally reviewed statutes, regulations, and policy statements related to individuals with intellectual disabilities. We solicited input from service providers regarding the impact of regulations on their ability to provide community-based services.

We reviewed publications, including those from the Supporting Individuals and Families Systems Project (FISP) from the University of Minnesota, the *State Plan Update 2012-2016* by the Pennsylvania Developmental Disabilities Council, *Deinstitutionalization: Unfinished Business* by the National Council on Disability (October 23, 2012), the *Pennhurst Longitudinal Study*, U.S. Department of Justice and U.S. Department of Health and Human Services guidance, among others.

To address the economic impact of the closure of state centers, we looked at the impact of past state center and other facility closures in Pennsylvania. Due to issues related to the confidentiality of personnel information, we did not have access to DHS files related to prior state center closures and the placement of state center staff. We contacted local economic development agencies for those areas of the state near the remaining state centers to determine how the centers factor into their long-range planning. We also reviewed the University of Illinois study *Impact of the Closure of DHS Facilities, 2011*, and reviewed closings in other states, using both news reports and a survey of the state agencies directly involved in the closings.

Acknowledgements

We thank the staff of the DHS and ODP for their assistance throughout this project. We also thank the various stakeholders, too many to list individually, who responded to our questions and assisted with our work. We especially thank the Pennsylvania Advocacy and Resources (PAR) Board of Directors and the Rehabilitation and Community Providers Association (RCPA) IDD subcommittee for inviting us to participate in their meetings. In addition, we thank the residents, their families, and staff of the White Haven State Center, and the two individuals we visited in their community placement for their willingness to welcome us into their homes.

Important Note

This report was developed by Legislative Budget and Finance Committee staff. The release of this report should not be construed as indicating that the Committee's members endorse all the report's findings and recommendations.

Any questions or comments regarding the contents of this report should be directed to Philip R. Durgin, Executive Director, Legislative Budget and Finance Committee, P.O. Box 8737, Harrisburg, Pennsylvania 17105-8737.

II. Evolution of Pennsylvania's Services to Individuals With Intellectual Disabilities

The 1999 *Olmstead v. L.C. by Zimring*, 527 U.S. 581 (1999), decision held that compliance with the Americans with Disabilities Act (ADA) required services for the disabled to be provided in an integrated setting appropriate to that person's needs. Specifically, public entities are required to provide community-based services to persons with disabilities when:

- such services are appropriate;
- the affected persons do not oppose community-based treatment; and
- community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity.

See Appendix B for additional information on the *Olmstead* decision and selected applicable laws. The Medicaid Act provides the right to intermediate care facilities for individuals with intellectual disabilities (ICF/IID) placement for individuals needing that level of service, and, for states with state-operated ICFs/IID, like Pennsylvania's state centers, services in the state institutions.

By the time *Olmstead* was decided, Pennsylvania, like many other states, already had begun to increasingly serve those with intellectual disabilities in home and community-based services (HCBS). Providing long term support services in home and community settings was facilitated by the Home and Community-Based 1915(c) Waiver Program. Beginning in 1981, states were required to demonstrate reductions in the number of recipients of, and total expenditures for, institutional Medicaid-funded settings approximately equal to the increases in HCBS participants and expenditures. Those requirements have since been relaxed, and now the test is whether costs in the aggregate for community placement are less than that for institutional placements.

HCBS are services that an individual needs or is likely to need in the home and community. They include licensed day habilitation, therapy services, and assistive technology. Institutional settings include state ICFs/IID and private ICFs/IID. In the years prior to *Olmstead*, the state operated as many as 20 ICFs/IID, known as state centers.

In March 2014, the Pennsylvania House Human Services Committee held a hearing on the impact of the *Olmstead* decision on persons with intellectual disabilities. Many of the participants testified about the benefits of community placements and how Pennsylvania compares to other states in utilizing community placements.

These participants included former residents of state centers who testified about the positive changes in their lives since moving from a state center to living in the community.

In particular, one of the former residents who had been in a state center for 30 years and is now in “life share” in the community testified about working and volunteering in the community. Lifesharing is a community-based approach defined by DHS as “living with and sharing life experiences with supportive persons who form a caring household.”¹ DHS regulations require that shared living be considered first when residential habilitation service is determined to be needed by the ISP team, and, reportedly, costs for these services are less than community-based group homes. In addition to lower costs, lifesharing is an integrated approach to services for individuals with intellectual disabilities.

Other participants, however, spoke about the continued need for the state centers. In particular, one of the participants spoke about how well his daughter has been cared for in a state center, and noted, correctly, that *Olmstead* supports “treatment in the most integrated setting possible for that person, recognizing on a case-by-case basis that that setting may be an institution.”

Pennhurst Closing

A significant closure in the decade before *Olmstead* occurred with the Pennhurst Center, which closed in 1987 as a result of a consent decree. Allegations of abuse led to the first lawsuit of its kind in the United States, a federal class action, *Halderman v. Pennhurst State School & Hospital*, 446 F.Supp. 1295 (E.D. Pa., 1977), which asserted that the developmentally disabled in the care of the state have a constitutional right to appropriate care and education.² The courts later found that conditions at Pennhurst were unsanitary, inhumane, and dangerous, violating the Fourteenth Amendment, and that Pennhurst used cruel and unusual punishment in violation of the Eighth and Fourteenth Amendments, as well as the Pennsylvania Mental Health and Intellectual Disability Act.³ The District Court ruled that certain of the patients’ rights had been violated. Ultimately, however, the U.S. Supreme Court vacated the judgment based on the Eleventh Amendment principle that federal courts cannot order state officials to comply with state laws. The institution was eventually closed pursuant to a consent decree that required community-based services be offered to all of its residents.

¹ Lifesharing through Family Living, (Mental Retardation Bulletin, Commonwealth of Pennsylvania, Department of Public Welfare, Number 00-05-04, August 8, 2005), p. 1.

² The plaintiff in the case, Terry Lee Halderman, had been a resident of Pennhurst, and upon release she filed suit in the federal district court. The suit had started after Terry had visited her parents at home and was found to have unexplained bruises.

³ This act is the former Mental Health and Mental Retardation Act of 1966. Act 2011-105 amended the name of the act.

A longitudinal study of the transfer of the Pennhurst residents to community placements found that their adaptive behavior growth was greater than those who remained at Pennhurst.⁴ Additionally, the study found that the majority of individuals who moved into community placements were happy in those placements, including individuals who had expressed happiness when living at Pennhurst, and wanted to keep living in the community setting. The families of the residents were also interviewed and were found to increase their support of community placements after their family member was transferred into the community.

The study also found, however, that although the cost of serving individuals in the community is generally less on average than those at the institution, most of the differential could be traced to differences in salaries and fringe benefits between the state employees at Pennhurst and the private employees in the community placements. The study concluded that these savings may only be temporary, as over the long run forces may lead to changes in those differentials.

State Center Activities

As shown on Exhibit 1, in addition to Pennhurst, seven other state centers for individuals with intellectual disabilities (or ID units associated with state mental health facilities) closed after 1987 and prior to the *Olmstead* decision. Since the decision, Pennsylvania has closed two state centers and one ID unit, although the closure of the Western Center was initiated prior to the 1999 decision. Table 1 shows that Pennsylvania reduced its state center population by a larger percentage than the national average between 1980 and 2012 but has reduced that population by less than half the national average between 2010 and 2012. See Chapter V for further discussion of these closures.

⁴ Conroy, James W. and Bradley, Valerie J., *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis*, U.S. Department of Health and Human Services (March 1985).

Exhibit 1

Closure of IDD Facilities in Pennsylvania*
1988 to Present



* The following IDD facilities in Pennsylvania closed prior to 1988: Cresson Center (1982), Harrisburg ID Unit (1982), Hollidaysburg ID Center (1976), Marcy Center (1982), Warren ID Unit (1976), and Wernersville ID Unit (1987).

Source: Developed by LB&FC staff using information from DPW, RISP, and various newspaper articles.

Table 1

PA's Average Daily Population of Persons With IDD Living in Large State IDD Facilities and Percentage Changes Between 1980-2012 Compared to National Total*

	1980	1985	1990	1995	2000	2005	2010	2012	% Change	
									1980-2012	2010-2012
PA	7,290	5,980	3,986	3,460	2,127	1,452	1,189	1,123	85%	6%
U.S. Total Reported	131,345	109,614	84,239	63,762	47,872	40,532	31,654	27,665	79	13

*Large state IDD facilities are defined as having 16 or more residents.

Source: University of Minnesota, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through 2012*. Average daily population for the District of Columbia is excluded from the U.S. reported totals.

Pennsylvania currently operates five state centers for individuals with intellectual disabilities that provide long-term services and supports in institutional settings. (See page 52 for a map showing the locations of the state centers.) Department officials have indicated that all the state centers will close at some point, primarily due to the shift from institutional placements to community placements, however, the Department has no specific plan for closing any of the five centers.

In order to assist individuals who reside in state centers and their families understand the alternatives of home and community-based services, DHS funds Self Advocates United as One (SAU1). SAU1 members go into the state centers telling

their stories and answering questions about living in the community. This year, families will be invited to an event at each center before the end of June where SAU1 members will talk about their lives in the community, including challenges they have faced, and answer questions and address concerns family members may have about community services. SAU1 also conducted training in the centers after the *Benjamin* litigation, discussed below, was filed, which included the option for people to live in the community.

DHS Plans for Individuals With Intellectual Disabilities⁵

DHS developed plans for providing services to individuals with intellectual disabilities prior to the *Olmstead* decision. In 1997, the Department adopted *A Multi-Year Plan for Pennsylvania's Mental Retardation Service System*. This plan was developed with the efforts of an advisory committee consisting of over 70 people, including individuals with disabilities, family members, advocates, service providers, legislative staff, and county and state government officials. The plan covers a five-year period beginning with state FY 1997-98 and ending with FY 2001-02.

As shown on Exhibit 2, the plan called for a shift from facility-based programs to services that build on natural supports and provide choices for people with ID in the area of housing, transportation, and jobs. In addition, the plan included moving a total of 1,500 residents at state centers to community placements over the course of five years. The total number of residents in state facilities actually declined by 1,284 during that period, although we could not determine whether that decline was due solely to resident placement in the community.

In 1999, the department adopted *A Long-Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*. This plan was created to address the needs of people with intellectual disabilities and their families who were waiting for community services. It supplemented, not replaced, the *Multi-Year Plan*. Due to the lack of a clear definition of the waiting list, created by counties not employing a uniform procedure to capture waiting list data, the Prioritization of Urgency of Need for Services for Persons with Mental Retardation (PUNS) form was developed and used to collect data from the counties. A survey of counties found that 14,083 persons were on waiting lists for services. Each person on the list was categorized by need and service. See Exhibit 3.

The plan focused on addressing the needs of the persons on the emergency and critical needs list and shadow list for an estimated 4,000 individuals.⁶ This plan recommended expanding service capacity in both the short term to address the

⁵ This section highlights DHS-developed plans for providing services to individuals with disabilities and is not meant to be an exhaustive listing of all such plans and policies.

⁶ Individuals in state centers were excluded from this list since the provision of community opportunities for people in the state centers had its own budget initiative. The shadow list is based on the finding during the initial phase of the study that about half of the persons coming into service were not previously on the waiting list.

needs of persons on the waiting list, and in the long term to ensure that waiting lists do not grow again. Regarding the capacity of the intellectual disability system to meet the needs of the individuals on the waiting list, the plan also factored in the *Multi-Year Plan* initiative to move individuals from the state centers to the community as recommended in that plan. This plan anticipated an overall capacity increase for the intellectual disability system of approximately 11 percent would be required (with a 20 percent growth in the community program). The plan was proposed to be implemented over a two-year period beginning in FY 2000-01. As of January 31, 2015, 14,021 people were on the waiting list, with almost 5,000 in the emergency needs category, 5,800 in the critical needs category, and 3,700 in the planning needs category.

Exhibit 2

Summary of 1997 Multi-Year Plan

Goals:

1. System Reform: To restructure the system to one that is: consumer-driven, values-based, outcome-oriented, and cost-efficient.
2. Resource Realignment: To realign existing resources to meet the needs of those on the waiting list while maintaining necessary supports and services for individuals currently receiving them.

Recommendations:

- Restructure the administration of the program to assure quality, efficiency, and positive individual/family outcomes and satisfaction.
- Shift priorities for resource allocation from facility-based programs to services that build on natural supports.
- Create mechanisms for individuals and families to control resources allocated to meet their need.
- Pursue regulatory reform.
- Unify funding and eliminate categorical within the intellectual disability system.
- Reinvest savings from system reorganization into community services.
- Provide services and supports in the community for 1,500 people who are currently living in Intermediate Care Facilities for People with Intellectual Disabilities (ICFs/IID) over five years.
- At present, more than 3,000 people are receiving state and federal funding for services in private ICFs/IID. Transfer the state and federal funding for 2,100 of these individuals into the community funding system by conversion to the 2176 Medicaid Waiver Program.

Source: *A Multi-Year Plan for Pennsylvania's Mental Retardation Service System*, presented to the Pennsylvania Department of Public Welfare by the Planning Advisory Committee to the Office of Mental Retardation, July 1997.

Summary of the Waiting List Study

Background: In the fall of 1998, the Temple University waiting list study data collection phase began through the statewide implementation of the Prioritization of Urgency of Need for Services for Persons with Mental Retardation (PUNS) form. Each county program was requested to complete a PUNS form for each of the individuals within the county program who was identified on the waiting list. By April 1999, Temple University had collected, edited, entered, and analyzed data from all 45 county programs across Pennsylvania.

Definition for the urgency of need and intensity of services were established for the purpose of the study:

Emergency – person needs services immediately	Case Management – only case management services and nothing else
Critical – person needs services within one year	Low Intensity Service – support or ancillary services (therapies, F.S.S., transportation) in addition to case management services
Planning – person with needs more than one year away	Medium Intensity Service – vocational/day services, possibly in addition to support/ancillary services and case management
	High Intensity Service – residential services, possibly in addition to vocational/day services, ancillary/support services, and case management

Recommendations:

- Expand service capacity in the short and long term.
- Establish an on-going process to review and respond to the waiting list.
- Develop state and county capacity.
- Improve consumer and facility outreach and education.
- Reinvest to improve the quality of services and supports.
- Encourage self-determination by creating efficient policies and procedures to allow individuals and families to control the use of resources without unnecessary restrictions and red tape.
- Prepare for school to adult life transition.
- Provide people living in state operated facilities the opportunity to live in the community as recommended in the Multi-Year Plan.

Source: *A Long-Term Plan to Address The Waiting List for Mental Retardation Services in Pennsylvania, DPW-OMR Planning Advisory Committee, October 1999.*

Both the 1997 *Multi-Year Plan* and the *Waiting List Plan* were influenced by the values underlying the intellectual disability service system as reflected in *Everyday Lives*, a booklet created by the Department's Mental Retardation Planning Advisory Committee with the participation of numerous stakeholder organizations

in 1991. *Everyday Lives* expresses the concept of people having a life like other people in the community. It identified what life was like for individuals in the system, what they would like, and how to move in that direction. Emerging trends identified included the shift in expectations with people wanting to be served in the community, use of generic services, and more variety and choice. In 2001, an updated version of *Everyday Lives* was produced by the Self-Determination Consumer and Family Group to evaluate whether changes as envisioned in the original booklet had occurred.

Everyday Lives, Making It Happen, reported significant growth in the system, with an increase in individuals living in small community settings and living at home, and a decrease in those living in public institutions. The report concluded that although progress had occurred, challenges remained and stated:

Our vision for the future is a time when everyone has an everyday life. There is still much work that needs to be done before this will become a reality for all people. The system needs to move to an individual basis from a collective program model. Self-determination needs to be a way of life for everyone.

No additional updates have been undertaken.⁷

In 2013, the Office of Developmental Programs began work on a long-range development plan for the Pennsylvania services system. This process is known as “Futures Planning.” As part of this planning process, person-centered long-range goals were established, which led to the development of eight near-term objectives and action plans relating to services for people with disabilities. In general, Futures Planning includes these eight objectives: person-centered budgeting; people supported by appropriately qualified professionals; newer and better ways to provide services at reduced costs; flexible service models that are able to meet people’s changing needs; quality measures in order to improve the quality of life for people supported by ODP; a pilot program for managed care of developmental disability services; and making Pennsylvania an “employment first” state, with employment as the priority for people with disabilities.⁸

During 2014, ODP staff conducted research internal to Pennsylvania and across other states by engaging the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to identify best practices in each of the eight objective areas. In 2015, ODP and external stakeholders are refining a set of eight workgroups to accomplish priorities within each objective area. Emphasis is

⁷ House Bill 2015-133 would require DHS to develop and submit a plan to address the waiting list for community-based services for people with intellectual disabilities. The plan is to include statistical information on the current and projected annual increase in the waiting list on a county basis and certain fiscal information.

⁸ For more information, visit <http://www.odpconsulting.net/odp-futures-planning/>.

being placed on including representation on each workgroup that includes a greater number of participants immediately engaged in or affected by the processes under consideration—including individuals, families, supports coordinators, and direct support professionals. In May 2015, an update was provided to the entire Futures Planning Extended Team during a statewide webinar. Additional meetings for all stakeholders involved are scheduled for August 2015 (in-person) and November 2015 (by webinar).

DHS Implementation of Service Preference

In 2000, to meet federal requirements that assure service preference in the provision of home and community-based services funded under the Medicaid Waiver, the Department replaced prior procedures applicable to service preference noting that “service preference is consistent with the values of *Everyday Lives* and the principles of self-determination as expressed in the *Multi-Year Plan for Pennsylvania’s Mental Retardation Service System*.” The bulletin requires individuals requesting services who are likely to require an ICF/IID level of care, or their legal representatives, to be informed of feasible home and community-based services funded under the waiver prior to the individual being given the choice of Medicaid-funded services in an ICF/IID or in their home and community under the waiver. Priority of need is determined under PUNS.

In implementing *Olmstead* provisions, the bulletin states that individuals who do not indicate their preference for home and community-based or ICF/IID placement will have their preference designated as home and community-based. For individuals age 19 and over who cannot signify a preference, an independent qualified intellectual disability professional is assigned by the county.

In 2008, a new bulletin addressing procedures for service delivery was issued by the Department. This bulletin is currently in effect and provides that individuals who do not designate a service preference may choose to do so at a later date and will be provided assistance in locating needed services.

Olmstead Plans

The *Olmstead* decision stated that the ADA requires states to provide community-based services rather than institutional placements for people with disabilities if:

- such services are appropriate;
- the affected persons do not oppose community-based treatment; and
- community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity.

The regulations implementing the ADA allow states to “resist modifications that entail a ‘fundamenta[l] alter[ation] of the States’ services and programs.” The U.S. Supreme Court, in considering that regulation, noted that a state can meet its *Olmstead* obligations by having a plan for placing individuals in less restrictive settings. The court stated:

If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met.

The Department of Justice (DOJ) has interpreted the ADA and its implementing regulations to generally require an *Olmstead* Plan as a prerequisite to raising a fundamental alteration defense, particularly in cases involving individuals currently in institutions or on waiting lists for services in the community. DOJ guidance states that an *Olmstead* Plan must do the following:

1. reflect an analysis of the extent to which the public entity is providing services in the most integrated setting and contain concrete and reliable commitments to expand integrated opportunities;
2. have specific and reasonable time frames and measurable goals for which the public entity may be held accountable;
3. have funding to support the plan, which may come from reallocating existing service dollars; and
4. include commitments for each group of persons who are unnecessarily segregated, such as individuals residing in facilities for individuals with developmental disabilities, psychiatric hospitals, nursing homes, and board and day care homes, or individuals spending their days in sheltered workshops or segregated day programs.

The Department of Health and Human Services (DHHS) has also issued guidance regarding the development of a plan. In its *Olmstead* Update 2, DHHS stated the following:

We recognize that there is no single plan that is best suited for all States, and accordingly that there are many ways to meet the requirements of the ADA. . . . In developing their plans, States must take into account their particular circumstances. However, we believe there are some factors that are critically important for States that seek to develop comprehensive, effectively working plans. Our intent in this enclosure is to identify some of the key principles, including the

involvement of people with disabilities throughout the planning and implementation process. These principles also will be used by the Office for Civil Rights as it investigates complaints and conducts compliance reviews involving “most integrated setting” issues. We strongly recommend that States factor in these principles and practices as they develop plans tailored to their needs.

The update also included guidance for developing an Olmstead Plan. See Exhibit 4.

As reported in *The States’ Response to the Olmstead Decision*,⁹ Pennsylvania established a steering committee consisting of executive level DPW (now DHS) staff to assess current long-term care systems and to develop plans. No specific timeline was adopted. At the time this report was published in 2001, only four states were identified as having comprehensive plans.¹⁰

Exhibit 4

DHHS Principles for Olmstead Plans

- Principle:** Develop and implement a comprehensive, effectively working plan (or plans) for providing services to eligible individuals with disabilities in more integrated, community-based settings.
- Principle:** Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up.
- Principle:** Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities.
- Principle:** Ensure the Availability of Community-Integrated Services.
- Principle:** Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings.
- Principle:** Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.

Source: DHHS Update 2, January 14, 2000.

Regarding Pennsylvania, the report states:

In their plan, state officials will focus on deinstitutionalizing people in state facilities and on addressing the needs of those who currently are living in the community but are facing institutionalization due to a loss

⁹ Fox-Grage, Wendy, Folkemer, Donna, and Horahan, Kevin, *The States’ Response to the Olmstead Decision* (2001), is a publication of the Forum for State Health Policy Leadership at the National Conference of State Legislatures.

¹⁰ Missouri, North Carolina, Ohio, and Texas.

of services. Further, the plan will include those with physical and developmental disabilities, people with mental illness and the elderly. Because state officials believe they already provide services in a manner consistent with *Olmstead*, there will likely be a clear focus on process improvement, technological advancements, and efficiency. In addition, it has been suggested that the state shift away from building facilities in favor of funding additional services.

Reportedly, a draft plan was proposed but not adopted by the Department. At least one other *Olmstead* Plan was developed but not adopted by the Department since that time.

As of May 2015, the DHS does not have an *Olmstead* Plan beyond the *Benjamin* Settlement Agreement that specifically addresses individuals with intellectual disabilities. The Department considers the *Benjamin* Settlement Agreement, which addresses the identification and transition of certain individuals currently living in the state centers, to be its *Olmstead* Plan for persons with intellectual disabilities. Although some advocates consider the agreement to serve as an *Olmstead* Plan for this population, others point out that it does not provide for the ongoing movement of residents into community placements in a structured manner as delineated by the *Olmstead* decision. As shown on Exhibit 5, 27 states had *Olmstead* Plans in 2013. The DHS does have an *Olmstead* Plan for individuals receiving mental health treatment.¹¹ Exhibit 6 provides a brief description of that plan.

The *Olmstead* Plan for individuals receiving mental health treatments generally meets the standards as articulated by the court in *Frederick v. DPW*:¹²

- specify the time frame or target date for patient discharge,
- specify the approximate number of patients to be discharged each time period,
- specify the eligibility for discharge, and
- provide a general description of the collaboration required between the local authorities and the housing, transportation, care, and education agencies to effectuate integration into the community.

¹¹ DHS has developed a Mental Health *Olmstead* Plan that “details specific steps the Commonwealth, in partnership with the counties, will take to ensure essential and appropriate community supports are in place to serve individuals as they transition from institutions to communities of their choice.”

¹² *Frederick v. DPW*, 422 F.3d 151 (3d Cir. 2005), involved approximately 300 class members with serious and persistent mental disabilities who were institutionalized at Norristown State Hospital (NSH). Appellants filed this class action lawsuit in September 2000, claiming that, because the class members are qualified and prepared for community-based services, their continued institutionalization violates the anti-discrimination and integration mandates of the Americans with Disabilities Act (ADA).

Exhibit 5

Olmstead Plan as of 2013

<u>State</u>	<u>Olmstead Plan as of 2013</u>	<u>State</u>	<u>Olmstead Plan as of 2013</u>
Alabama	Yes	Montana.....	Yes
Alaska	No	Nebraska	No
Arizona	Yes	Nevada	Yes
Arkansas.....	Yes	New Hampshire.....	No
California	Yes	New Jersey.....	Yes
Colorado	No	New Mexico.....	No
Connecticut.....	Yes	New York	Yes
Delaware	Yes	North Carolina	No
Florida.....	No	North Dakota	Yes
Georgia.....	Yes	Ohio.....	Yes
Hawaii.....	Yes	Oklahoma	Yes
Idaho.....	No	Oregon.....	No
Illinois.....	No	Pennsylvania	No
Indiana.....	Yes	Rhode Island	No
Iowa.....	Yes	South Carolina.....	No
Kansas.....	No	South Dakota.....	No
Kentucky.....	Yes	Tennessee.....	No
Louisiana	No	Texas.....	Yes
Maine.....	No	Utah.....	Yes
Maryland.....	No	Vermont.....	Yes
Massachusetts.....	Yes	Virginia.....	Yes
Michigan	No	Washington.....	Yes
Minnesota	No	West Virginia	No
Mississippi	Yes	Wisconsin	Yes
Missouri	No	Wyoming.....	Yes

Source: http://pascenter.org/state_based_stats/olmstead/olmsteadplans.php (accessed July 2, 2014).

The Benjamin Settlement Agreement

In April 2009, five people institutionalized in Pennsylvania state centers for individuals with intellectual disabilities filed a lawsuit seeking community placements for themselves and others similarly situated. They alleged that, in violation of Section 504 of the Rehabilitation Act and Title II of the ADA, Pennsylvania failed to offer community placements to state center residents who did not oppose community placement and for whom such placement was appropriate. The court found for the plaintiffs, and a settlement agreement on the remedy was reached in June 2011. The settlement agreement was subsequently vacated by the Third Circuit Court in December 2012 in response to a legal challenge from a group of state ICF/IID residents who claimed that the settlement requirements were contrary to their wishes. A new settlement agreement, developed and agreed upon by all parties was signed in June 2014. The court approved the settlement agreement in September 2014.

Summary of Pennsylvania's Olmstead Plan for Mental Health

Pennsylvania's State Mental Health Olmstead Plan was first issued in 2011 and reflected the Commonwealth's continued progress toward ending the unnecessary institutionalization of adults who have a serious and persistent mental illness. The DHS Office of Mental Health and Substance Abuse Services revised the plan in August 2013. As noted in the plan, as of March 2013, the Commonwealth has closed 3,134 beds in the state mental hospital system by transferring over \$244 million in FY 2012-13 to fund and support the development of community-based services for individuals with mental illness.

Plan Provisions

The plan identifies the following priorities: (1) return individuals residing in state psychiatric hospital units to a community of their choice; (2) provide individuals residing in other institutions or large segregated and/or congregated settings the opportunity to live in more integrated settings; and (3) diverting individuals from institutions and large segregated congregate settings. This means providing individuals with behavioral health needs with opportunities to live in housing where non-disabled individuals reside and providing opportunities to work or experience daytime activities in the community—not in special programs or jobs primarily created for persons with disabilities. In support of these priorities:

- At least 90 beds are to be closed each fiscal year by discharging at least 90 state hospital residents each fiscal year.
- As state hospital units are closed, state funds used to support those units are to be provided to the counties to develop and support necessary community services and infrastructure.
- OMHSAS is to provide necessary supports and assistance to counties to create a variety of residential housing options for persons with mental illness.
- Counties are directed to identify other potential public and private funding sources that may be available to serve the needs of individuals with mental illness. Such funding sources may include, for example, medical assistance, medical assistance home and community-based waivers, Medicare, services provided through the Pennsylvania Department of Aging and the Office of Long Term Living, and private foundations.
- OMHSAS is to review the implementation of the plan annually to assess and determine the need for revision and updates.
- Stakeholders, including individuals who have a mental illness, family members, advocates, service providers, county mental health officials, state officials, and others, are to be involved at all levels in the planning and implementation of the plan.

Local/Regional Implementation

Counties, either individually or in partnership with other counties, are required to develop and submit a local/regional Olmstead implementation plan that identifies all types of services, supports, and infrastructure that will be needed to meet the needs of the individuals discharged from state hospitals, the diversion population, and individuals living in other settings. The county local/regional implementation plan should address, at a minimum: stable, affordable housing in integrated settings; and "housing first" approaches that do not require consumers to participate in other services.

State Mental Hospital Consolidation

The implementation of this plan is to result in decreasing reliance on state hospital resources. DHS is to implement its decision-making protocol and approach to consolidate and close hospitals. In 2011 it was estimated that only 5 percent to 7 percent of the state hospital population required supervised, structured settings because of their clinical and/or criminal histories.

Source: *DHS OMHSAS Updated Olmstead Plan for Pennsylvania's State Mental Health System*, August 2013.

The settlement agreement requires, in part, that the Department establish a planning list to include those class members:¹³ (1) who had the capacity to make an informed choice and chose community placement in FY 2011-12 or FY 2012-13; (2) for whom a choice of community placement was made by their guardians or substitute decision-makers in FY 2011-12 or FY 2012-13; and (3) those who choose or on whose behalf community placement is chosen based on the procedures established by the agreement. Exhibit 7 shows key provisions of the settlement agreement.

The term of the agreement is through June 30, 2018, and requires the Department to move up to 230 residents of the state centers into community placements through the development of a viable integration plan. The agreement states, however, that “no party will seek the removal of a class member from a state ICF/IID to a community placement or will seek to restrict the ability of any class member to move to a community placement other than in accordance with this Agreement.” It also includes protections for class members who choose to remain in a state ICF/IID. In addition to requiring that the level of care for state ICF/IID residents be maintained, the Department is prohibited from using funds appropriated for state ICFs/IID to fund community services and supports, and agreed to “not give funding of state ICFs/IID any lower priority in its budget requests than funding for community placements.”¹⁴

Status reports are required quarterly. As shown on Exhibit 8, the first report was issued in November 2014 and, at that time, 40 class members on the planning list had been discharged to community placements. Most of these community placements, however, occurred prior to the actual signing of the settlement agreement (as allowed by the agreement). The next three status reports showed six additional discharges. DHS reports that many individuals are active in the transition process, and they are expecting between 6 and 22 additional discharges by the end of August 2015, although the agreement required 80 individuals to be transitioned to the community by June 30, 2015.

Although the *Benjamin* Settlement Agreement serves as a plan to transition residents of the state centers who do not object to community placements to community placements, as noted above, the plan terminates in June 2018. The Department does not otherwise have a plan for the continued discharge of state center residents to community placements and considers the *Benjamin* Settlement Agreement to be its Olmstead Plan for persons with intellectual disabilities. In addition, the *Benjamin* agreement is silent on admissions to the state centers. In FY 2012-13, 12 individuals were admitted to state centers; in FY 2013-14, 8 individuals were admitted to state centers; and during FY 2014-15 (through March 20, 2015), three

¹³ The class members are defined in the settlement agreement to include “all individuals who have resided or will reside in a state ICF/ID at any time from the effective date of this agreement until the termination of this agreement” *Benjamin, et al. and Craig Springfield, et al. v. Department of Public Welfare*, No. 1:09-cv-1182-JEJ (2014). p. 5.

¹⁴ *Benjamin*, pp. 15-16.

individuals have been admitted to state centers. The majority of these admissions were from psychiatric facilities, hospitals and prisons.¹⁵

Exhibit 7

Summary of *Benjamin* Settlement Agreement

Background

In April 2009, the Department of Public Welfare (DPW) was subject to the *Benjamin* lawsuit, which alleged that individuals with an intellectual disability were unnecessarily segregated in state-operated ICFs/IID in violation of the Americans with Disabilities Act in that DPW failed to offer ICF/IID residents placement in a community setting. The court found for the Plaintiffs and a settlement agreement on the remedy was reached in June 2011. The agreement was subsequently vacated by the Third Circuit Court in December 2012 in response to a legal challenge from a group of ICF/IID residents who claimed that the settlement requirements were contrary to their wishes. A new settlement agreement was signed in June 2014 and approved by the court in September 2014.

Settlement Overview

The settlement requires that DPW's Office of Developmental Programs (ODP) take measures to protect individual choice and facilitate transition to community residence for those who so choose. These measures include:

- Ensuring that each individual residing in a state-operated ICF/IID who has the capacity to make an informed choice and expresses a preference for community living will move to the community;
 - Ensuring that everyone who is capable of making a choice about where he or she lives may make a choice at any time;
 - Committing to respecting the wishes of individuals, legal guardians, and substitute decision makers who decide to continue residency at a state-operated ICF/IID and honoring their choice of living arrangement;
 - Committing to maintain the level of care currently provided to individuals residing in state-operated ICFs/IID, and assure that the state ICFs/ID continue to meet the criteria needed to protect the health, welfare, and safety of individuals, and to provide them with active treatment;
 - Transitioning at least
 - 80 individuals to the community by June 30, 2015,
 - 50 individuals to the community between July 2015 and June 2016,
 - 50 individuals to the community between July 2016 and June 2017, and
 - 50 individuals to the community between July 2017 and June 2018.
- If at any time there are fewer individuals on the planning list than the number of individuals slated to move in the agreement, the Department will work to move only the number of individuals remaining on the list.
- Creating a website that allows providers to view information about individuals who choose to transition to the community and to notify ICF/IID staff of their potential interest in serving an individual; and
 - Monitoring community transition to ensure positive outcomes, including prevention of arrests or unnecessary readmissions to ICFs/IID.

Source: PA Department of Human Services.

¹⁵ DHS reports that admissions occur only if court ordered and planning starts right away after admission to prepare for transition to the community.

Summary of Benjamin Settlement Agreement Status Reports

	Report 1 (November 21, 2014)	Report 2 (February 10, 2015)	Report 3 (April 15, 2015)	Report 4 (July 15, 2015)
Facility Directors Determinations and Review Committee ^a	50 reviewed (49 recommended for community placement)	No completed decisions	13 reviewed (0 recommended for community placement)	No completed decisions
Planning List ^b	124	117	100	92
Class Members Added to Planning List	124	2	2	No members added
Class Members Removed from Planning List	55 (14 due to family preference; 40 discharged to community placements)	9 (3 due to individual preference; 6 due to family/guardian preference)	18 (6 due to family/guardian preference; 4 due to individual preference; 6 due to facility director determination; 1 discharged to community placement; 1 deceased)	9 (5 discharged; 4 due to family/guardian preference)
Individuals Admitted to Psychiatric Hospital or State Center	1 (has returned to community placement)	1 (has returned to community placement)	1 (has returned to community placement)	2 (both have returned to community placement)
Individuals Returned to State Center After Moving to Community	0	0	0	1
Individuals Arrested or Jailed After Moving to Community	2 (1 in community placement awaiting hearing; 1 incarcerated)	0	0	0
Number of Subjects of Abuse or Neglect ^c	16 in state center 5 in community	14 in state center 2 in community	8 in state center 1 in community	3 in state center 2 in community
Member Deaths Other Than Natural Causes	0	0	0	1
Termination or Notice of Termination From Provider	0	2 (1 has new placement; 1 is not eligible for waiver services due to stay in hospital and skilled nursing facility)	0	0

^aThe Agreement requires the facility directors of the state centers to decide whether class members (defined as all individuals who have resided or will reside in a state ICF/IID at any time from the effective date of the agreement until the termination of the agreement) should continue to live at the state center or move to a community placement in cases where class members do not have the capacity to make an informed decision and do not have guardians or substitute decision-makers. These recommendations are reviewed by an executive review committee in ODP to ensure that the decisions were made in accordance with the provisions of the agreement.

^bThe planning list is a list of those class members for whom ODP is to provide community placements comprised of class members in any of the following three groups: (1) those who had the capacity to make an informed choice and chose community placement in FY 2011-12 or FY 2012-13, (2) those for whom a choice of community placement was made by their guardians or substitute decision-makers in FY 2011-12 or FY 2012-13, and (3) those who choose or on whose behalf community placement is chosen based on the procedures in the agreement.

^cSubjects of founded abuse or neglect.

Source: Benjamin Status – Report 1 (November 21, 2014) and Benjamin Status – Report 2 (February 10, 2015).

The *Jimmie* Settlement Agreement

Another settlement agreement applicable to certain individuals with intellectual disabilities also requires community-based services. On June 11, 2009, several residents of state-run psychiatric institutions who had intellectual and developmental disabilities (IDD) filed a class action lawsuit¹⁶ in the U.S. District Court for the Middle District of Pennsylvania alleging that the Department of Public Welfare (DPW) violated the Americans with Disabilities Act, §504 of the Rehabilitation Act, and the due process clause of the 14th amendment of the U.S. Constitution by failing to provide community-based treatment and habilitation services that would prevent them from being institutionalized. Some of the plaintiffs had diagnosed psychiatric disorders, while others were individuals with disabilities who claimed to be housed in psychiatric facilities even though they had no mental illness. On July 30, 2010, the parties entered into a settlement agreement, which was approved by the court on September 2, 2010. See Exhibit 9 for a summary of the settlement agreement.

In general, as part of the settlement, DPW agreed to:

- assess each class member for eligibility for Medicaid waiver services and develop individualized assessment plans,
- establish a review committee to determine which institutionalized individuals are eligible for placement into community settings,
- develop new individualized treatment plans for all class members, and
- provide funding for additional services both in institutions and in the community.

In addition, the agreement provided that DPW was to ensure that all state hospital direct care and clinical staff members were provided with specialized training before working directly with class members. Training was to include, for example, an overview of intellectual disabilities, conducting diagnostic assessments, and treatments for persons with IDD, among other topics. Finally, the settlement agreement provided for DPW to establish a statewide task force to oversee a comprehensive assessment of Pennsylvania's community resources and services for individuals with dual diagnoses of IDD and mental illness. The task force was to include representatives from ODP and OMHSAS, peers, family members, and other stakeholders and was to:

- Undertake a statewide resource assessment regarding supports for individuals with dual diagnosis in community programs.
- Review monitoring reports of class members' treatment in state hospitals.
- Review class members' status and progress in community programs after discharge from state hospitals.
- Oversee and review ongoing implementation of the settlement agreement and provide feedback to DPW.

¹⁶ Class members include all individuals with mental retardation who, on or after September 8, 2009, were institutionalized in state psychiatric facilities and were not subject to the jurisdiction of the criminal courts.

As of May 2015, seven class members remained in state mental health hospitals for the following reasons: (1) class member opposes moving to HCBS; (2) class member family opposes HCBS; and (3) class member is significantly medically involved.

Exhibit 9

Summary of *Jimmie* Settlement Agreement

Background

On June 11, 2009, residents of state-run psychiatric institutions with developmental disabilities filed a lawsuit in the U.S. District Court for the Middle District of Pennsylvania alleging that the Department of Public Welfare failed to provide community-based treatment and habilitation services that would prevent them from being institutionalized. Some of the plaintiffs had diagnosed psychiatric disorders, while others were individuals with disabilities who claimed to be housed in psychiatric facilities even though they had no mental illness. On July 30, 2010, the parties entered into a settlement agreement, which was approved by the court on September 2, 2010.

Settlement Overview

The settlement agreement required that by February 28, 2010, OMHSAS identify all individuals who are class members covered by the agreement.^a For all class members identified, DPW's Office of Developmental Programs (ODP) was to assess by May 30, 2010, whether they meet the eligibility criteria for community intellectual disability services. For those who were deemed eligible, ODP was to determine eligibility under the ID waiver programs. This was to be completed by June 30, 2010.

As the next step, DPW was to develop appropriate community ID and MH service plans for those individuals determined to be eligible for such services. The settlement agreement directed DPW to seek sufficient funding through the budget process to provide appropriate services as follows:

- In FY 2010-11, funding for community services for at least 20 eligible individuals.
- In FY 2011-12, funding for community services for at least 35 eligible individuals.
- In FY 2012-13, funding for community services to all remaining eligible individuals.^b

The settlement agreement additionally provided a protocol to improve services and supports for class members in state hospitals on the units where they reside. Specifically, within 90 days of the execution of the agreement, Multidisciplinary Teams for Residents with Intellectual Disabilities, established at each state hospital, were to review each individual's treatment needs to consider the appropriateness of moving him or her to another living area for continued treatment, the decision for which was to be based on the individual's clinical treatment and support needs. Further, the multidisciplinary teams were to review persons with ID admitted to the state hospitals in the future to determine their appropriate placement within the facility.

According to the settlement agreement, by July 1, 2010, and annually thereafter, DPW was to begin issuing status reports to plaintiffs' counsel describing the status of funding requests for community services. Further, DPW was required to report every six months on the discharge of individuals and funding for those services; admissions of persons with intellectual disability diagnoses to state hospitals and assessments conducted under the agreement; and implementation status of the protocol to improve services to individuals covered under the agreement.

^a Class members include all individuals with intellectual disabilities who, on or after September 8, 2009, were institutionalized in state psychiatric facilities and were not subject to the jurisdiction of the criminal courts.

^b The settlement agreement provided that the plaintiffs had the option to reinstate the litigation if, by July 1, 2013, DPW had not provided community services to at least 75 percent (or some other percentage to which the parties have agreed) of the persons identified as eligible for community intellectual disability services.

III. Pennsylvania's ID Services Expenditures Post-Olmstead

Funding for Pennsylvania's services to persons with intellectual disabilities comes from both state general funds and the federal Medicaid program and totaled \$3.0 billion¹ in FY 2014-15. Since the *Olmstead* decision in 1999, overall expenditures for ID in Pennsylvania have increased, reflecting increases from both federal and state sources. Total funds available for FY 2014-15 were 0.4 percent greater than FY 2013-14.

General Fund expenditures by the state centers have increased 1.4 percent since 1999 (0.1 percent annually), with federal funds expenditures increasing 7.0 percent. By comparison, the resident population at the state centers decreased 63 percent, from 2,533 in 1998 to 948 as of July 2015. The state centers provide services to about 2 percent of the total number of clients receiving ID services.

Expenditures by private ICFs, on the other hand, grew 20 percent from 1999 to the present, while the number of clients served decreased 36 percent, from 3,109 in FY 1998-99 to 1,982 in FY 2014-15. Community-based services showed the largest increase in expenditures, growing by 191 percent since 1999, with waiver expenditures increasing by 51 percent since FY 2007-08. By FY 2014-15, home and community-based services accounted for 80 percent of all funds expended for ID. The number of clients served in the community has increased over 15 percent since FY 2006-07, and as of FY 2014-15, totaled over 51,000.

In a study conducted by the University of Minnesota, based on 2012 data, Pennsylvania's percentages of recipients receiving HCBS services and those receiving ICF/IID services were at about the national average, while its percentages of expenditures for HCBS exceeded the national average and the expenditures for ICF/IID were less than the national average. However, 31 states had a higher percentage of HCBS recipients and a lower percentage of individuals receiving services in ICFs/IID than Pennsylvania.

Intellectual Disability Funding Sources

ID services are funded through a combination of state and federal appropriations. State-appropriated General Fund monies and augmentations support the state centers and provide funding to private intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), as well as home and community-based ID services. Combined state and federal expenditures for FY 2014-15 were \$3.0 billion.

¹ Final actual expenditures for FY 2014-15 are not yet available. The calculations used actual expenditures plus (July 30, 2015) commitments as provided by the Department of Human Services.

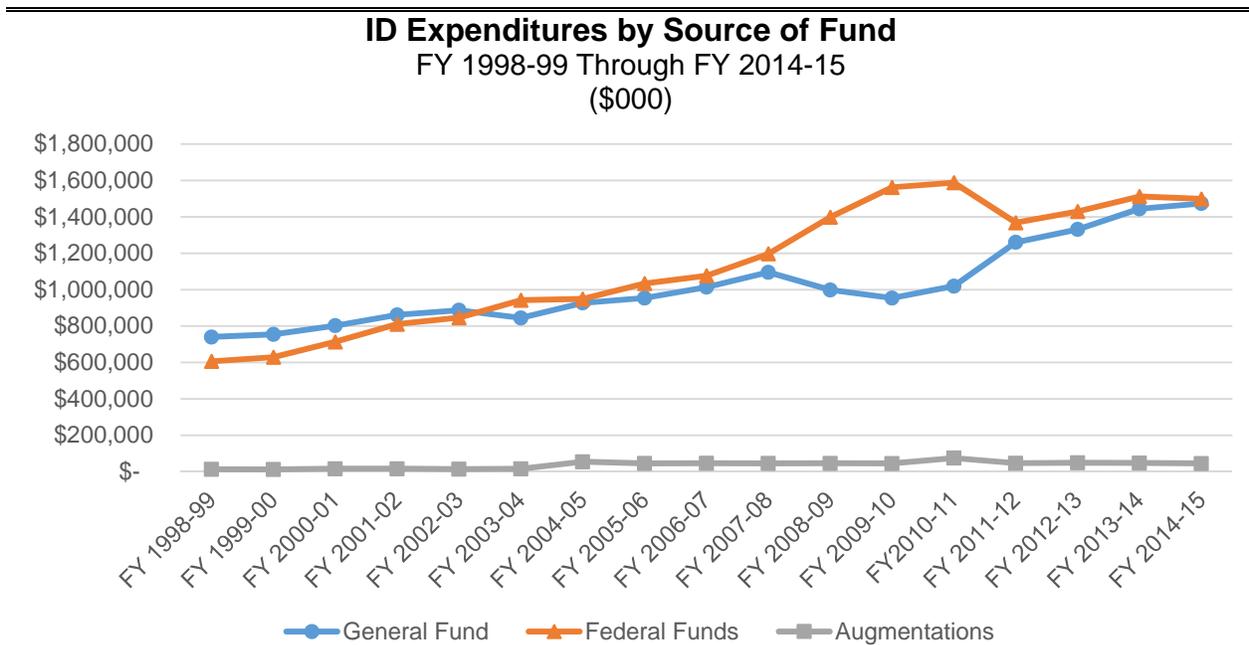
State Funding. In FY 2014-15, General Fund expenditures totaled \$1.47 billion. Augmentation amounts vary each year and may include institutional assessments, institutional collections (funds coming into the facility that include donations, profits from vending machines, and the sale of manufactured goods), institutional reimbursements, rental income, or intergovernmental transfers. In FY 2014-15, expenditures from augmentations were \$45.1 million, making total state funds expenditures \$1.52 billion.

Federal Funding. The primary source of federal funding is through Medical Assistance programs and the state’s Medicaid waiver. State centers also receive modest amounts from Medicare and the Community Base Program from the Social Services Block Grant (SSBG). Total federal funds expended in FY 2014-15 were \$1.50 billion, \$0.5 million of which was Medicare and \$7.45 million was SSBG.

Funding Trends (FY 1998-99 Through FY 2014-15)

Overall, ID program expenditures increased 122 percent, from \$1.36 billion in FY 1998-99 to \$3.0 billion in FY 2014-15.² General Fund expenditures grew 99 percent (6.2 percent annually) during this time period. Federal fund expenditures increased by 147 percent and augmentations grew by 243 percent. See Exhibit 10.

Exhibit 10



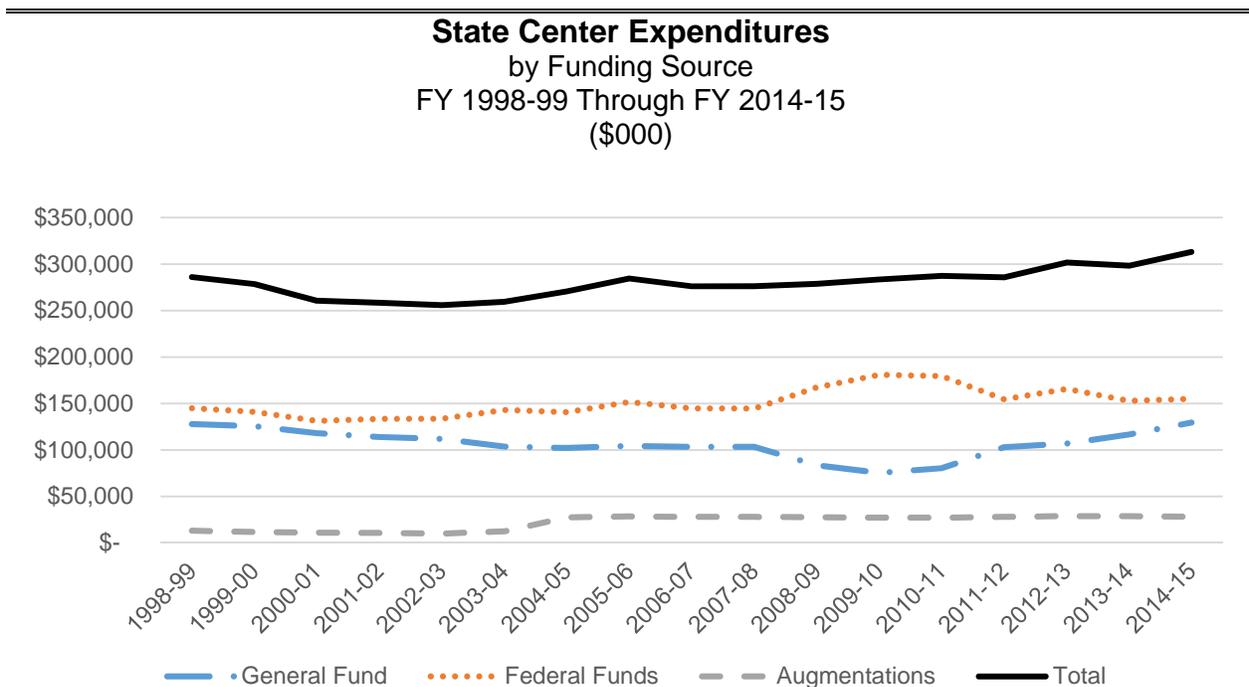
Source: Developed by LB&FC staff using actual expenditures from the Governor’s Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

² Totals do not include expenditures for autism services or for early intervention services.

State Centers for Intellectual Disabilities

State center expenditures were 21 percent of the total expended for ID services in FY 1998-99, but only 10 percent of the total in FY 2014-15. Between FY 1998-99 and FY 2014-15, General Fund expenditures for the state centers increased 1.4 percent, or 0.1 percent annually, while combined federal Medicaid and Medicare expenditures increased 7.0 percent. Overall expenditures for state centers increased 9.4 percent (see Exhibit 11). Expenditures on a per resident basis are shown in Exhibit 12.

Exhibit 11



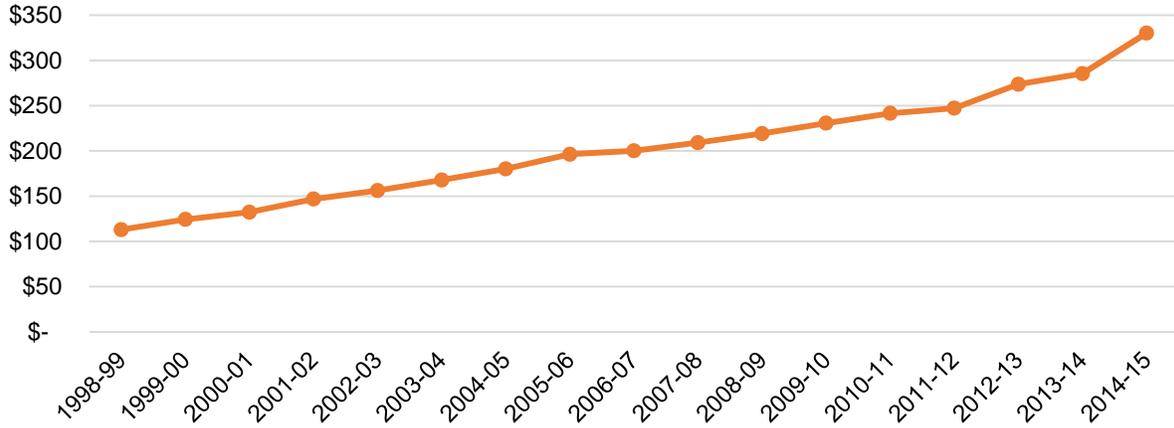
Source: Developed by LB&FC staff using actual expenditures from the Governor's Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

Private Intermediate Care Facilities for Individuals With Intellectual Disabilities (ICFs/IID)

Expenditures for private ICFs/IID were 18 percent of the total ID expenditures in FY 1998-99, but decreased to 10 percent of this total in FY 2014-15. General Fund expenditures for ICFs/IID increased 9 percent, or 0.6 percent annually, from \$111.3 million in FY 1998-99 to \$121.4 million in FY 2014-15. Federal fund expenditures increased 17 percent to \$150 million in FY 2014-15, resulting in an overall expenditure of \$287.7 million in FY 2014-15, an increase of 20 percent over the FY 1998-99 ICFs/IID expenditures (see Exhibit 13).

Exhibit 12

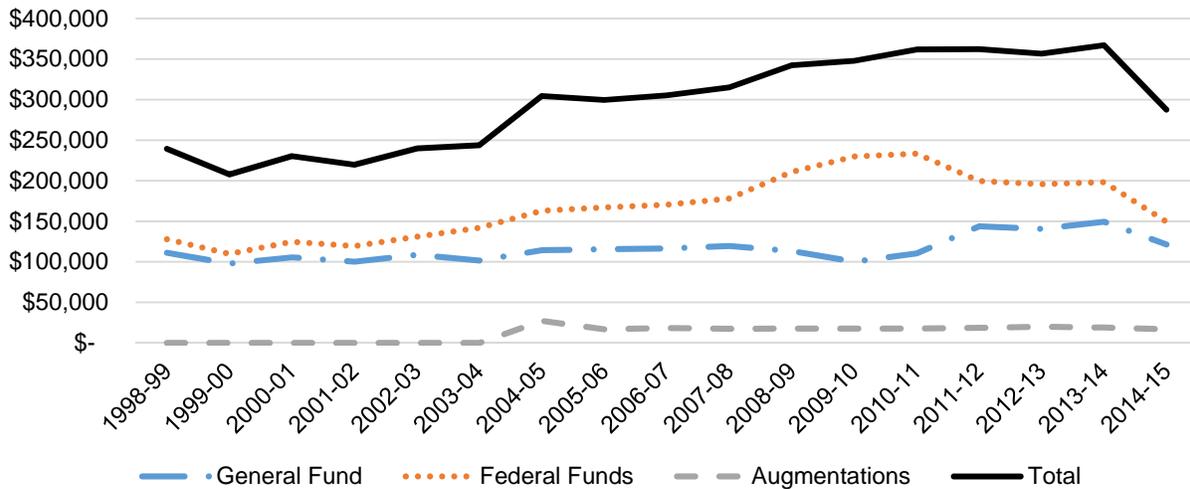
State Center Expenditures Per Person
 FY 1998-99 Through FY 2014-15
 (\$000)



Source: Developed by LB&FC staff using actual expenditures from the Governor's Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

Exhibit 13

Private ICF/IID Expenditures
 by Funding Source (FY 1998-99 Through FY 2014-15)
 (\$000)



Source: Developed by LB&FC staff using actual expenditures from the Governor's Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

In 1971, legislation was enacted providing for federal financial participation for ICFs/IID as an optional Medicaid service. Funding supports state-operated institutions and private ICFs/IID that are certified facilities complying with federal standards in eight areas, including management, client protections, facility staffing,

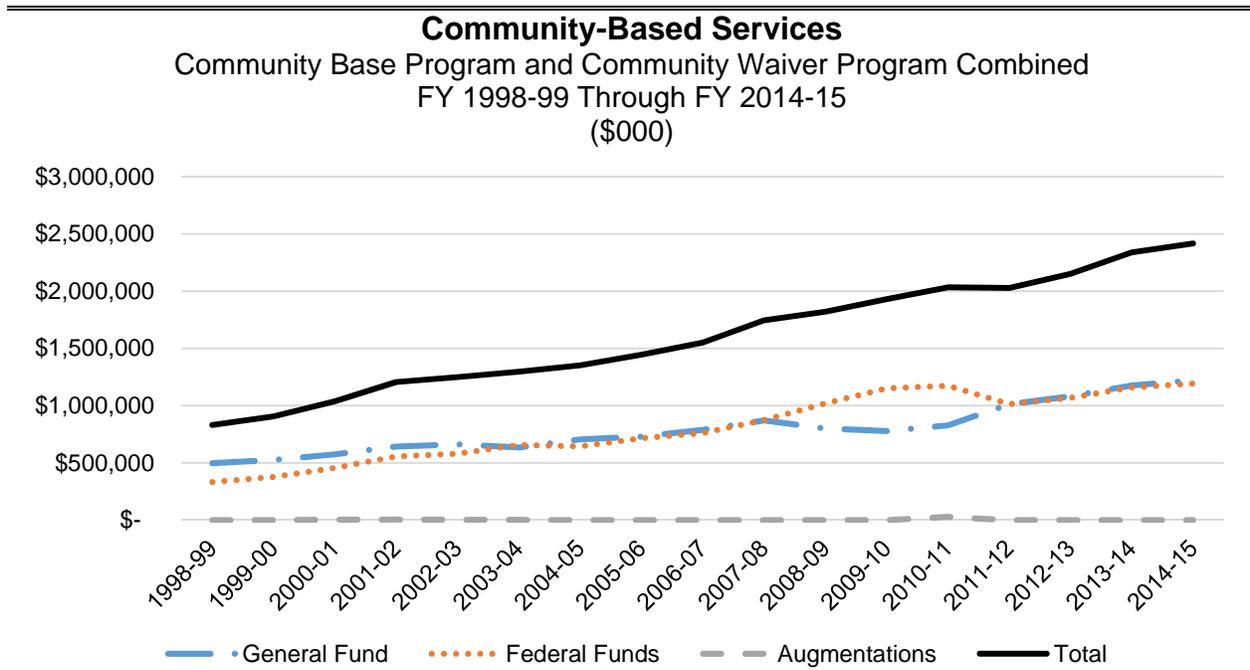
active treatment services, client behavior and facility practices, health care services, physical environment, and dietetic services. Federal regulations are the basis for both financial eligibility and eligibility based on disability. Included in the funding provided is the cost for room and board services. Many of the individuals who receive care provided by ICFs/IID have other disabilities as well as an intellectual disability and may also be non-ambulatory, have seizure disorders, behavior problems, mental illness, be visually-impaired or hearing-impaired, or have a combination of these conditions.

Money Follows the Person. A federal rebalancing demonstration grant provides additional funding to those states participating in the demonstration to fund Medicaid-eligible individuals in transitioning from facilities to homes and communities. The focus of the grant is to build home and community-based service capacity to allow recipients to live in the least restrictive environment. The grant provides funding for services not otherwise funded through Medicaid, e.g., the purchase of household items or non-medical transportation, and it is used to pay 100 percent of some costs (transition activities) and 50 percent of the state's share of other services. This allows Medicaid-eligible individuals to continue to receive services both in the state centers and in the community during the transition period. Once the transition is complete, HCBS funds pay for services.

Home and Community-Based Services (HCBS)

Community-based services accounted for 61 percent of the total ID expenditures in FY 1998-99 and grew to 80 percent of the total \$3.0 billion expended in FY 2014-15. Overall, expenditures for community-based services increased 191 percent between FY 1998-99 and FY 2014-15 (see Exhibit 14). General Fund expenditures for HCBS increased at an annual rate of over 9 percent, for an overall increase during this time period of 146 percent. Federal expenditures for community services (Community Base Program and the Community Waiver) increased 246 percent, or 15 percent annually. In FY 2014-15, \$1.2 billion from the General Fund and \$1.2 billion in federal funds were expended.

Exhibit 14



Source: Developed by LB&FC staff using actual expenditures from the Governor’s Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

Community Base Program. ID services not provided in a state center or under the Medicaid Waiver are funded by Community Base funding. Generally, in the county, Medicaid services are funded through Medicaid, and, if not a Medicaid service, services are funded through the county’s Community Base Program funds. Historically, these funds were placed in “categoricals” such as: residential, day programs, group homes, lifesharing, etc. Beginning in FY 2013-14, a pilot program comprising 20 counties³ funded county-provided services through a Human Services Block Grant. The block grants included funds that could be used for ID services, with each county allocating its funding as it deems appropriate. In FY 2014-15, the pilot was expanded by 10 counties,⁴ for a total of 30 counties receiving the block grants.

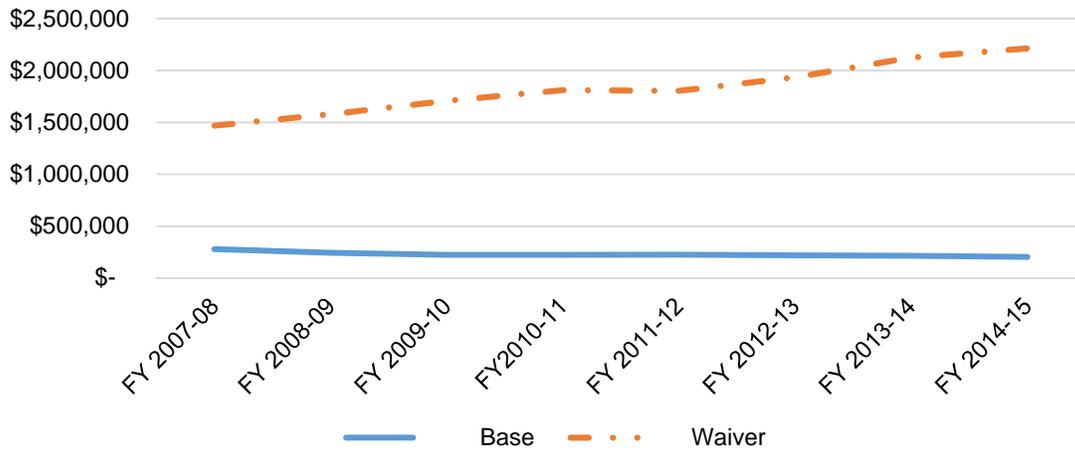
Community Base Program expenditures decreased 27 percent between FY 2007-08 and FY 2014-15, from \$276.6 million to \$201.9 million. During that same period, waiver expenditures increased 51 percent. See Exhibit 15.

³ The original 20 counties that participated in the block grant pilot included: Allegheny, Beaver, Berks, Bucks, Butler, Centre, Chester, Crawford, Dauphin, Delaware, Erie, Franklin, Fulton, Greene, Lancaster, Lehigh, Luzerne, Tioga, Venango, and Wayne.

⁴ The 10 new counties added to the block grant were: Blair, Cambria, Lackawanna, McKean, Montgomery, Northampton, Potter, Schuylkill, Washington, and Westmoreland.

Exhibit 15

Community Base vs. Community Waiver Expenditures
FY 2007-08 to FY 2014-15
(\$000)



Source: Developed by LB&FC staff using actual expenditures from the Governor's Executive Budget FY 2009-10 through FY 2015-16 and FY 2014-15 actual expenditures and commitments provided by DHS.

Community-Based Service Waivers

Pennsylvania administers a Medicaid waiver program⁵ for individuals with intellectual disabilities consisting of the Consolidated Waiver and the Person/Family Directed Supports Waiver, collectively known as the Community Waiver. The state determines the number of people to be served in the waiver program and includes this number in a waiver application or amendment to the Centers for Medicare and Medicaid Services (CMS). This number then becomes part of the waiver application or amendment approved by CMS. Individuals can only be enrolled in one waiver at a time.

⁵ The Adult Autism Waiver is another HCBS waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults with an Autism Spectrum Disorder (ASD). Priority is given to adults not receiving ongoing state or federally-funded services. The Adult Autism Waiver is available statewide and provides a choice of an enrolled provider for each service. Residential services are an option if a need is determined through assessment. The waiver does not include physical health services.

Consolidated Waiver. Under the Consolidated Waiver there is no individual cap on funds, however, the test for using the waiver is whether the costs in the aggregate are less than using institutional placement. Additionally, certain services have cost limits.

Person/Family Directed Supports Waiver. The Person/Family Directed Supports Waiver (P/FDS) is currently capped at \$30,000 per person per year; however, this amount excludes waiver-funded supports coordination services. The cap is subject to change through a waiver amendment.

Consolidated Waiver Expenditures

In FY 2014-15, waiver expenditures were 73 percent of the total funds expended for ID services and 92 percent of expenditures for all community-based services (Community Base Program plus Waiver Program). This is an increase from FY 2007-08,⁶ when the percentages were 63 and 84 respectively.

Consolidated Waiver expenditures increased 51 percent from FY 2007-08 through FY 2014-15, or 7 percent annually, and this is the primary driver for the 38 percent increase in community-based service expenditures over this time period. According to DHS officials, waiver expenditures are growing at a faster rate than the costs saved from deinstitutionalization. The increase can be attributed to the rising costs of services and an increase in the number of persons receiving waiver services. However, in FY 2014-15, 17,005 individuals received consolidated waiver services, an almost 250 person decrease from the 17,251 recipients in FY 2013-14. P/FDS waiver recipients also decreased from 12,580 in FY 2013-14 to 12,123 in FY 2014-15, a 457 person decrease.

Population Trend for Individuals Receiving ID Services

From FY 2006-07⁷ through FY 2014-15, the number of individuals receiving ID services increased 6 percent, or just under 1 percent annually, from 50,139 to 53,207.

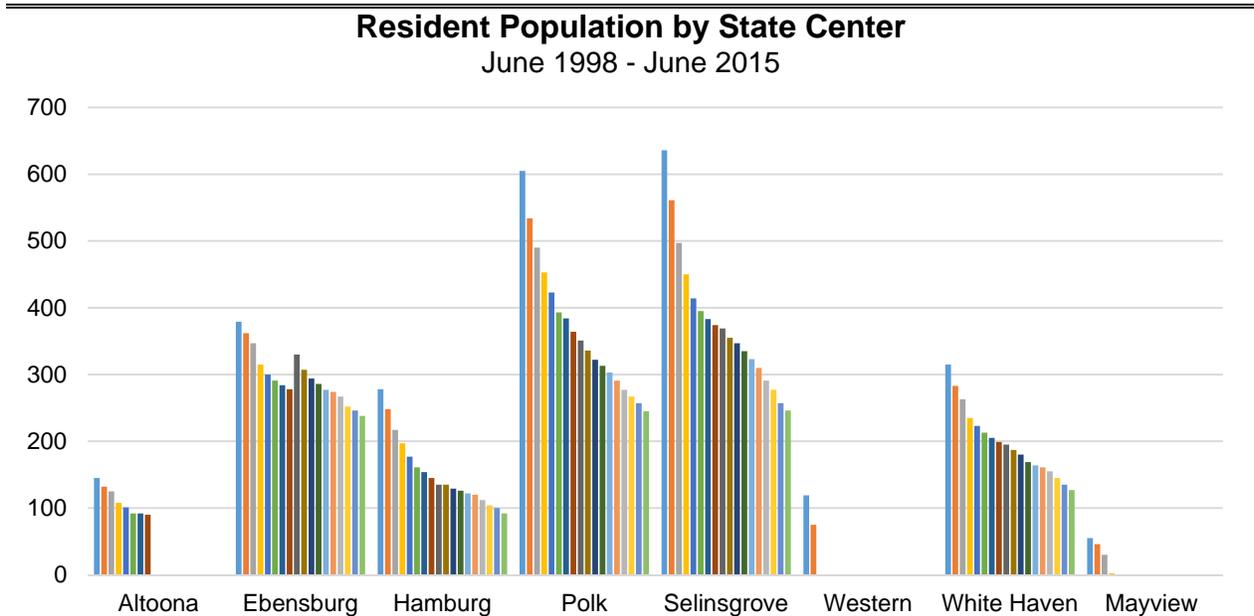
⁶ Beginning with the FY 2007-08 actual expenditures, the base program and the waiver program funds were reported separately in the Governor's Budget document.

⁷ Population counts prior to FY 2007-08 included individuals no longer in the system, receiving early intervention services, or on the waiting list. Data was adjusted as the Department transitioned in a new information system.

State Center Client Population Trends

Overall, since 1998, resident population in the state centers has decreased 63 percent, from 2,553 to 948 as of June 30, 2015. See Exhibits 16 and 17.

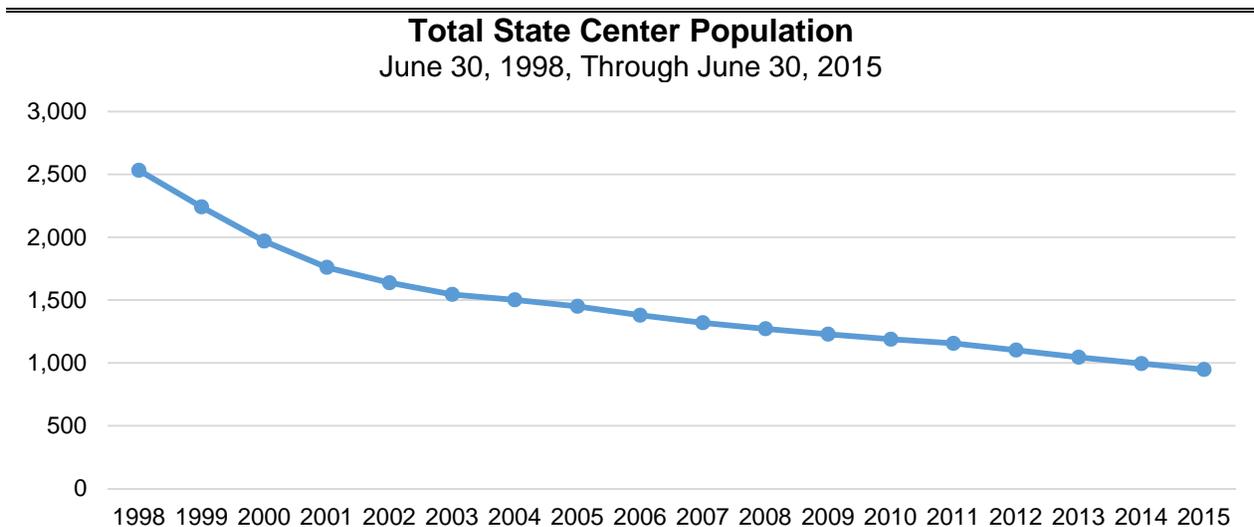
Exhibit 16



Note: Laurelton Center closed in 1998. As of June that year, center population was one resident. Altoona Center closed in 2006. Western Center closed in 2000. Mayview Center closed in 2008.

Source: Developed by LB&FC staff using actual population census as reported in the Governor's Executive Budget FY 2000-01 through FY 2015-16 and June 2015 resident census from DHS.

Exhibit 16

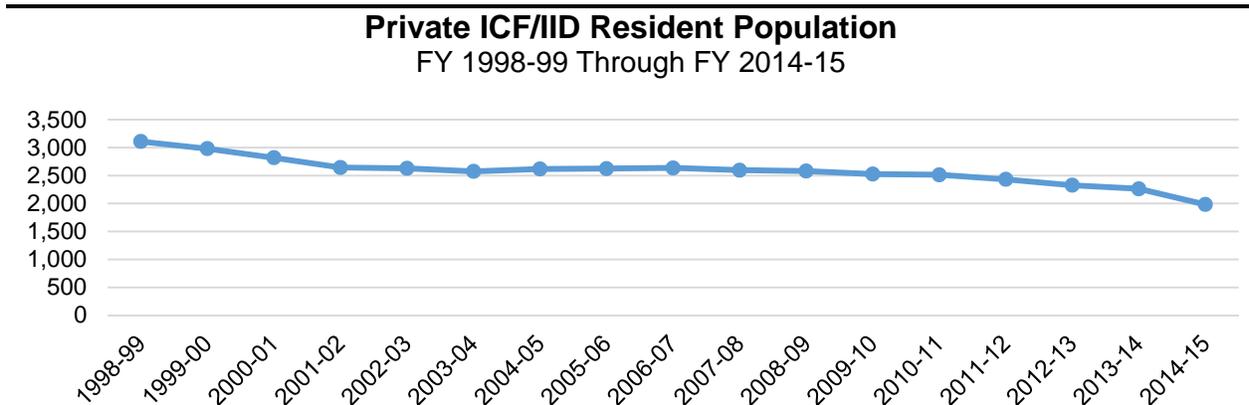


Source: Developed by LB&FC staff using actual population census as reported in the Governor's Executive Budget FY 2000-01 through FY 2015-16 and June 2015 resident census from DHS.

Population Trend for Private ICFs/IID

From FY 1998-99 to FY 2014-15, the reported resident population at private ICFs/IID has decreased over 36 percent, from 3,109 to 1,982. See Exhibit 18. As noted earlier, however, actual expenditures by private ICFs/IID have increased 20 percent since FY 1998-99.

Exhibit 18

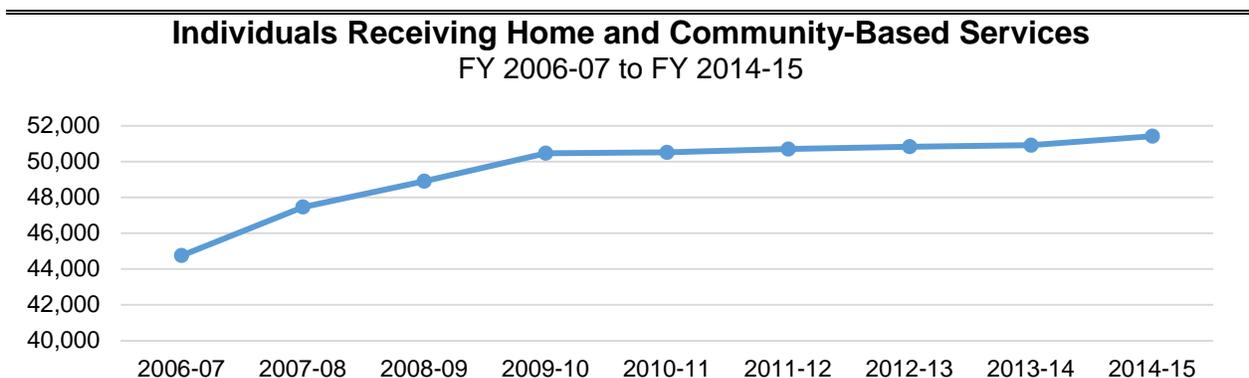


Source: Developed by LB&FC staff using actual population census as reported in the Governor’s Executive Budget FY 2000-01 through FY 2015-16 and FY 2014-15 data provided by DHS.

Home and Community-Based Service Population Trends

From FY 2006-07 through FY 2014-15, the number of individuals receiving HCBS increased 15 percent, from 44,752 to 51,418. As the result of the Waiting List initiative, 430 clients were added to the Consolidated Waiver Program, and 700 to the P/FDS waiver in FY 2012-13. In FY 2013-14, an additional 400 and 700 respectively were added to the waiver programs. The Governor’s FY 2014-15 Executive Budget provides HCBS for an additional 400 and 700 individuals under the Expanded Services to Older Pennsylvanians and Individuals with Disabilities Initiative. See Exhibit 19.

Exhibit 19

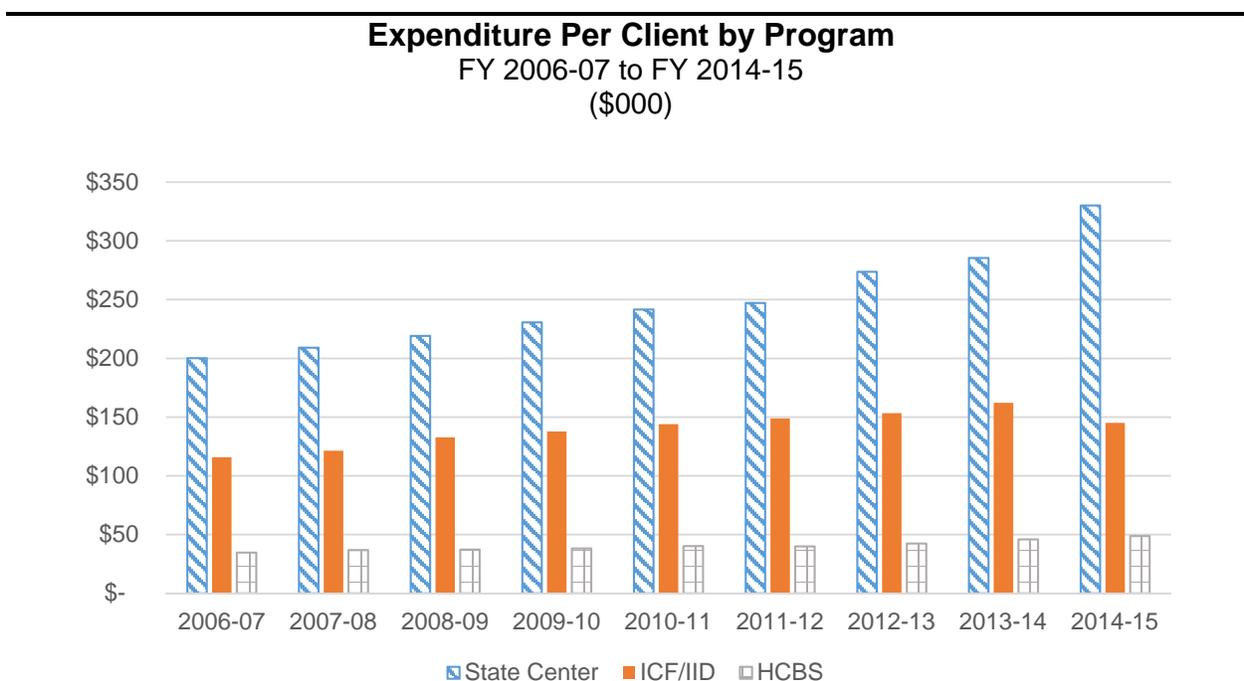


Source: Developed by LB&FC staff using the Governor’s Executive Budget FY 2009-10 through FY 2015-16 and FY 2014-15 data provided by DHS.

Annual Operating Costs Per Client: State Center, ICF/IID, HCBS

Annual expenditures per resident at the state centers increased from \$200,100 in FY 2006-07 to \$330,000 in FY 2014-15, a 65 percent increase. In the private ICFs/IID, expenditures per resident increased 25 percent, from \$115,900 to \$145,170. Home and community-based services expenditures per individual grew 36 percent, from \$34,700 in FY 2006-07 to \$47,000 in FY 2014-15. See Exhibit 20. Funds expended per individual at a state center averaged seven times the funds expended for an individual being served in the community; however, approximately 88 percent of the current residents of state centers are diagnosed as severely or profoundly disabled, compared to 16 percent of individuals similarly diagnosed who are receiving HCBS.

Exhibit 20



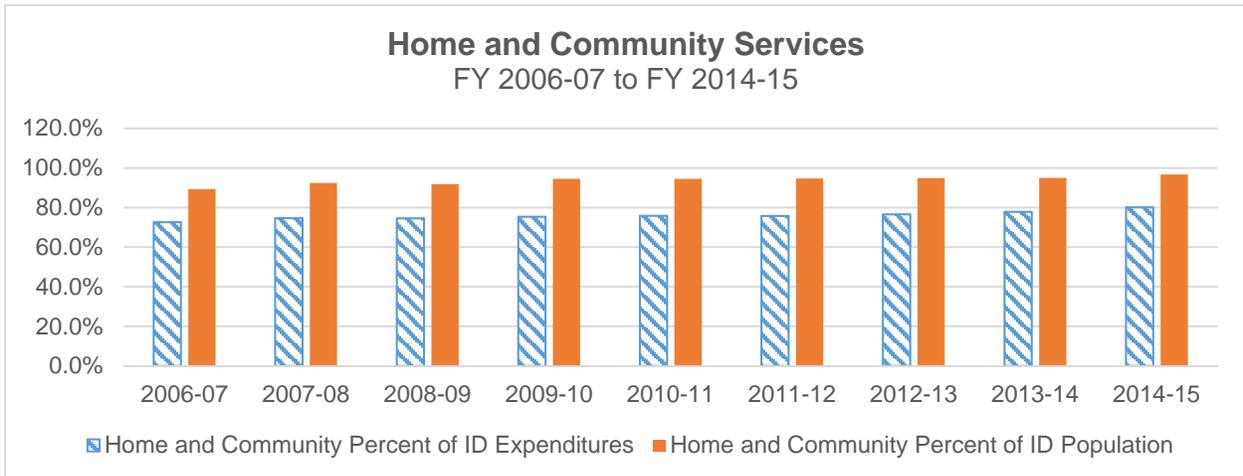
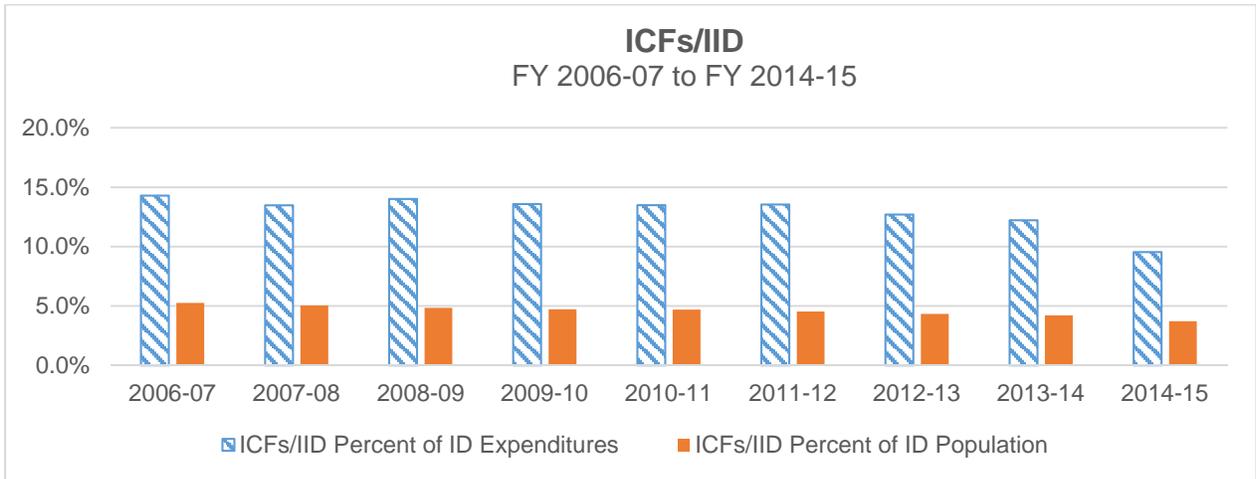
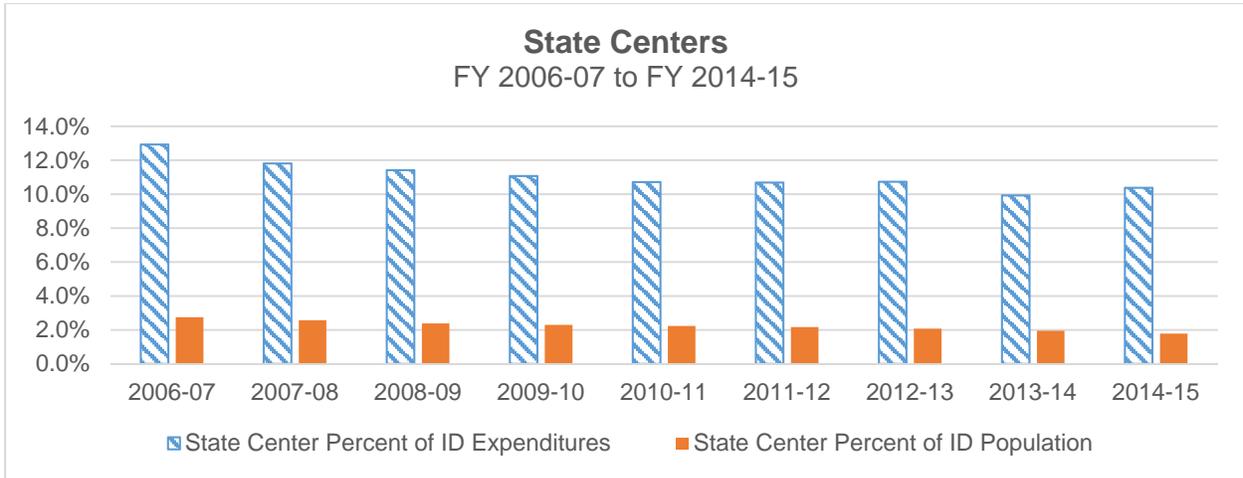
Source: Developed by LB&FC staff using actual expenditures and census data as reported in the Governor's Executive Budget FY 2009-10 through FY 2015-16 and FY 2014-15 data provided by DHS.

Percentage of ID Expenditures and Percentage ID Population by Program Area

From FY 2006-07 through FY 2014-15, institutional placements served 7 percent of the ID population, but expended one-quarter of the funds. State centers accounted for, on average, 11 percent of total ID expenditures while serving 2 percent of the ID population, and private ICFs/IID accounted for 13 percent of the total expenditures and served, on average, 5 percent of the ID population over this time period. The majority of expenditures, 76 percent, and the majority of the population served, 94 percent, were by home and community-based services. See Exhibit 21.

Exhibit 21

Percent of ID Expenditures and Percent of ID Population



Source: Developed by LB&FC staff using the actual expenditures and program census as reported in Governor's Executive Budget FY 2009-10 through FY 2015-16 and FY 2014-15 data provided by DHS.

Pennsylvania's Service Break-out Compared to Other States

On June 30, 2012, a total of 781,190 people using ID services received long-term supports and services (LTSS) through an ICF/IID or the HCBS Waiver program in the United States. Combined annual expenditures totaled \$41.8 billion. Overall, 89 percent of the individuals receiving supports used the HCBS Waiver Program, and 11 percent used ICF/IID services.

As shown in Table 2, the percentages of recipients receiving HCBS services and ICF/IID services in Pennsylvania were about the national average, while Pennsylvania's percentages of expenditures for HCBS exceeded the national average, and the expenditures for ICF/IID were less than the national average. However, 31 states had a higher percentage of HCBS recipients and a lower percentage of individuals receiving services in ICFs/IID than Pennsylvania. Regarding expenditures for HCBS waiver services, 30 states had a higher percentage of HCBS expenditures than Pennsylvania, and 19 states had higher ICF/IID expenditures than Pennsylvania. Two states, Michigan and Oregon, reported no expenditures for ICFs/IID.

Table 2

**ICF/IID Residents and HCBS Waiver Recipients and Expenditures by State on
June 30, 2012**

State	% of Recipients		% of Expenditures	
	HCBS	ICF/IID	HCBS	ICF/IID
AL	99.3	0.7	99.7	0.3
AK	100.0	0.0	97.8	2.2
AZ	99.4	0.6	95.2	4.8
AR	73.3	26.7	52.5	47.5
CA	91.8	8.2	74.5	25.5
CO	96.1	3.9	89.3	10.7
CT	90.4	9.6	74.0	26.0
DE	92.9	7.1	84.4	15.6
FL	91.3	8.7	72.9	27.1
GA	97.5	2.5	98.6	1.4
HI	97.0	3.0	93.0	7.0
ID	85.8	14.2	77.9	22.1
IL	68.7	31.3	46.2	53.8
IN	76.9	23.1	62.1	37.9
IA	85.1	14.9	56.2	43.8
KS	94.2	5.8	83.7	16.3
KY	97.5	2.5	75.7	24.3
LA	68.4	31.6	46.9	53.1
ME	95.6	4.4	87.3	12.7
MD	99.6	0.4	98.4	1.6
MA	95.7	4.3	98.5	1.5
MI	100.0	0.0	100.0	0.0
MN	91.8	8.2	89.0	11.0
MS	39.8	60.2	14.0	86.0
MO	95.0	5.0	83.1	16.9
MT	98.0	2.0	86.1	13.9
NE	91.3	8.7	81.0	19.0
NV	94.1	5.9	81.5	18.5
NH	99.4	0.6	98.4	1.6
NJ	78.2	21.8	52.3	47.7
NM	94.7	5.3	92.0	8.0
NY	92.0	8.0	62.8	37.2
NC	76.5	23.5	54.0	46.0
ND	87.9	12.1	58.3	41.7
OH	83.0	17.0	61.4	38.6
OK	77.1	22.9	69.1	30.9
OR	100.0	0.0	100.0	0.0
PA	89.8	10.2	75.4	24.6
RI	98.8	1.2	98.1	1.9
SC	86.5	13.5	65.9	34.1
SD	94.2	5.8	77.2	22.8
TN	87.4	12.6	73.1	26.9
TX	75.5	24.5	50.7	49.3
UT	84.4	15.6	66.7	33.3
VT	99.8	0.2	99.1	0.9
VA	88.0	12.0	90.2	9.8
WA	95.0	5.0	80.4	19.6
WV	88.8	11.2	82.3	17.7
WI	96.3	3.7	84.4	15.6
WY	96.5	3.5	77.4	22.6
Est. U.S. Total	88.9	11.1	70.6	29.4

Source: University of Minnesota, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through 2012*. Data for District of Columbia is excluded.

IV. Factors Affecting the Availability of Home and Community-based Services and Transition From State Centers

As discussed in Chapter II, Pennsylvania, like other states, has been moving away from institutional placements and to community placements since before the *Olmstead* decision. To assist in this effort, DHS funds Self Advocates United as One (SAU1) to speak with state center residents and their families about living in the community to continue to encourage transition into the community. Stakeholders have noted, however, that reducing the population in state centers is directly dependent on having the capacity in the community to provide services for those residents. Many of the current residents of the state centers have highly complex conditions, and therefore, need significant supports to transition to the community. According to representatives of the providers, due to funding issues related to the Chapter 51 regulations, there has been a slow-down in the last four years among the providers in bringing new services into the system.

This chapter addresses the Chapter 51 regulations and several other issues that have been cited as causing delays in providing community services. These include the delay in processing PROMISe applications, limited funding for start-up costs, restrictive service definitions, and restrictive exceptions processes. Taken together, these delays and policies are reportedly having the effect of discouraging providers from accepting more involved cases or offering new services.

In addition, the CMS Final Rule that requires increased integration in providing services will require changes to current community service options. This includes new definitions of community placements that are acceptable to meet the integration standard. To comply with the rule, the Department is in the process of assessing its regulations and policies to identify revisions that may be needed to meet the new standard. Meeting this standard will also require providers to adjust their services to ensure that individuals are served in appropriate settings.

Accessing Intellectual Disability Services

Eligibility for services is determined by the local administrative entity, which may be the county human services office or a contracted agency. The essential feature of an intellectual disability is significantly sub-average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. The onset must occur before the individual's 22nd birthday.

Once eligibility is determined, the individual selects a supports coordinator who assists in developing an individual support plan (ISP). The supports coordinator provides information about those providers willing and qualified to provide the supports identified in the ISP. Home and community-based services may be funded through the Consolidated Waiver, P/FDS Waiver or the county base funds. Waiver services are paid directly by ODP, while services funded with the county base funds are paid by the county. See Chapter III for additional information about service funding.

When funding is not available, the eligible individual is placed on the waiting list until a waiver slot is available. As discussed in Chapter II, the individual will be assessed by need through the PUNS system. The Supports Intensity Scale©, an instrument developed and copyrighted by the American Association on Intellectual and Developmental Disability (AAIDD), is used to assess needs. It was developed to:

- assess support needs of individuals aged sixteen (16) and older,
- determine the intensity of the need, and
- over time to monitor individual progress and evaluate outcomes.

Individuals who qualify have a right under the Medicaid Act to receive services in an ICF/IID. (An individual needing residential services may choose a private ICF/ID.) A private ICF/ID provides institutional care in a congregate setting.

Institutional services at a public ICF/ID (State Center) are accessed only through a court determination under the Mental Health and Intellectual Disability Act of 1966.¹ In those cases, a court must specifically find:

- The person is impaired in adaptive behavior to a significant degree and is functioning at an intellectual level two standard deviation measurements below the norm as determined by acceptable psychological testing techniques.
- The impairment and resultant disability were manifested before the person's 18th birthday and are likely to continue for an indefinite period.
- The person, because of his intellectual disability, presents a substantial risk of physical injury to himself or physical debilitation as demonstrated by behavior within 30 days of the petition, which shows that he is unable to provide for, and is not providing for his most basic need for nourishment, personal and medical care, shelter, self-protection and safety *and that provision for such needs is not available and cannot be developed or provided in his own home or in his own community without residential placement.* (emphasis added)²

¹ 50 P.S. §4406.

² This regulation was the result of an order of the United States District Court for the Middle District of Pennsylvania in the matter of *Goldy v. Beal*, 429 F. Supp. 640, 648 (M.D. Pa. 1976).

Chapter 51 Regulations Reportedly Slowed Growth in Provider Services

One of the factors affecting the growth of home and community-based services cited most frequently by providers was the adoption of the Chapter 51 regulations establishing payment methodologies and provider qualifications in 2012. These regulations were the result of Act 2011-22, which amended the Public Welfare Code and authorized the Department to bypass the regulatory review process. According to the Department, “this final-omitted rulemaking will enable the Commonwealth to efficiently use federal funding for HCBS programs and will ensure that the Department’s expenditures for state FY 2011-2012 do not exceed the aggregate amount appropriated by the General Assembly.” The Department, in response to the CMS requiring statewide consistency in the waiver programs, began implementation of a statewide rate-setting system to ODP-administered waiver programs intended to “ensure program integrity and further promote efficient use of federal and state resources.”

These regulations made significant changes in the rates received by providers for services and the service definitions. For example, the regulations established a residential habilitation vacancy factor of 97 percent, with an exception process that considered the provider’s total vacancy level for waiver residential HCBS locations as well as the provider’s financial status. This vacancy rate (or occupation rate) affects providers who may have residents who are medically fragile and need hospitalization, or those who visit family, since they cannot bill for days that the resident is not in the home for at least 12 hours. A 97 percent vacancy factor allows a resident to be absent from the provider home for 10 days annually before the provider reimbursement is reduced. Although some costs will decrease, e.g., staff in certain circumstances, fixed costs will not, and, therefore, depending on the placement, the funds provided may not cover the actual costs incurred by the provider. See Exhibit 22 for a description of how the regulations affect dual diagnosis placements.

Due to concerns related to the regulations, such as the vacancy rate change, several provider associations³ negotiated a settlement agreement with the Department to avoid the costs and uncertainty of litigation. As part of this agreement, the Department revised certain payment provisions for the period July 1, 2015 through June 30, 2017. First, the Department adjusted the vacancy factor that is applied to residential rehabilitation payment rates. The vacancy factor is intended to adjust rates to limit certain vacancies in a particular program, such as the number of therapeutic leave vacancies. The Department adjusted the vacancy factor from 97 percent to 96 percent, which allows for more vacancies in the program. The Department also adjusted its policy relating to the process for allowing exceptions to application of the vacancy factor. Finally, the Department implemented a “retention factor” that increased payment rates by a certain percentage under certain circumstances.

³ Pennsylvania Advocacy and Resources for Autism and Intellectual Disability, The Arc of Pennsylvania, The Rehabilitation and Community Providers Association, and United Cerebral Palsy of Pennsylvania, Inc.

Example of Start-Up Service Needs and Funding Gaps for Individuals With a Dual Diagnosis of Intellectual Disability and Psychiatric or Behavioral Health Challenge Transitioning From Residential Treatment Facilities Into the Community

The experience of SPIN (Special People In Northeast) includes the following challenges:

- An opening in a community living arrangement is typically not suitable for a young adult who is referred from a residential treatment facility. Typically to provide for a person with a dual diagnosis, we need to open a new home and prepare to provide individualized, intensive services.
- We then need referrals for one or two other compatible people before we procure a home to provide services to two or three people. Opening a home with a vacancy is not feasible as costs are 100% and reimbursement is 50%. Matching people for compatibility is time consuming.
- Rentals typically do not work for people with psychiatric and/or behavioral challenges. A home must be located, purchased, renovated and licensed. This requires a minimum of a 20% deposit, closing costs, two months minimum of holding costs, renovations and furnishings before visits can take place. Average cost for all described is \$57,000. ODP will reimburse provider \$5,000 per person until their allocation is depleted (typically early in the fiscal year). If two people will live in the home (which is our typical), we will spend a minimum of \$47,000 without reimbursement.
- Startup also includes the recruitment and training of staff. This process costs more for hiring people to work with people with behavioral challenges as there is more training required and we pay staff \$1.00 an hour more. It is very difficult to find people who want to work with people with behavioral challenges and/or who have experience with this population. Cost of recruitment and training (including On-the-Job) is \$4,000 per employee and the typical staffing for two people is 8 direct support staff. Once recruited and trained, the staff need to spend time meeting the person at their current location and then supporting the person to come to the new home for visits. These visits are not able to be billed, but the provider must pay the staff. This will cost an additional \$500 per employee until the person moves in and we can bill. Cost for staff startup is \$36,000.
- Other team members have been working on this transition: Behavior Specialist and clinical team is assessing and beginning a behavior plan, Residential management are handling licensing and preparing the home, schedules, etc., a vehicle is procured, Health Services is creating the Health Record and establishing community physicians and a psychiatrist, admissions is handling referral records, etc. Much of this is seen as “sunk” costs, but preparing for a person with a psychiatric challenge requires more time and people. The Behavior Specialist is not administrative and the cost of their time can be \$1,000 in lost billings until we are able to begin billing for service.

Chapter 51 Impact: *Start-up costs will be capped at \$5,000 per new participant per provider.* Under the prior regulations there was no cap and any funds a provider invested of their own money received up to 8% annual equity return. Losses that are incurred from the startup of a home for a person with ID and psychiatric needs is approximately \$84,000.^a

^a Does not include all costs, e.g., vehicle, that may be incurred.

Source: Special People In Northeast with concurrence from other service providers.

The settlement agreement was amended in February 2015 to further adjust the exception process and to provide for partial recoupment of certain payments when the payments are not eligible for federal participation. As part of the initial settlement agreement, ODP's stakeholder workgroup was reconvened to continue the review of the regulations and to make recommendations for amendments to Chapter 51.⁴ The recommendations are to be presented to the Department by December 15, 2015.

PROMISE Response Time Delays Services

PROMISE is the Department's claims processing and management information system. PROMISE enrollment is required prior to providing services, and, according to DHS, the average time needed to process PROMISE applications is 90 business days. Providers report this process can take six to nine months to complete. The length of time it takes for this processing can affect the availability of a community placement since services cannot be billed retroactively; therefore, the providers will not be paid for services provided prior to the PROMISE application approval. These delays affect the provider, who may be paying rent or a mortgage on homes they have secured, as well as maintaining staff for those homes, by creating a situation where they have resources committed for lengthy periods of time without funding for those commitments. Additionally, the person seeking the service does not receive it in a timely manner.

This particular issue with PROMISE is exacerbated by the limited funds that are available to the providers for residential start-up costs. Under the Chapter 51 regulations, these costs are capped at \$5,000 per new participant to the provider, and are additionally contingent on the availability of funds within the waiver appropriation.⁵ Reportedly, these funds are depleted within the first few months of the fiscal year. This issue is not specifically addressed in the Chapter 51 settlement agreement.

DHS is in the process of addressing the concerns with the length of time it takes to process PROMISE applications. ODP staff were trained in the process utilized by Office of Medical Assistance Programs (OMAP) to complete the PROMISE enrollment process and began enrolling ODP providers into PROMISE. One and one-half FTEs are now devoted to the ODP PROMISE enrollment process in the enrollment unit. Effective May 1, 2015, ODP adopted the same policy as the Office of Long-Term Living and OMAP regarding incomplete or incorrectly completed applications. In those cases, the application will be denied and returned to the provider with an explanation of what was wrong and informing them of their appeal rights.

⁴ The revised regulations will be Chapter 6100.

⁵ These funds are required to be repaid to the Department if the residential habilitation service location is sold within a five-year period, or, in the alternative and with the permission of the Department, the provider can re-invest the reimbursement amounts from the start-up funds into any capital asset used in the program.

In the past, ODP reports that it would work an average of 25 days with these providers to complete the application so it could be approved. It was determined that since this adds significantly to the overall timeline to complete PROMISe enrollment, ODP would no longer provide technical assistance but would provide the link to the website where line by line directions will assist the providers in completing the application correctly prior to resubmission.⁶

Recruitment and Retention of Staff

Many direct care staff for home and community-based service providers are relatively low paid, and providers report turnover rates of 10 to 80 percent, with 30 to 40 percent being cited as the typical turnover rate. Pay rates reported for direct care staff ranged from \$7.25 in central Pennsylvania to \$16.76 in northeastern Pennsylvania. The difficulty in attracting and retaining these employees has been a recognized national issue. In 2007, a report from the Research and Training Center on Community Living noted that:

A steadily aging population is increasing the challenge and perhaps eventually the outright competition for the resources needed of increasing numbers of persons with disabilities. Among the resources for which competition will likely occur is the essential human resource of the direct support workforce. Growing this already scarce resource will require adequate wages, benefits and career opportunities all of which themselves will compete with resource demands of the growing population of persons with disabilities.⁷

According to DHS officials, although the Department has given cost-of-living increases to providers, these increases may not necessarily be used to increase the pay of the direct care workers. Also, pay increases for direct care staff may necessitate a pay increase to other staff throughout the provider agency. In the case of an agency driven model (where services are provided through an agency to the individual), if there is no overall increase in the amount of funding for ID services, the providers will have to shift their funding around and may end up offering fewer services. In a consumer directed model (the individual is given a budget for services and hires their own direct care staff), any salary increase would be negotiated between the worker and the consumer within that budget.

CMS Final Rule Regarding Integration Standards

New integration requirements from the Centers for Medicare and Medicaid Services (CMS) were published in January 2014 and address several sections of Medicaid law under which states may use federal Medicaid funds to pay for HCBS.

⁶ The Department reports that the average time to qualify and enroll as a new provider is now down to 18 days, and enrollment can be retroactive to the date enrollment documents are submitted.

⁷ K. Charlie Lakin and Roger J. Stancliffe, *Residential Supports for Persons with Intellectual and Developmental Disabilities*, Research and Training Center on Community Living, University of Minnesota, (2007) p. 158.

The rule supports enhanced quality in HCBS programs, defines person-centered planning, and adds protections for individuals receiving services. In addition, the rule reflects CMS' intent to ensure that individuals receiving services and supports through Medicaid's HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting.

The final rule establishes requirements for home and community-based settings in Medicaid HCBS programs operated under sections 1915(c), 1915(i), and 1915(k) of the Act. According to CMS, the rule creates a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The purpose of the regulatory change is to maximize the opportunities for HCBS program participants to have access to the benefits of community living and to receive services in the most integrated setting and will effectuate the law's intention for Medicaid home and community-based services to provide alternatives to services provided in institutions.

To implement the changes required by the CMS final rule, DHS has a transition plan to determine its compliance with the requirements for home and community-based settings, and to describe to CMS how it will comply with the new requirements. A statewide plan covering all waivers was due by March 17, 2015, and a waiver specific plan was due when the waiver amendments were submitted after March 2014. DHS issued a draft transition plan for public comment and has met with providers to discuss its implications for home and community-based services. After consideration of the input received on the draft transition plan, an amended version was transmitted to CMS.

The transition plans for the Consolidated and P/FDS Waivers consist of three sections:

- *Identification* – The Office of Developmental Programs will use its waiver transition plan as a way to determine its compliance with CMS's rule on home and community-based services. ODP will determine what state actions are needed for compliance. This will include a review of current licensing requirements, policies, regulations, rules, standards and statutes.
- *Assessment* – ODP's assessment activities will include a review of policy documents and provider enrollment documents and a review of licensing requirements. Action items related to provider assessment are included in Section 3 Remediation Strategies for each HCBS requirement.
- *Remediation Strategies* – ODP's overall strategy will rely heavily on its existing HCBS quality assurance processes to ensure provider compliance with the HCBS rule. This will include provider identification of remediation strategies for each identified issue, and ongoing review of remediation status and compliance. ODP may also prescribe certain requirements to

become compliant. ODP will also provide guidance and technical assistance to providers to assist in the assessment and remediation process. Providers that fail to remediate noncompliant settings in a timely manner may be subject to sanctions.

The plans are to include start and end dates for each activity. States are to be fully compliant with the federal requirements by the time frames approved in their transition plan, but no later than March 17, 2019.

CMS limits the purpose of the transition plan to settings where waiver services are delivered. For example, the federal regulations state that home and community-based settings do not include a nursing facility, institution for mental diseases, ICFs/IID, and hospitals. It further states that settings in a publicly or privately owned facility that provide inpatient treatment; settings on the grounds of, or immediately adjacent to, a public institution; or settings that have the effect of isolating individuals receiving HCBS from the broader community of individuals not receiving HCBS, will be presumed not eligible. The requirement is that the setting is integrated in, and supports full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving HCBS.⁸

As services are reviewed by the Department, if they are found to have the effect of isolating individuals, the provider will be notified. These providers may demonstrate how the service currently meets the home and community-based characteristic policy, or they can submit a plan outlining how operations will be altered to meet the requirements for a home and community-based setting. This part of the process is to be completed by December 2017.

In those cases where a provider is determined to be ineligible, ODP will notify the individuals served by those providers, the Administrative Entities, and Supports Coordination Organizations that the provider is ineligible and what actions the individuals may expect by September 2018. The ISP team must discuss the option of other willing and qualified providers or other services that will meet the individual's needs and ensure their health and safety.

At this point, DHS efforts are focused on assessing regulations, standards, policies, licensing requirements, and other provider requirements to determine how

⁸ Sheltered workshops are one of the services that may be restricted under the integration standards as well as under a new rule designed to encourage competitive employment for most people with disabilities through modifications to the vocational rehabilitation program. In addition, H.R. 2015-188 proposes to phase out special wage certificates that allowed individuals with disabilities to be employed at subminimum wage rates.

to meet the federal requirements. In response to comments received about the need for revised service definitions from stakeholders, DHS stated that

...during implementation of the transition plans, the ODP will be reviewing whether new waiver service definitions are needed or current waiver service definitions should be revised to comply with the new federal regulations. Once this step has been completed, the ODP will work to develop provider capacity to render the services.

Transition of Residents From State Centers to Home and Community-based Services

Transition of a current state center resident to a community placement begins with a resident who does not object to the community placement. In the *Benjamin* settlement agreement there is a process to determine whether the resident should transition to the community when the resident cannot make his desires known and does not otherwise have a representative. (See Chapter II for a discussion of the settlement agreement.) At least some families are concerned that the level of services in the community may not be adequate to provide for the safety of their family members, and therefore, prefer their family member remain in the state center with the services, staff, and other residents whom they consider friends.

Many of the issues discussed above affect the growth of services in general, but also specifically impact the ability of state center residents to be transitioned to community placements. The process used to transition residents from the Embreeville Center when it closed in 1997 was pursuant to a settlement agreement and involved providing an individual transition plan for each resident moving to the community, developed through the person-centered planning process. Each resident was assigned a service coordinator and had an interdisciplinary team to assist making appropriate professional decisions regarding the resident's care, habilitation, and education. The agreement also required the Department to allocate funds to Embreeville residents' county of choice necessary to develop and provide the services and support needed by these residents. Additional state funds were allocated to participating counties equal to the amount of state funds allocated for residents of Embreeville to support unserved and underserved people. This type of funding to serve the residents moving into the community and additional funding to serve non-residents was also part of the process used to close the Western State Center.

The *Benjamin* settlement agreement similarly requires the development of an individualized plan to enable the resident to move to the community. Funding to assist in the community placement for start-up costs needed to develop new community residential services for the class members is to be sought from the federal Money Follows the Person program. A website was developed describing each class member and their specific service needs and supports that can be accessed by providers to offer their services. If a class member is not offered services within 45

days, a Department regional staff person will contact potential providers to identify what is needed in order for them to be able and willing to provide services and supports to that class member.⁹ Prior to discharge from the state center, an ISP is to be developed specifying the projected discharge date and describing the services and supports needed for the individual to live in the community. The ISP is to be developed by the resident's interdisciplinary team and include each type of service, including the residential placement, day or vocational programs, health care or nursing services, community psychiatric or behavioral health services, and assistive technology the class member will receive in the community, the amount of the service, and the provider who will provide the service.

Reportedly, this process has resulted in ISPs that are difficult for providers to fully address due to the limitation on the funding and the restrictive "exceptions" process in the regulations. Other difficulties cited by providers that are affecting their ability to transition residents from state centers to the community include inadequate assessments of the residents that result in additional services being necessary to support the individual in the community. This may be due to the state center staff involved in the assessments only being familiar with the individual's needs in the context of the state center, (e.g., on-site medical services).

At the March 2014 hearing of the PA House Human Services Committee, the Waiting List Project representative stated their recommendations as including a plan to close the state centers and for the Commonwealth to "commit to fully funding a robust and responsive community system capable of supporting all people with intellectual disabilities and autism. Each person in the community must be fully and appropriately served." She went on to note that this included improving the current service definitions to allow for real person-centered supports based on assessed needs. She also commented on the need to revise the restrictive regulatory language to enable providers and families more flexibility in organizing services to meet the individual's needs.

Services to assist dual diagnosed individuals, those with an intellectual disability and mental health or behavioral issues, are also needed since many of the current residents of the state centers have such needs. The need for these services was recognized by ODP in 2012 when it began an emphasis on the development of training for direct support staff and supports coordinators on the topic of dual diagnosis. The impact of the Chapter 51 regulations, as discussed previously, is particularly significant for providers offering services to this population. Exhibit 22 describes the difficulty in opening a community placement for an individual with a dual diagnosis transitioning from a residential treatment facility due to the start-up cost restrictions.

⁹ The third and fourth Benjamin status reports identify class members for whom the department is seeking providers to offer services. These class members have significant medical or behavioral issues.

V. Economic Development Potential of the Remaining State Centers

State centers have closed in Pennsylvania and in other states, directly impacting both the residents and staff of the facilities and, to a degree, local economies. The challenges facing DHS with a future closure of a state center are the relocation of residents, the impact on center staff, and the ability to sell or repurpose the facilities given the mostly rural locations of the remaining centers.

In the past, as state centers and units for individuals with intellectual disabilities have closed in Pennsylvania, many of the residents from these facilities have transitioned into community settings, but others have opted to transfer to another state center. Similarly, staff at these closed facilities have transferred to other operating facilities, accepted different positions within DHS, accepted positions in other state agencies, sought employment in the private sector, or retired. The facilities have been repurposed for public use, sold for redevelopment by the private sector, or maintained awaiting disposition. For example, the Washington County Authority redeveloped the Western Center to include office space, hotels, and restaurants, and a private holding company purchased the Embreeville Center property for residential development.

According to DHS officials, the funds that had been used for state center operations have remained with the Department to meet the increased need for community services when state centers have closed. The stakeholder groups have expressed their concern that these funds remain with the Department to serve individuals in community placements, rather than be used for other non-related activities. Proceeds from the sale of the facilities may, however, be required to be deposited into the state's General Fund. The General Assembly could establish a fund to collect the savings achieved through the transition of center residents into community placements and certain proceeds from the sale of facilities to provide a transparent means of tracking how these monies are used to provide community services to individuals leaving the centers. This fund could operate similarly to the Pennsylvania Justice Reinvestment Fund, which applies the savings from reductions to the inmate population to programs that support the delivery of criminal justice services throughout the Commonwealth.

Closed Facilities in PA

The Commonwealth has closed state centers in furtherance of its policy to support community living, whether or not as a result of litigation.¹ Final disposition

¹ Pennhurst is an example of a state center that closed after a lawsuit.

of the sites has been diverse; but until final disposition of the property, the Commonwealth accrues costs to maintain and secure the site.² The majority of closed state centers, however, have been sold for development. A prime example of this is the Western Center in Washington County, which closed in 2000.³

Western Center. The 37 buildings and 304 acres of land were purchased for \$2 million in 2003 by the Washington County Authority (WCA). All the buildings of the Center were cleaned of asbestos and removed. According to officials with the Authority, 217 acres of the Western Center have been developed into the Southpointe II Business Park with the core infrastructure completed in 2006. The final parcel of land was recently sold and construction of the final office building is expected during 2015.

The Authority estimates \$412 million of private investment was used to construct 19 Class A office buildings, two hotels, 360 upscale apartments, 60,000 square feet of retail space (primarily restaurants), and to create 5,000 jobs (currently employment is at 3,000 with the remainder to be hired when all the construction is completed). No Washington County tax dollars were used to develop Southpointe II. The WCA borrowed \$8 million, secured \$9 million in grant funding, and used land sales proceeds to clear the site, install the infrastructure, and pay down the debt.

Laurelton Center. The 336 acre Laurelton Center in Union County, closed in 1998, two years after the decision to close the facility was made. It was sold to Mountain Valley Inc. (MVI) for \$1.6 million in 2006. While negotiating the sale of the property, DHS expended between \$1 million and \$2 million annually for site security and maintenance.

Proceeds from the sale went to the state's General Fund less a portion, \$181,000, which went to the Agricultural Conservation Easement Purchase Fund.⁴ Plans by MVI to turn the site into a convention center, restaurant, dude ranch, and other outdoor activities have not yet been realized.

Altoona Center. The Altoona Center in Blair County closed in 2006 and was sold to the Altoona Regional Health System, a nonprofit community healthcare provider, in 2007 for \$250,000.⁵ The former center (now Building G of the Altoona Hospital Campus) became part of a \$60 million facility and service enhancement project.

² For example, in FY 1998-99, the Commonwealth expended \$4 million dollars to maintain and secure Embreeville, Laurelton, and Torrance. In FY 1999-00, maintenance and security at these same three facilities was \$2.8 million. From FY 1998-99 through FY 2010-11, expenditures ranged from a low of \$547,000 in FY 2010-11 to a high of \$5.1 million in FY 2000-01.

³ DPW made the decision to close the Western Center in 1998.

⁴ Act 2005-26.

⁵ Although the property's market value was determined to be \$1.5 million, DGS officials note that the valuation did not take into account significant adverse environmental conditions needing remediation.

Embreeville Center. The Embreeville Center in Chester County closed in 1997 and was purchased by a holding company for \$1 million for residential development in 2012. While awaiting final sale of the facility, about half of the property (just under 500,000 square feet) was rented to several tenants including: the Chester County Intermediate Unit, PA Clinical Schools, PA State Police, VisionQuest, and Southeast Secure Treatment Unit. The Department of General Services reported that the sale also eliminated \$500,000 in annual maintenance costs.

Other State Facilities. In addition to state centers that have closed, several state hospitals have also closed and are now serving a variety of other purposes. For example, Somerset State Hospital in Somerset County closed in 1995 and has been transformed into the Laurel Highlands State Correctional Institution (SCI). At least three other closed state facilities have become SCIs: Cresson, Retreat, and Waymart.

Woodville State Hospital in Allegheny County was demolished and is now the site of the PennDOT District 11 office with the remainder of the property sold for use as a school, shopping mall, and residential development. Scranton State Hospital was demolished in 1991 and construction completed on the site of the Gino J. Merli Veteran's Center in 1994. Haverford Township, Delaware County, purchased the Haverford State Hospital for \$3.5 million in 2002. The Township sold about 40 acres of the 209 acre site for residential development in 2007 for \$17.5 million. The Allentown State Hospital in Lehigh County closed in 2010 but remains for sale.

Other possible uses for closed centers have been suggested.⁶ These suggestions include: placing Career and Technology Centers (CTCs) on the campuses to offer educational and professional opportunities for individuals transitioning into communities, as well as community members in general, or establishing Community College campuses at these locations.

Closed ID Facilities in Other States

Other states have also closed large state-operated institutions and have either used the facilities for other state government purposes or sold the sites to other entities for development. For example, the Great Oaks Center in Maryland placed its residents in community settings and sold the site for the development of a \$250 million retirement community. Vermont's ICFs/IID either closed or were transitioned into group homes, and when Hawaii closed its one large facility in 1999, the residents were placed in the community, and the buildings on the campus are now being used by a variety of other state programs. Oregon sold one of its facilities and, like Hawaii, repurposed its other center as office space for the IDD program

⁶ Lindsay Shea, DrPH, MS; Kaitlin H. Kotter, MPH; Paul Turcotte, MPH; and Mary Mathew, MPH; *Olmstead Decision Implementation and the Five Pennsylvania State Centers*, Report III.

and a mental health program. Maine's Pineland Institution was sold to a foundation that renovated the property, and today it encompasses 5,000 acres of public recreational trails and areas.

Impacts of Closing a Facility

In 2011, an analysis of the impact of the closing of MH and developmental disabilities facilities in Illinois was undertaken by the University of Illinois' Regional Economics Applications Laboratory in the Institute for Government and Public Affairs⁷ in response to a bill before the Illinois Legislature. An expanded input-output model was used to capture the direct as well as the indirect and induced effect of the proposed closing in terms of county employment, income and production, and also state income and sales taxes. The study found that the total impact on the state's economy of closing the selected facilities would be the equivalent to approximately 8 percent of the jobs lost in the state during July 2011. However the magnitude of the economic impact would likely vary depending on the size of the communities involved, the accessibility to alternatives both in terms of jobs and care for residents, and the expected growth of other parts of the local economies in which the facilities were located.

The study suggests that finding alternative employment for the staff of the facilities could be difficult in smaller communities; and even in larger communities, specific job openings for the kinds of skills possessed by staff may not be available. Also noted was the difficult task of selling the houses of relocating employees given the depressed state of the housing market in some communities. In fact, this was thought to be more difficult than the task of finding another job.

The authors noted that important indirect impacts of closing these facilities were not addressed by the study. These impacts include, for example, the nature and volume of charitable contributions—both in time and money—provided by the facility employees, and the impact of the closure and relocation of facility employees and their families on school district enrollments.

In another study,⁸ three different cost categories associated with operating a state institution were defined. The first of these, variable costs, are those costs that vary with the number of individuals served or the number of hours of service delivered. The second category are fixed costs, which are those costs that do not vary with the number of individuals in the facility; for example, the costs of the physical plant and equipment. Finally, other costs, which are semi-variable in that they cannot be reduced in direct proportion with falling resident numbers, but over time these costs will decline. Food service personnel or medical records staff would be

⁷ Hewings, Wan, Du, and Dias; *Impact of the Closure of DHS Facilities, 2011*. Regional Economics Applications Laboratory, Institute of Government and Public Affairs, University of Illinois, August 2011.

⁸ Roger J. Stancliffe, PhD. and K. Charlie Lakin, PhD.; *Costs and Outcomes of Community Services for People with Intellectual Disabilities*; 2005.

examples of semi-variable costs. The degree to which a reduction in institutional expenditures will follow a reduction in the institutional population is determined by the relationships between these three categories of costs.

The closing of an institution would also include the costs for the continued operation of the institution during downsizing for the residents who remain and the additional costs associated with the transition assistance from institutional staff. The cost of community services for the former institution residents will also need to be met: one-time start-up costs, operating costs of community services, and additional case-management and transition assistance by community case managers.

As noted by several sources, intellectual disability services are staff intensive. With institutional residents transitioning into the community when a facility closes, the need for the number of community-based direct care workers increases, while the need for the number of workers at institutional settings declines. The large wage and benefit differential between the state employees who serve as direct care workers in public institutions and the private sector workers in community-service settings is seen as an issue that will impact the long-term costs of community-based services as community providers look to hire these displaced workers.

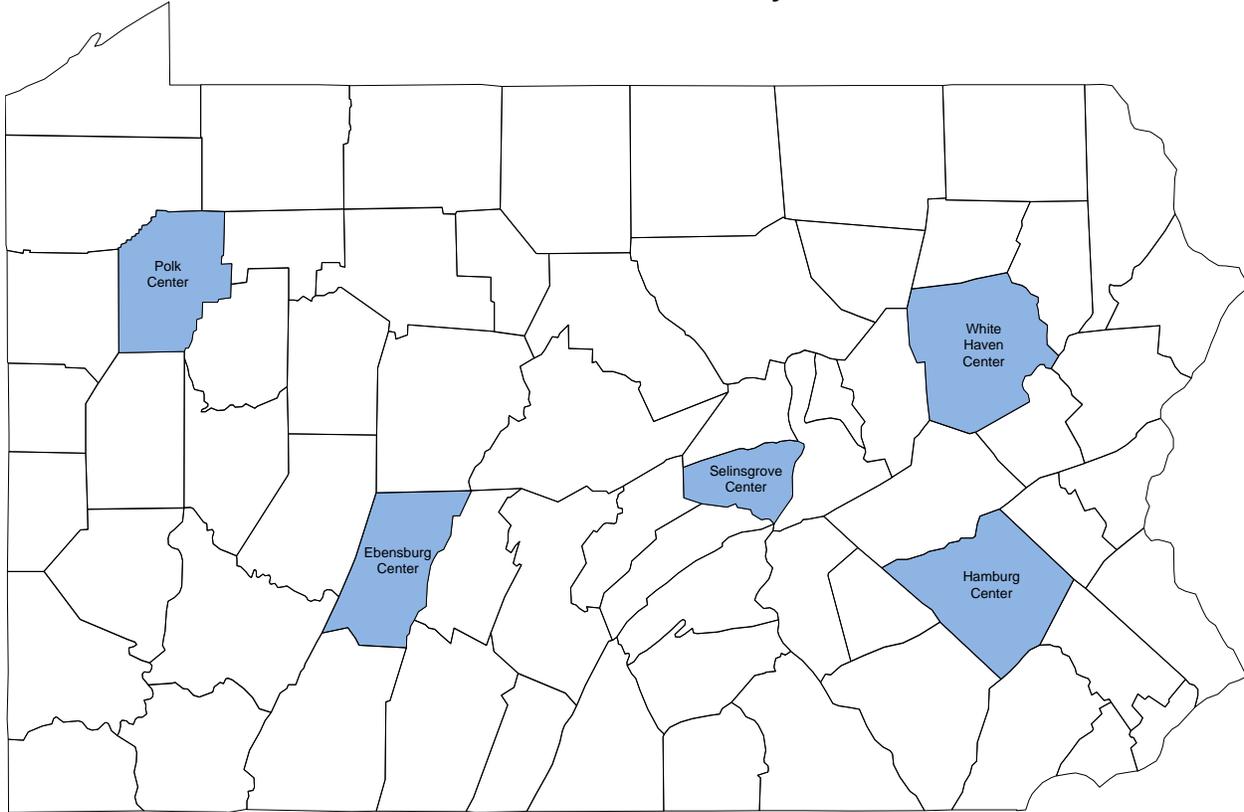
State Centers Currently Operating

As shown in Exhibit 23, the five remaining state centers are geographically dispersed and generally located in lesser populated, rural areas.

The five operating centers are:

- The Ebensburg Center in Cambria County opened in 1957 and is located on 61 acres near Ebensburg, about 21 miles west of Holidaysburg and Interstate 99.
- The Hamburg Center in Berks County opened in 1960 and is located on 157 acres about two miles from the intersection of Interstate 78 and State Route 61.
- The Polk Center in Venango County opened in 1897 and is located on over 800 acres near Polk and about 7 miles west of Franklin.
- Selinsgrove Center in Snyder County opened in 1917 and is located on 254 acres near Selinsgrove and about 12 miles southwest of Sunbury.
- White Haven Center in Luzerne County opened in 1956 and is located on 184 acres about 4 miles west of the intersection of I-80 and I-476.

ODP State Centers in Pennsylvania



Source: Developed by LB&FC staff using information from DHS.

As can be seen in Table 3, the five centers comprise 145 buildings currently in use on just under 1,400 acres of land. There are an additional 59 buildings not in use on the campuses of Hamburg, Polk, and Selinsgrove, with the majority, 37, at the Selinsgrove Center.

We contacted local economic development and planning officials to determine if they had included future development of the five remaining sites in their long-range planning. While each indicated that they would be interested in the opportunity to develop a closed state center in their area of the state, none of the groups reported having written plans anticipating this possibility nor would venture an opinion on the estimated market value of the center in their area.

To develop a rough estimate of how much might be saved in annual operating costs if all state centers were closed and ownership transferred, we took the average cost per individual receiving services in a state center in FY 2014-15 (\$330,223), subtracted from that the average cost to provide services to individuals in a private ICFs/ID (\$145,170) to yield an average savings of \$185,053 per individual moved

from a state center to a community-based setting.⁹ Using this approach, we estimate the saving to be generated by closing all state centers (total population of 948) would be approximately \$175.4 million annually (in 2015 dollars) in both federal and state funding. A more accurate estimate of potential savings should be available in a year or two after the Department has had experience with the individuals transferred to community settings as a result of the *Benjamin* decision.

Table 3

Size, Number of Buildings in Use, and Approximate Value of Currently Operating State Centers

	<u>Acres</u>	<u>Buildings In Use</u>	<u>Replacement Value^a</u>
Ebensburg	66	25	\$ 58,858,898
Hamburg	154	42	135,804,488
Polk	801	42	285,074,902
Selinsgrove ^b	254	40	17,592,051
White Haven	184	21	2,829,074

^a DGS has advised us that the replacement value is a representative value of the cost to build when built, i.e., if it was built in 1990, it would be the cost to build in 1990. The value information is inconsistently updated and is not intended to reflect market value. Appraisals are conducted prior to sale and because these are often purpose-specific facilities having limited adaptive reuse possibilities, the actual sale value may be less than the amount shown.

^b Building replacement value for Selinsgrove is only for 18 buildings.

Source: Developed by LB&FC staff using information from the Department of General Services (DGS).

Impact on Center Residents

As shown in Table 4, 948 individuals with intellectual disabilities currently reside in the state centers. In the event one of these closes, it is likely there will still be clients residing there, and arrangements would be necessary for the care of these residents elsewhere. In past state center closings, residents have been transferred to a different state center or to a community placement. For example, all 243 residents at Embreeville, the 54 residents at Somerset’s ID Unit, and the 22 residents at Mayview’s ID Unit were placed in community settings after the facilities closed. The 68 residents remaining at the Western Center when it closed were moved into the community, with a few opting to transfer to the Ebensburg Center. About half of Altoona’s 90 residents were placed in the community with the rest moving to Ebensburg. Most of the 193 residents of the Somerset ID Unit were moved into the community, but several transferred to the Selinsgrove Center. The

⁹ Although the average cost to serve an individual in the community setting (\$47,000) is much less than in a private ICF/ID, a much higher proportion of the individuals residing in a state center are severely or profoundly disabled (88 percent) as compared to individuals served in home and community based settings (16 percent). We therefore thought the cost to provide services in a private ICF/ID would yield a more realistic estimate of achievable savings.

residents in the Allentown State Hospital ID Unit were either placed in community settings or were moved to Wernersville State Hospital.

Table 4

Current Population and Staff by Center

As of July 2015

	<u>Resident Population</u>	<u>Total Staff</u>
Ebensburg.....	238	741
Hamburg	92	369
Polk	245	811
Selinsgrove	246	834
White Haven.....	<u>127</u>	<u>474</u>
Total	948	3,229

Source: Developed by LB&FC staff using information from the Department of Human Services (DHS).

According to DHS officials, with proper supports any resident of a state center can be served in the community. As discussed in Chapter IV, it may, however, be difficult to find providers able to offer the level of services needed. Many of the current residents of the state centers are medically involved, with 88 percent of the current residents diagnosed as severely or profoundly disabled. This compares to 16 percent of individuals similarly diagnosed who are receiving care through the HCBS system.

Impact on Staff

As with the center resident population, closing a state center would also impact staff working at the facility. As shown in Table 4, total staff employed at the centers was more than 3,200 in 2015. This is a decline of 365 employees, or 10.2 percent, since 2004. The majority of the staff working at the centers can be classified as direct care. See Table 5. Direct care workers declined by 7.8 percent since 2004, while center resident population declined 34 percent over this time period. As shown in Table 5, the reduction in staff differed among the state centers, with Ebensburg State Center direct care staff increasing 7.5 percent since 2004.

Union staff covered by furlough policy may be able to “bump” staff at other locations either within DHS or within other state government departments in the event of a closing. For example, the majority of the staff working at the Altoona Center, when it closed, transferred to positions at the Ebensburg Center. Staff at the Embreeville Center either retired, accepted other Commonwealth positions, or accepted furlough. Staff working at the Allentown State Hospital’s ID Unit either

Table 5

Staffing by Facility

	<u>2004</u>	<u>2015</u>	<u>% Change 2004 to 2015</u>
Ebensburg			
Administrative	43	35	-18.6%
Service	56	53	-5.4
Bldg. & Grnds. Maint.	69	68	-1.4
Direct Care	424	456	7.5
Medical and Program	<u>128</u>	<u>129</u>	0.8
Ebensburg Total	720	741	2.9%
Hamburg			
Administrative	26	25	-3.8%
Service	31	17	-45.2
Bldg. & Grnds. Maint.	51	51	0.0
Direct Care	229	206	-10.0
Medical and Program	<u>62</u>	<u>70</u>	12.9
Hamburg Total	399	369	-7.5%
Polk			
Administrative	53	32	-39.6%
Service	66	52	-21.2
Bldg. & Grnds. Maint.	102	87	-14.7
Direct Care	552	494	-10.5
Medical and Program	<u>191</u>	<u>146</u>	-23.6
Polk Total	964	811	-15.9%
Selinsgrove			
Administrative	44	39	-11.4%
Service	61	46	-24.6
Bldg. & Grnds. Maint.	103	85	-17.5
Direct Care	604	524	-13.2
Medical and Program	<u>177</u>	<u>140</u>	-20.9
Selinsgrove Total	989	834	-15.7%
White Haven			
Administrative	35	33	-5.7%
Service	42	33	-21.4
Bldg. & Grnds. Maint.	63	65	3.2
Direct Care	310	274	-11.6
Medical and Program	<u>72</u>	<u>69</u>	-4.2
White Haven Total	522	474	-9.2%

Source: Developed by LB&FC staff using information provided by DHS.

accepted positions in the Mental Health office or with other state agencies, retired, left for unspecified reasons, or were furloughed.¹⁰

With retirement as an option for employees affected by a closing, we looked at the center staff to determine how many current employees may be approaching retirement. Using either 60 years of age or 30 years of service as our criteria, 236 individuals, or 6.9 percent of staff, would meet these criteria. Those who may not be eligible to retire would be faced with the task of securing other employment, by either looking to continue with state government in a different location or capacity or by exploring job opportunities outside of state government.

It may be simplistic to assume staff working in state centers and opting to continue their career path within the community would be able to utilize their job skills to obtain equivalent positions with community providers. Although providers have told us they are always looking to hire direct care staff, the pay and benefits offered by private providers is typically significantly less than what direct care workers can earn in state government. Providers indicated a turn-over of direct care staff ranging from 10 percent to as high as 80 percent annually. The average is reported to be about 31 percent. The reasons cited for this high turnover rate are the demanding nature of the work and the relatively low pay offered these employees.

According to information from the residential and community provider association, direct care employees of their members are paid within a range from \$7.25 per hour to \$16.76, with the majority of starting wages at about \$10 per hour. In contrast, in state centers, residential aides are paid between \$11.66 (first step of pay range) and \$41.43 (last step of pay range). The difference in the hourly rates paid by the state centers and those offered by community providers make accepting a position working for a community provider less attractive to state center employees. Providers also acknowledge that they cannot compete with the benefits package offered to state center workers.

Treatment of Funds From Sale of State Property and Legislation Redirecting Savings to Community-based Services

Stakeholder groups have expressed concern regarding the use of both the proceeds from the sale of a closed ID property and the institutional savings generated from that closing. These parties believe the funds should be used to further support home and community-based services, but fear the money may end up in the General Fund and allocated to non-ID programs.

¹⁰ For confidentiality reasons, DHS was unwilling to provide us with access to its files related to prior state center closings and the placement of state center staff.

The current process in Pennsylvania for disposing of surplus property consists of first offering the property to any other state agency that may have a need. This is how, for example, the Somerset and Fairview State Hospitals became state correctional centers. If no state agency is interested in the property, then a member of the General Assembly or the Governor's Office can introduce legislation proposing how the property and any proceeds generated are to be disposed. Legislation authorizing the sale of the Laurelton Center, for example, also earmarked a portion of the proceeds to be deposited in the Agricultural Conservation Easement Fund.

Pennsylvania statute requires the Department of General Services to publish a public notice of the intent to sell the property if legislation is not used to dispose of the property. The lowest possible bid is the fair market value of the property. Once a bid is accepted, the General Assembly and Governor must approve the sale and, in this case, proceeds are deposited into the General Fund.

The use of the funds formerly used to provide institutional services for MH clients has been addressed by DHS in the Olmstead Plan developed by OMHSAS. In this plan, DHS states its intention to continue to re-direct funds from state hospitals to community settings. As units and facilities close, the funds and resources supporting the operation of the state mental hospital system (but not necessarily the proceeds of a sale) are to be used to expand the community-based infrastructure to serve and support those individuals now in the community.

In addressing a similar issue, the Maryland legislature established a continuing, non-lapsing Waiting List Equity Fund¹¹ to ensure that funds equal to the net average cost of serving individuals in a state residential center follow the individual leaving the center into the community. Any funds that may remain after the individual leaving the center is served in the community, subject to the appropriations process, are used to obtain services for individuals who are eligible but not currently receiving community-based services. Any balance at fiscal year's end remains in the Waiting List Equity Fund and is not transferred to the General Fund.

Establishing a special fund to capture and redistribute savings to community programs has also occurred in Pennsylvania. Act 2012-196 created the Pennsylvania's Justice Reinvestment Fund, where savings generated by improved efficiencies and the reduction of the inmate population are placed. These funds are then distributed as grants to support programs and activities that improve the delivery of criminal justice services within the Commonwealth. The Office of the Budget works in conjunction with the Department of Corrections to calculate the savings to be deposited into the Justice Reinvestment Fund.

¹¹ MD Code Ann. Health – Gen. §7-205.

VI. Appendices

APPENDIX A

PRINTER'S NO. 3738

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 903 Session of
2014

INTRODUCED BY MURT, DIGIROLAMO, MILLARD, KIRKLAND, DAVIS,
MCGEEHAN, ROZZI, MAHONEY, D. MILLER, DeLISSIO, COHEN,
READSHAW, O'NEILL, PARKER, PAINTER, THOMAS, ROEBUCK AND
McCARTER, JUNE 16, 2014

REFERRED TO COMMITTEE ON HUMAN SERVICES, JUNE 16, 2014

A RESOLUTION

Directing the Legislative Budget and Finance Committee to conduct a comprehensive review and issue a report of the Department of Public Welfare, Office of Developmental Programs' implementation of the 1999 ruling by the Supreme Court of the United States in *Olmstead v. L.C.*, relating to the closure of State centers for people with intellectual disabilities and the provision of home-based and community-based services.

WHEREAS, Known as the 1999 *Olmstead* decision, in a landmark interpretation of the Americans with Disabilities Act of 1990 (Public Law 101-336, 104 Stat. 327) (ADA), the Supreme Court of the United States ruled that people with disabilities have a right to receive care in the most integrated setting appropriate and that unnecessary institutionalization violates the ADA; and

WHEREAS, All states must comply with *Olmstead* and are required to have an *Olmstead* Plan with measurable objectives demonstrating how *Olmstead* will be implemented; and

WHEREAS, The Department of Public Welfare has not produced an *Olmstead* Plan for the Office of Developmental Programs demonstrating how the Commonwealth will move individuals with intellectual disabilities out of State centers; and

WHEREAS, In fiscal year 2013-2014, 1,060 individuals with intellectual disabilities were still residing in State centers; and

Appendix A (Continued)

WHEREAS, In fiscal year 2013-2014, 51,970 individuals with intellectual disabilities were receiving home-based and community-based services; and

WHEREAS, In fiscal year 2013-2014, the Department of Public Welfare had allocated funds to move 100 individuals from the State centers to the community; and

WHEREAS, From January 2013 through February 2014, 18 individuals have been moved from State centers into the community; and

WHEREAS, From January 2013 through February 2014, eight individuals with intellectual disabilities have been admitted to one of the State centers; and

WHEREAS, As of February 2014, 13,888 individuals with intellectual disabilities are on the waiting list for home-based and community-based services; therefore be it

RESOLVED, That the House of Representatives request the Legislative Budget and Finance Committee to conduct a comprehensive review and issue a report on the Department of Public Welfare, Office of Developmental Programs' implementation of *Olmstead* as it relates to the closure of the five State centers for people with intellectual disabilities and the provision of home-based and community-based services; and be it further

RESOLVED, That the report shall include the economic impact of the closure of the State centers, the potential for economic development of the five properties, opportunities for employees in the post-closure environment and the potential to reinvest post-closure financial savings in community-based supports for people on the waiting list for intellectual disabilities services; and be it further

RESOLVED, That the committee report to the House of Representatives on its activities, findings and recommendations by June 30, 2015, and issue interim reports to the House of Representatives as the committee deems necessary.

APPENDIX B

Background Information on the *Olmstead* Decision and Related Statutes

In May 1995, a mentally disabled woman identified as L.C. filed suit in the United States District Court for the Northern District of Georgia, challenging her continued confinement in a segregated environment. Three years prior to filing the suit, in May 1992, L.C. was voluntarily admitted to Georgia Regional Hospital at Atlanta (GRH) where she was confined for treatment in a psychiatric unit. By May 1993, L.C.'s treatment team agreed that she had stabilized and her needs could be met appropriately in a community-based state-supported program. Despite this evaluation, L.C. remained institutionalized until February 1996, when she was placed in a community-based treatment program.

Like L.C., another woman, identified as E.W., was voluntarily admitted to GRH in February 1995. In March 1995, GRH decided to discharge her to a homeless shelter; however, GRH abandoned this plan after E.W.'s attorney filed an administrative complaint. In 1996, E.W.'s treatment team decided that she could be treated in a community-based setting. However, she remained institutionalized until 1997. E.W. intervened in the suit filed by L.C., stating an identical claim.

In L.C.'s 1995 complaint, she alleged that the state failed to place her in a community-based program once her treating professionals determined that such placement was appropriate. Additionally, she requested that she be placed in such a community residential setting and that she receive treatment with the goal of integrating her into the mainstream of society. In its 1997 ruling, the District Court granted partial summary judgment in favor of L.C. and E.W., holding that the state violated Title II of the Americans with Disabilities Act. The District Court also rejected the state's argument that their failure to place L.C. and E.W. in a community-based setting was due to inadequate funding and not discrimination. The state also resisted court intervention of requiring immediate transfers to community-based programs because requiring such would "fundamentally alter" the state's activity in that the state was already using all available funds to provide services to other persons with disabilities. The court held that unnecessary institutional segregation of the disabled constitutes discrimination per se, which cannot be justified by a lack of funding. Further, the court held that providing community-based treatment services would cost considerably less than what is required to maintain them in an institution.

The Court of Appeals for the Eleventh Circuit affirmed the District Court's decision, but remanded to the District Court the state's cost-based defense for reassessment. The Court of Appeals held that, while the state's duty to provide integrated services is not absolute, Congress, in enacting Title II, wanted to permit a cost defense only in the most limited of circumstances.

Upon further appeal, in 1999, the United States Supreme Court issued its landmark decision known as the *Olmstead* decision.^a As noted earlier, this case involved an interpretation of the Americans with Disabilities Act of 1990 (ADA). In it, the court ruled that people with disabilities have a right to receive care in the most integrated setting appropriate and that unnecessary institutionalization violates the ADA. More specifically, the court held that unjustified segregation of individuals with disabilities is prohibited by Title II of the ADA, which states that public entities are required to provide community-based services to persons with disabilities when

- Such services are appropriate;
- The affected persons do not oppose community-based treatment; and
- Community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who are receiving disability services from the entity.

^a *Olmstead v. L.C.*, 527 U.S. 581 (1999).

To comply with the ADA's integration mandate, public entities must reasonably modify their policies, procedures, or practices when necessary to avoid discrimination. The obligation to make reasonable modifications may be excused only where the public entity demonstrates that the requested modifications would fundamentally alter its service system.

An Olmstead Plan is a public entity's plan for implementing its obligation to provide individuals with disabilities opportunities to live, work, and be served in integrated settings. The Plan must have specific and reasonable time frames and measurable goals for which the public entity may be held accountable, and there must be funding to support the plan, which may come from reallocating existing service dollars.

Relevant Legislation

Federal

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) gives civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications.

More specifically, the ADA, at 42 U.S.C. §12132, prohibits discrimination against individuals with disabilities by public entities:

No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

As directed in the law, the Attorney General issued regulations implementing these provisions, which are based on regulations issued under §504 of the Rehabilitation Act. These regulations require public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The preamble discussion of these "integration regulations," as they are commonly known, explains that "the most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible...."

Public Health and Welfare Code, §12101

In this federal law, Congress declared that, "historically, society has tended to isolate and segregate individuals with disabilities." Congress also declared that, "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." Thus, Congress set out in §12101, that the purpose of the law is

- to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- to ensure that the federal government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

State

Mental Health and Intellectual Disability Act^b

Under this act, the Department of Public Welfare is to, among other duties,

assure within the State the availability and equitable provision of adequate mental health and intellectual disability services for all persons who need them, regardless of religion, race, color, national origin, settlement, residence, or economic or social status.

This act also provides for mental health and intellectual disability services to be provided by counties. Specifically,

The local authorities of each county separately or in concert with another county or counties, as the secretary may approve, shall establish a county mental health and intellectual disability program for the prevention of mental disability, and for the diagnosis, care, treatment, rehabilitation and detention of the mentally disabled and shall have power to make appropriations for such purposes.

Public Welfare Code

This law provides that the Department of Public Welfare is to have supervision over all state institutions, including those facilities for persons with physical and mental disabilities. This supervision includes, for example, visiting and inspecting the facilities and examining the care and treatment of residents of the facilities.

Pennsylvania

In fiscal year 2013-2014, there were 1,060 individuals with intellectual disabilities residing in state centers, and 51,970 individuals with intellectual disabilities receiving home-based and community-based services. As of February 2014, 13,888 individuals with intellectual disabilities were on a waiting list for home-based and community-based services. The five state centers include: Ebensburg, located in Cambria County; Selinsgrove, located in Snyder County; White Haven, located in Luzerne County; Polk, located in Venango County; and Hamburg, located in Berks County.

In June 2014, a class consisting of more than 1,200 intellectually disabled individuals residing in Pennsylvania's state facilities agreed to settle with the Department of Public Welfare in a suit that alleged that DPW violated the Americans with Disabilities Act by failing to provide integrated community-based services. The settlement agreement would give institutionalized individuals a choice of where they can be placed—either in a community setting or at a state-operated intermediate care facility.

Pursuant to the settlement, class members who prefer to live in a community setting will be placed on a planning list, and DPW will be responsible for implementing an "integration plan" to schedule the moves. The settlement calls for 80 class members to be moved by June 30, 2015, and an additional 50 will be moved in each of the fiscal years 2015-2016 through 2017-2018. The settlement agreement is scheduled to terminate on June 30, 2018, by which time all class members who desire to move to a community setting are expected to have been moved.

^b This act is the former Mental Health and Mental Retardation Act of 1966. Act 2011-105 amended the name of the act.

Source: Developed by LB&FC staff from a review of the laws and court cases cited herein.

APPENDIX C

Pending Bills

HB 132: provides for Commonwealth support for a Mental Health and Intellectual Disability Staff Member Loan Forgiveness Program.

HB 133: establishes a bill of rights for individuals with intellectual and developmental disabilities; requires the Department of Human Services to develop and submit a plan to address the waiting list for community based services for people with intellectual disabilities.

HB 183: repeals the Human Services Block Grant program and replaces it with a simplified and less costly method for counties to reallocate human services money at the local level.

HB 199: provides for a 65 cents per ounce tax on the retail sale of smokeless tobacco products to help fund the Intellectual Disabilities and Autism Waiting List Account, which is to be used to fund home and community based services for those who are waiting for such services.

HB 221: provides for training for law enforcement and minor judiciary to recognize individuals suffering from mental health conditions or intellectual disability.

HB 400: establishes the "Work Experience for High School Students with Disabilities" Act.

HB 949: amends the funding formula for county MH/MR services to include population demographics in the formula.

HB 991: provides for a \$3 waste disposal fee for all solid waste disposed of at a municipal waste landfill to help fund the Intellectual Disabilities and Autism Waiting List Account, which is to be used to fund home and community based services for those who are waiting for such services.

HB 995: provides for a 4 cents per cigarette tax on cigarettes to help fund the Intellectual Disabilities and Autism Waiting List Account, which is to be used to fund home and community based services for those who are waiting for such services.

HB 1017: provides for a \$2 per patron casino admission fee to help fund the Intellectual Disabilities and Autism Waiting List Account, which is to be used to fund home and community based services for those who are waiting for such services.

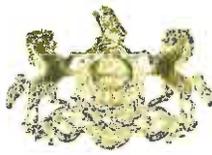
SB 200: establishes the "Work Experience for High School Students with Disabilities" Act.

SB 613: expands the Human Services Development Block Grant program by removing from statute the limit on the number of counties that are able to participate in the grant program.

SB 671: provides for Commonwealth support for a Mental Health and Intellectual Disability Staff Member Loan Forgiveness Program.

Source: Developed by LB&FC staff, as of July 31, 2015.

APPENDIX D
Response to This Report



COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF HUMAN SERVICES

September 28, 2015

Mr. Philip R. Durgin
Executive Director
Legislative Budget and Finance Committee
P.O. Box 8737
Harrisburg, Pennsylvania 17105-8737

Dear Mr. Durgin:

Thank you for providing a draft copy of the Legislative Budget and Finance Committee's (LBFC) report titled *Department of Human Services' Implementation of the Olmstead Decision As It Pertains to State Centers*, and allowing the Department of Human Services (Department) to submit comments.

House Resolution 2014-903 directed the LBFC to conduct a comprehensive review of and report on the implementation by the Department's Office of Developmental Programs (ODP) of the U.S. Supreme Court's 1999 ruling in Olmstead v. L.C., as related to the five state-operated centers for individuals with an intellectual disability. In addition, the resolution requested that the report include an assessment of the economic impact of the closure of the state centers, and post-closure potential economic development of the five properties, opportunities for employees, and potential reinvestment of savings in the community system for individuals with an intellectual disability.

As the draft report describes, the Department has made significant strides in developing community services for residents of state centers. The process of offering community alternatives began in the 1970s. This work continued into the 1980s, with the closure of the Pennhurst, Marcy, Woodhaven, and Cresson Centers, as well as several units on the grounds of state hospitals. The report recognizes the adoption of the 1997 Multi-Year Plan, under which the Department closed the Laurelton and Embreeville Centers and the Torrance Unit, before the Olmstead decision, and the Western Center and the Mayview Unit after Olmstead was decided. The census dropped by over 1,200 of the approximately 3,000 people living in state centers at the time the Department adopted the plan. In accordance with the Multi-Year Plan, the Department also closed the Altoona Center in 2006.

In response to advocacy for the needs of people on the waiting list, not just those living in state centers, the Department adopted the *Long-Term Plan to Address the Waiting List for Mental Retardation Services* in Pennsylvania in 1999. The adoption of this plan

resulted in significant expansion of services for individuals on the waiting list and underscored a new balance – addressing the needs of people on the waiting list as well as in the state centers for community services. Going forward, this balance must continue in our planning and budgeting efforts.

The historical growth of community services, and the accompanying decline in the number of people living in state centers, slowed considerably for a few years after 2007. Unlike many states that implemented reductions in service, Pennsylvania managed to maintain levels of services. Growth in the program did not resume in the community system until FY 2011-2012.

The movement of individuals from state centers, as well as from private facilities, continues. As noted in the report, under the Benjamin Settlement Agreement, the Department will plan for individuals who themselves or whose guardians do not object to transferring to the community. As of August 31, 2015, 43 individuals moved from state centers to reside in community settings under the terms of the Benjamin Settlement Agreement. The Benjamin status report states this number as 46, which reflects the number of people who moved from the Planning List because they moved from the state centers. Of that number, two former residents moved to nursing facilities, which the Department does not consider a “community setting” for purposes of this sentence, and one returned to the state center from the community.

As a result of the Department’s effort to develop community services for both persons on the waiting list and residents of state centers, 95 percent of the 53,200 people receiving services are receiving their services in the community.

After careful review, the Department offers the following comments regarding the findings in the LBFC’s report:

Page S-2, Benjamin Settlement section, I. 7 – “The resulting settlement agreement requires the Department to move 230 residents of the state centers into community placements through the development of a viable integration plan ...”

Comment: Note that the agreement explicitly provides that the annual number of people is contingent on the number of residents who want to move or whose guardians want them to move to the community or are determined to be appropriate for the community.

Page S-2 – “Formal Olmstead Plan” section

Comment: The Benjamin Settlement Agreement is the Department’s Olmstead plan for persons with an intellectual disability through June 2018. The agreement was developed as such, and accepted as such by the court, the Plaintiffs (represented by the Disability Rights Network), and the intervenors (residents of the state centers who opposed moving to the community). It is not required that an Olmstead plan go into the indefinite future or address admissions to state centers in order to be considered a

comprehensive, effectively working plan. The Department intends to develop an Olmstead plan that will be effective when the Benjamin Settlement Agreement expires.

Page S-3 – “The DHS does have an Olmstead Plan for individuals receiving mental health treatment. This plan requires at least 90 patients to be discharged, with their beds closed to future admissions, each fiscal year with the resultant savings to be provided to the counties to develop and support necessary community services and infrastructure.”

Comment: House Resolution 2014-903 was limited to addressing the Department’s implementation of the Olmstead decision, as related to the five state-operated centers for individuals with an intellectual disability. In addition, the resolution requested that the report include an assessment of the economic impact of the closure of the state centers, and post-closure potential economic development of the five properties, opportunities for employees, and potential reinvestment of savings in the community system for individuals with an intellectual disability. The resolution does not request the LBFC to address the Department’s work related to the state hospital system for individuals with mental illness.

Page 17 – “At least 90 beds are to be closed each fiscal year by discharging at least 90 state hospital residents each fiscal year.”

Comment: Again, the resolution is not directed to the Department’s work related to individuals with mental illness. However, the Office of Mental Health and Substance Abuse Services plan is under review and the Department plans to release the revised plan in October 2015. One change will be that the Department will request funding to move 90 individuals out of the hospitals each year, but will not automatically close 90 beds as referenced above. The Department has repurposed beds for specialty units or as supplement to the forensic level of care delivery and will continue to do so.

Page 18, 2nd paragraph

Comment: See comment to S-2, Benjamin Settlement section, above.

Page 39, “Chapter 51 Regulations Reportedly Slowed Growth in Provider Services”

Comment: This section notes the Department’s 55 Pa Code Chapter 51 regulations are the major reason for the delay in the development of community services. While it is true that finding a provider match can be challenging, the Department has developed programs for individuals. For example, 3,300 people on the waiting list started receiving services after the regulations were issued. In fact, growth has continued every year while Chapter 51 regulations have been in place – more services, more units, and more people receiving services.

Page 47, first and second full paragraphs

Comment: ODP is working with providers to address the concerns identified in these paragraphs.

In addition, the Department responds to the recommendations made by the LBFC as follows:

1. ***“The General Assembly consider ensuring that monies saved due to the transitioning of residents of state centers to community services, or from the future closure of state centers, be used to provide additional community based services for individuals with intellectual disabilities. These funds should supplement, and not supplant, ongoing funding for these services, and could be used specifically to reduce the waiting list for services. One approach would be to create a special fund, similar to the Pennsylvania Justice Reinvestment Fund (see page 58), for these funds. Such a fund would provide transparency regarding the use of the funds to the stakeholders and public.”***

Comment: Funding levels for ODP over the past two decades reflect growth in the community service system greater than the decreases in the budget for state centers. Without creation of a special fund or requirement, all previous administrations have appreciated that the needs of individuals and families who are on the waiting list must be met and have therefore committed to increasing funding for community services beyond the resources needed for people leaving state centers.

Funds have been redistributed from reducing the census at or closing state centers through adjustments to the appropriation for ODP programs, including the line items for the state centers and community services. This practice can and should continue in the future.

2. ***“DHS create an Olmstead Plan for the continued transition to community placements of state center residents who do not object to community placements using the Benjamin Settlement Agreement and the MH Olmstead Plan as guides. The plan should be adopted on or before the expirations of the Benjamin Settlement Agreement in June 2018. This plan should be developed with the input of the ODP Advisory Committee for Mental Health and Intellectual Disabilities, IDD service providers, county IDD staff, and other stakeholders. The plans should address fostering the availability of the supports necessary to ensure successful transitions through the identification of appropriate services and met the DOJ guidelines regarding the time frames and management goals (see page 14).”***

Comment: The Department will develop an amended Olmstead Plan for the transition of residents in state centers who do not object to moving to the community, to be adopted when the Plan reflected in the Benjamin Settlement Agreement, expires in June 2018.

3. ***“DHS conduct a review of the current operation of state centers to identify whether center operations could be consolidated. This would continue a past unofficial practice of the Department to review these centers when their census falls below 100 residents. At this time, one center has fewer than 100 residents and another has fewer than 150 residents.”***

Comment: The Department recognizes that the costs of individual centers increase as the census declines. Consolidation involves the movement of individuals in a center to another center in the Commonwealth, which is often not in the best interest of the residents who remain at the center when the census is reduced. Even when centers are not consolidated, the Department does consolidate operations within a center as the census in the center declines by, for example, closing or merging units, reassigning staff within units, and similar actions.

4. ***“DHS consider, with the input of the ODP Advisory Committee for Mental Health and Intellectual Disabilities, restricting new admissions to designated state centers. Although this may be difficult for families due to the locations of the state centers, as long as new residents continue to be admitted to all centers, fixed costs and staffing will remain high at all the centers, and closing due primarily to attrition will be less likely.”***

Comment: Admissions to state centers are limited to extraordinary situations, and are directed by court order. ODP staff go to considerable lengths to provide consultation and resources to administrative entities when an individual is at risk of admission. In addition, the Department routinely opposes court-ordered admissions of individuals for whom community services are available.

During FY 2014-2015, six individuals were admitted from psychiatric facilities, hospitals and prisons, all as court commitments. These individuals were in crisis when they came to the attention of ODP, with little notice and no alternatives. Because such crisis admissions almost always involve individuals who present with challenging behavior and the need for stabilization, the state center to which someone is admitted is given careful consideration. The relatively small number of admissions has minimal, if any, impact on fixed costs and staff at the centers.

Thank you for the opportunity to submit these comments. Should you need further information, or have questions, please contact Mr. Abdoul Barry, Director, Office of Legislative Affairs at 717-783-2554.

Sincerely,



Theodore Dallas
Secretary