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Profile of Pennsylvania: A Model for Assessing a State Long-Term Care System

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The opinions expressed in this report are those of the author and do not necessarily reflect the views of the Centers for Medicare and Medicaid Services or Thomson Medstat. The authors thank the many people in Pennsylvania who informed this report, with special thanks to the Commonwealth of Pennsylvania.

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Forward

In response to the advocacy of people with disabilities of all ages and their families, many states are rebalancing their long-term support systems to reduce institutionalization and increase opportunities for people to live in the community. Between 1995 and 2005, for example, the share of Medicaid long-term care spending for home and community-based services (HCBS) increased from 19 to 37 percent.[1] In addition to considerable work at the state and local levels, the Centers for Medicare & Medicaid Services (CMS) has supported state rebalancing efforts in several ways, including policy changes that allow states more Medicaid flexibility to design their long-term care systems and seed money for new initiatives through the Real Choice Systems Change Grants.

As states continue to rebalance their systems, it is important to assess their progress. Developing a profile of a state's long-term support system can assist with this assessment, as shown below.

A State Long-Term Care Profile Can:

- Provide policymakers and stakeholders with a high-level view of the long-term support system, to ensure a common knowledge base;
- Identify opportunities for improved coordination – among long-term support programs and with other health and social services;
- Acknowledge the success that has occurred;
- Identify service gaps; and
- Provide a framework for comparing rebalancing efforts across states.

Recognizing the importance of measuring progress toward rebalancing, CMS contracted with Thomson Medstat to develop a model profile of one state's long-term care system and a companion technical assistance guide that other states can readily use to replicate and adapt the profile. This document is the model profile, based upon an analysis of the Commonwealth of Pennsylvania's long-term support system across all disability and age groups.

The profile is based on a variety of state and federal sources and interviews with many Pennsylvanians involved in the system. To begin, Medstat analyzed several national sources that provide data about each state's long-term supports. Pennsylvania's budget and planning documents, along with the state Web sites, provided an overview of the Commonwealth's programs and program data such as the number of people served and expenditures. Pennsylvania staff supplemented these sources as requested by Medstat to fill any gaps in the data.

[1] Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006.

For qualitative information, Medstat interviewed senior and mid-level administrators of long-term supports; local administrative staff and management; and leaders from several consumer, family, and provider groups involved in long-term care. Medstat and Pennsylvania also arranged four group interviews with 8 to 10 people with disabilities and their family members to illustrate specific challenges people face and the degree to which they have been addressed. Medstat was only able to meet stakeholders near the two major cities and the capitol (Philadelphia, Pittsburgh, and Harrisburg, respectively), so this profile may not capture differences in the system that manifest in other regions. The technical assistance guide discusses the methods for developing the profile in more detail.

Organization of the Profile

The profile begins with a background section that focuses on three factors that have shaped Pennsylvania's long-term support system and its recent rebalancing efforts: 1) demographic indicators of long-term support demand; 2) traditional service utilization patterns; and 3) the support system's unique historical and political characteristics. The next section provides an overview of state and local long-term care administration. This section introduces the government agencies responsible for publicly funded services and describes the roles the legislature and consumers and families have typically played in systems change.

The bulk of this report describes the long-term support delivery systems for major population groups – defined by either age or type of disability – that account for most people who need home and community-based services. Five groups were selected that reflect the organization of Pennsylvania's long-term support system: older adults, people with physical disabilities, people with mental retardation[2], people with mental illness, and children.

For each population group, we present information on the range of available home and community supports for that group. Any notable gaps in coverage are discussed, whether a lack of needed services or people ineligible for service. The profile also presents data on demographic and utilization trends for each population group related to the state's rebalancing efforts. Finally, each population is profiled from the perspective of eight infrastructure components that have been previously identified by researchers as important to a rebalanced long-term support system (see below):[3]

[2] Pennsylvania operates a separate system specifically to serve people with mental retardation. Other long-term supports programs for people with developmental disabilities are part of the system that serves people with physical disabilities. As discussed on page 35, people who do not fit into either system do not have access to services.

[3] See, for example: Crisp, Suzanne et al. *Money Follows the Person and Balancing Long-Term Care Systems: State Examples* Medstat: September 29, 2003; Eiken, Steve and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Colorado's Single Entry Point System* Medstat: December 18, 2003; Horvath, Jane and Thompson, Rachel *Promising Practices in Long Term Care System Reform: New Hampshire's Community-Based Service System for Persons with Developmental Disabilities* Medstat: December 5, 2003; Justice, Diane *Promising Practices in Long Term Care System Reform: Vermont's Home and Community Based Service System* Medstat: September 8, 2003; Justice, Diane and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Oregon's Home and Community Based Services System* Medstat: June 18, 2003; Mullen, Dorothy et al. *Promising Practices in Long Term Care System Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation* Medstat: March 3, 2003; Reinhard, Susan C. and Fahey, Charles J. *Rebalancing Long-Term Care in New Jersey: From Institutional toward Home and Community Care* Milbank Memorial Fund: March 2003.

Key System Components:

1. **Consolidated state agencies** – a single agency for both institutional and community services that coordinates policies and budgets to promote community options;
2. **Single access points** – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of available options before receiving more restrictive services;
3. **Institution supply controls** – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
4. **Transition from institutions** – outreach to identify residents who want to move and assistance with their transition to the community;
5. **A continuum of residential options** – availability of support services in a range of options from mainstream single-family homes and apartments to integrated group settings for people who need 24-hour supervision or support;
6. **HCBS infrastructure development** – recruitment and training to develop a sufficient supply of providers with the necessary skills and knowledge to encourage consumer independence;
7. **Participant direction** – people who receive HCBS having primary decision-making authority over their direct support workers and/or their budget for supports; and
8. **Quality management** – an effective system that: a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

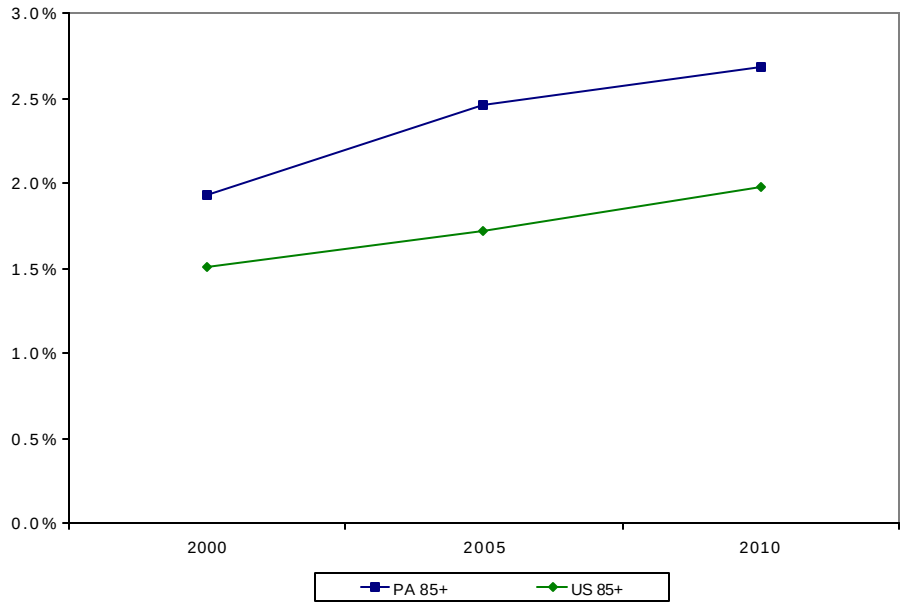
Section I. Background

Each state's long-term support system is shaped by factors that are unique to that state, including: the state's demographic makeup, historical service utilization patterns, and its political and organizational structure. This section describes how each of these factors has helped shape Pennsylvania's unique long-term support system.

Demographics

The Commonwealth of Pennsylvania has unique demographics that create a relatively high demand for long-term care services. First, its elderly population is large and growing. Pennsylvania has the third highest proportion of people over the age of 65 among the states.[4] The state's elderly population is also skewed toward older age cohorts and the population age 85 and older has been growing rapidly since 1990.[5] In the current decade, the U.S. Census Bureau projects this age cohort will grow 42%, from 238,000 to 338,000 people, while the overall population in the state will grow only two percent.[6] In essence, Pennsylvania is currently experiencing the kinds of demographic changes that most states will not experience for another 15 to 20 years.

Chart 1. Percentage of Population Age 85 or Older, 2000 – 2010

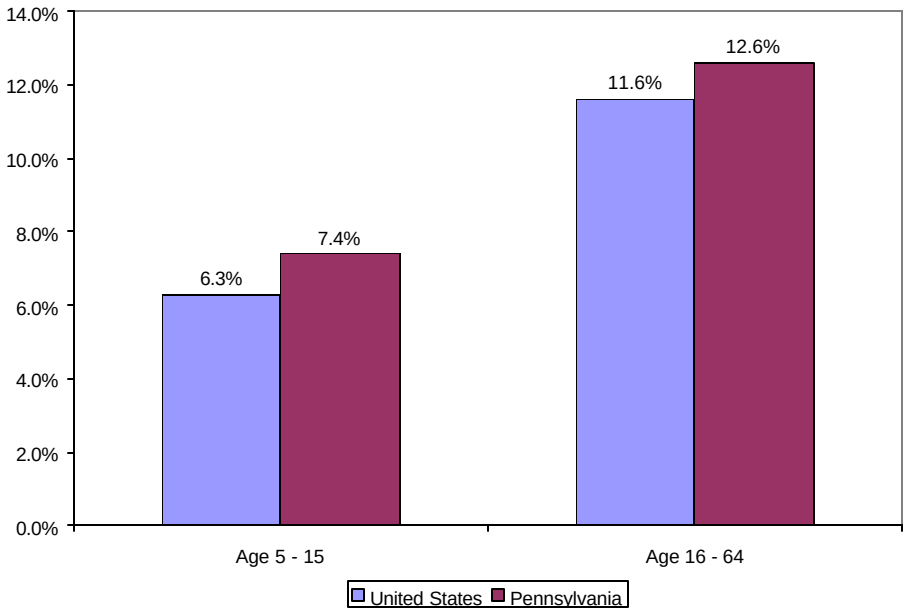


Sources:
See Footnotes 1 and 3

[4] U.S. Census Bureau "Table 1: Estimates of the Resident Population by Selected Age Groups for the United States and States and for Puerto Rico: July 1, 2005 (SC-EST2005-01)" August 4, 2006.
[5] Legislative Budget and Finance Committee *Long Term Care for the Elderly in Pennsylvania* Pennsylvania General Assembly: April 2005.
[6] U.S. Census Bureau "Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: July 1, 2004 (SC-EST2004-AGESEX_RES)" March 10, 2005 and U.S. Census Bureau "Interim Projections of the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030" April 21, 2005.

Second, the Commonwealth has a relatively high incidence of disability among people under age 65, as shown in Chart 2 below.

Chart 2. Percentage of People under Age 65 with Disabilities, 2004



Source: U.S. Census Bureau, American Community Survey, *2004 Ranking Tables* August 30, 2005

Service Utilization Patterns

Pennsylvania's demographic characteristics help put its relatively high Medicaid long-term care expenditures into perspective. Compared to the national average, the Commonwealth spends a high proportion of its Medicaid budget on long-term supports, particularly nursing facility care. See Table 1 for several measures of expenditures and utilization.

On a per capita basis (spending per state resident) Pennsylvania was the second highest state in Medicaid expenditures for nursing facility care in Federal Fiscal Year 2005.[7] One factor is the large older adult population in Pennsylvania. In addition, about 30 percent of nursing facility expenditures was payments above the cost of services in order to obtain additional federal matching funds.[8] States are allowed to pay certain providers supplemental payments that exceed the actual cost of services as long as total Medicaid payments do not exceed the amount Medicare would pay for the same services (called the Upper Payment Limit).

[7] Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006.
[8] Commonwealth of Pennsylvania *2006-2007 Governor's Executive Budget* February 8, 2006. Pennsylvania is gradually reducing these supplemental payments between 2005 and 2010 to meet federal requirements that limit these initiatives.

Even when removing Upper Payment Limit expenditures and adjusting for the number of people age 65 and older, Pennsylvania's nursing facility spending was 22 percent above the national average.[9] However, the latest data available for Medicaid nursing home utilization, measured on an age-adjusted basis, indicates Pennsylvania is slightly *below* average[10] (See Table 1). Relatively high nursing facility reimbursement rates, which are fairly typical in the northeastern United States,[11] are the primary factor for the state's high Medicaid spending for nursing homes.

Table 1. Long Term Care (LTC) Expenditures and Utilization, Pennsylvania and United States

	Pennsylvania	United States
Proportion of Medicaid budget spent on LTC (2004)[1]	36.4%	30.8%
Proportion of Medicaid LTC budget spent on nursing facilities (2004)[1]	60.9%	49.4%
Per capita Medicaid nursing facility expenditures, per person 65+ (2003)[2]	$1,285	$1,146
Medicaid nursing facility days, per thousand persons 65+ (2003)[2]	10,139	10,394
Per diem nursing facility reimbursement rates (2002)[3]	$138	$118
Total nursing facility residents, per thousand persons 65+ (June 30, 2005)[4]	40.8	38.2
Percent of total nursing facility residents indicating a preference to return to the community (2nd quarter, 2005) [5]	18.4%	20.6%
HCBS expenditures for older adults and people with physical disabilities, per capita (2005)[6]	$58	$63
Annual rate of growth in HCBS Waiver expenditures for older adults and people with physical disabilities (2000-2005)[7]	41%	12%

Sources:

[1] Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2004" Thomson Medstat: May 11, 2005, adjusted based on Medstat analysis of 27 states' budget and legislative documents regarding Upper Payment Limit programs

[2] See Footnote 9

[3] See Footnote 10

[4] See Footnote 11

[5] See Footnote 12

[6] See Footnote 13

[7] See Footnote 14

[9] Burwell, et al. "Medicaid Long Term Care Expenditures in FY 2005"; Commonwealth of Pennsylvania *2006-2007 Governor's Executive Budget*; and U.S. Census Bureau, "Table 1: Estimates of the Resident Population by Selected Age Groups for the United States and States and for Puerto Rico: July 1, 2005 (SC-EST2005-01)".

[10] Medstat analysis of data from the Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart and U.S. Census Bureau "SC-EST2004-AGESEX_RES: Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: July 1, 2004" March 10, 2005.

[11] Grabowski, D.C.; Feng, Z.; Intrator, O.; and Mor, V. "Recent Trends in State Nursing Home Payment Policies" *Health Affairs* Web Exclusive: June 16, 2004.

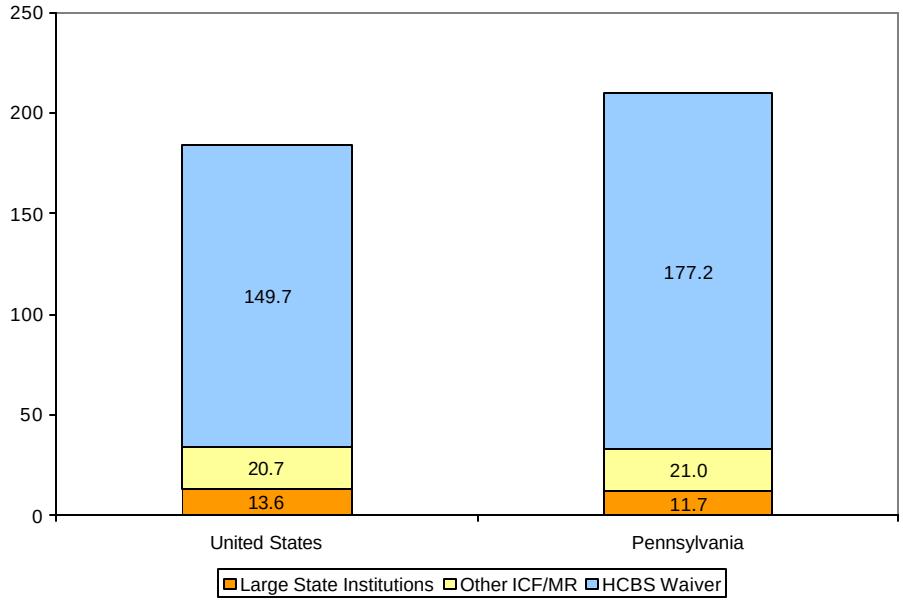
When including Medicare and privately funded residents, however, Pennsylvania's nursing facility utilization rate is above the national average. As of June 30, 2005, the Commonwealth had 77,254 total nursing facility residents, a rate of 40.8 residents per 1,000 people age 65 or older. The national rate was 38.2 residents per 1,000 elderly individuals.[12] Approximately 14,200 of these nursing facility residents (18.4%) indicated a preference to return to the community. This includes people expected to have short-term, rehabilitative stays after a hospitalization. By comparison, 20.6% of residents nationwide indicate they prefer a community setting.[13]

Compared to most states, Pennsylvania's support for community-based alternatives to nursing facilities is relatively low. Per capita HCBS expenditures for older people and people with disabilities in Pennsylvania – from all funding sources – are about 8% below the national average. This total includes both Medicaid services and state-funded community long-term care programs.[14] However, over the last decade the Commonwealth has made significant investments in expanding its HCBS system. Between 2000 and 2005, expenditures for waivers serving older adults and people with physical disabilities grew an average of 41% per year. Pennsylvania's waivers had the fourth-highest expenditure growth rate in the United States.[15]

Pennsylvania has had more success in rebalancing its long-term support system for persons with mental retardation and other developmental disabilities. Pennsylvania's utilization rate for large state institutions is 14% below the national average, and the number of people served in the community is 18% above the national average (See Chart 3). For this population, 64% of Medicaid funds go toward community-based services, compared to the national average of 58%.[16]

[12] Minimum Data Set (MDS) National Repository *Active Resident Count Report: June 30, 2005* and U.S. Census Bureau, "Table 1: Estimates of the Resident Population by Selected Age Groups for the United States and States and for Puerto Rico: July 1, 2005 (SC-EST2005-01)".
[13] Minimum Data Set (MDS) National Repository *Active Resident Information Report* "Q1a: Discharge Potential and Overall Status" Data reported for the Second Quarter of 2005.
[14] Medstat analysis based on: 1) 2005 Medicaid data from Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006; 2) 2004 Pennsylvania state-funded program data from Kane, Rosalie; Kane, Robert A.; Priester, Jacob *Rebalancing Long-Term Care Systems in Pennsylvania: Experience up to July 31, 2005* University of Minnesota: 2006; and 3) A national total of state-funded program data from Summer, Laura and Ihara, Emily *State-Funded Home and Community-Based Service Programs for Older People* AARP: 2004.
[15] Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006.
[16] Ibid.

Chart 3. Proportion of State Population Served by Large State Institutions, Other ICF/MR, and HCBS Waivers, 2005



Large state institutions are defined as state-operated facilities with 16 or more beds that serve people with developmental disabilities.

Sources:
Pennsylvania's Medicaid HCBS Waiver data provided by the Pennsylvania Department of Public Welfare. HCBS Waiver data do not include a waiver serving children under age 3 that is unique to Pennsylvania.
All other data from Prouty, Robert; Smith, Gary; Lakin, K. Charlie; Bruiniks, Robert; Coucouvanis, Kathryn. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005* University of Minnesota: July 2006

Historical and Political Factors

The early development of Pennsylvania's long-term support system has had an enduring effect on the current system. This section describes three particularly influential historical and political characteristics of Pennsylvania's long-term support system shown below.

Important Historical and Political Factors in Pennsylvania's Long-Term Support System

1. A long tradition of state-funded community supports;
2. A complex array of programs developed to address particular circumstances; and
3. A strong county role in service administration.

Tradition of State Funded Long-Term Support

Compared to other states, Pennsylvania has a high proportion of state funds supporting HCBS, particularly for older adults. When the state lottery was enacted in 1971, its enabling legislation dedicated 30% of lottery revenues to services for people age 60 and older.[17] Earlier, in 1966, the state began grants for community services for people with mental retardation[18] and for people with mental illness, to provide an alternative to state institutions. An additional state-funded program started in the mid-1980s to offer attendant care to adults under age 60 with physical disabilities.

Eventually, the need for community supports outstretched the available state funds. Pennsylvania developed Medicaid HCBS waivers to serve more individuals and to provide a richer service package. The state-funded programs still serve tens of thousands of people who are on a waiver waiting list or who do not qualify for Medicaid services. Many participants receive only a few hundred dollars worth of services per year. Pennsylvania will continue be challenged to adequately fund the current state-funded programs as service demand continues to increase and Pennsylvania – like many states – faces pressures to contain the growth of public spending.

Complex Array of Programs

Pennsylvania currently operates eleven HCBS waivers, each developed to meet the needs of a particular population. Only Florida has more waivers (12).[19] The state does not provide a personal care benefit as a state plan option, so people must access Medicaid HCBS services through one of the state's waivers. However, the state's 11 waiver programs do not offer services to all persons with disabilities who qualify for institutional services. As a result, some people with severe disabilities do not have access to HCBS. For example, unless there is a concomitant diagnosis of mental retardation, most adults with autism spectrum disorders do not qualify for any of the state's waivers.

Strong County Role in Service Administration

Historically, the state's long-term care system has been influenced by Pennsylvania's identity as a Commonwealth, with counties playing a strong role in the administration and allocation of public resources. The state's mental health, mental retardation, and aging systems were developed at the county level and remain locally administered. Only more recently has there been an effort to standardize policy and practices across counties for all programs. One impact of the counties' relative autonomy is that local policies and practices can have a significant impact on the entire state system. This is in part because a few counties (such as Philadelphia and Allegheny) include very large segments of the state population. For example, an outreach campaign in one of these counties could significantly increase the total number of consumers receiving services statewide.

[17] In State Fiscal Year 2004-05, the lottery provided $852 million for home and community-based services, transportation, and other supports (Pennsylvania Lottery "Pennsylvania Lottery Information: Where Does The Money Go?" December 28, 2006).
[18] Pennsylvania operates a separate system specifically to serve people with mental retardation. Other long-term supports programs for people with developmental disabilities are part of the system that serves people with physical disabilities.
[19] Eiken, Steve; Burwell, Brian; and Selig, Becky "Medicaid HCBS Waiver Expenditures, FY 2000 through 2005" Thomson Medstat: July 6, 2005.

Section II. System Administration and Management

Like many states, Pennsylvania has long had a fragmented administrative structure for long-term supports. Historically, state agencies have been organized around major disability categories. Many state agencies have counterpart agencies at the county level serving the same population, reflecting Pennsylvania's tradition of county administration. In many cases, the state and county agencies for a particular population developed independently of other agencies.

As the Commonwealth's commitment to HCBS grew, it became increasingly apparent that the historic organizational structures left many persons with significant disabilities underserved. Pennsylvania developed several interagency committees to facilitate communication among these agencies and their stakeholders. Since 2003, the current Governor has made significant organizational changes to consolidate the administration of long-term supports within the state.

This section provides some basic information on Pennsylvania's management of long-term supports. It starts with a basic overview of the state and local agencies involved, followed by recent organizational changes and new initiatives. The roles of the state legislature and consumers are then further described.

Organizational Structure

Pennsylvania's umbrella human services agency, the Department of Public Welfare (DPW) administers most long-term supports. DPW is also the designated State Medicaid Agency for Pennsylvania. A separate agency, the Pennsylvania Department on Aging (PDA), administers HCBS programs for adults age 60 and older, including both state-funded programs and the Aging Waiver.

The organization of long-term supports within Pennsylvania has historically been structured around major population groups. Most of the state agencies that serve specific population groups have a corresponding network of local agencies, often units of county government. The local agencies' duties include:

Common Local Agency Duties

- Providing information and assistance;
- Assessing functional or clinical eligibility for services;
- Enrolling participants in HCBS programs; and
- Providing case management or supports coordination to help people obtain necessary services.

Some of the 67 counties have combined agencies to create economies of scale. Table 2 lists the populations with statewide HCBS programs and the corresponding administrative agencies.

Table 2. Networks of State and Local HCBS Administration Agencies		
Age or Type of Disability	**State Agency**	**Local Agencies**
Age 60 and older	Department of Aging (PDA), Office of Community Services and Advocacy	County-level Area Agencies on Aging
Mental retardation[1]	Department of Public Welfare (DPW), Office of Mental Retardation	County-administered Mental Health and Mental Retardation Programs
Physical disabilities	DPW, Office of Long Term Living	Two networks of non-profit agencies contracted by DPW: 1) 15 non-profit agencies offering an attendant care program; and 2) Three non-profit agencies contracted to coordinate a broad range of services
Technology dependent	DPW, Office of Long Term Living	No local agencies.
HIV/AIDS	DPW, Office of Long Term Living	No local agencies.
Mental illness or serious emotional disturbance	DPW, Office of Mental Health and Substance Abuse Services	County-administered Mental Health and Mental Retardation Programs
Children under age three	DPW, Office of Child Development	County-administered Mental Health and Mental Retardation Programs

[1] Pennsylvania operates a separate system specifically to serve people with mental retardation. Other long-term supports programs for people with developmental disabilities are part of the system that serves people with physical disabilities.

Source: Information provided by Pennsylvania Department of Aging and Pennsylvania Department of Public Welfare

Pennsylvania is one of the few remaining states that do not have a single agency with management responsibility for all persons with developmental disabilities. Pennsylvania's Office of Mental Retardation serves individuals with a variety of developmental conditions, but only if there is also a corresponding diagnosis of mental retardation. Persons with developmental disabilities, but without a mental retardation diagnosis, are either served under the physical disabilities system or ineligible for long-term supports.

In addition to the HCBS responsibilities mentioned above, DPW manages institutional payment and policy. For people with mental retardation and people with mental illness, the DPW agency responsible for community supports also manages institutional services. DPW's Office of Long Term Living administers the nursing facility program. All institutions are licensed by the Department of Health's Bureau of Facility Licensure and Regulation.

Recent Organizational Changes

Pennsylvania has made three major changes in state government to plan systematic reform of the long-term support system and to improve coordination across department boundaries. In 2003, Governor Ed Rendell established an office specifically focused on health care reform, and included a team responsible for long-term care systems change. The Governor also combined early childhood programs into a new Office of Child Development and merged several HCBS programs for older adults and adults with disabilities into a new management structure. Each change is described further below.

Governor's Office of Health Care Reform

In 2003, Governor Rendell established the Governor's Office of Health Care Reform (OHCR) to lead health care system reform efforts and coordinate its work with several cabinet departments such as DPW and PDA. The long-term care unit within OHCR focuses on supports for older adults and people with disabilities. OHCR coordinates with DPW and PDA to design and implement new initiatives (shown below), and to expand them statewide as OHCR and the program departments determine.

OHCR Long-Term Support Initiatives

1. Community Choice, a ten-county pilot program to improve access to HCBS for older adults and people with physical disabilities. Community Choice enabled applicants to receive services within 72 hours of initial application, established an asset disregard so people could retain more assets while receiving long-term supports, and featured an outreach campaign to reach people before deciding to seek nursing facility care.
2. A statewide nursing home transition program to assist long-term nursing facility residents who want to move to a home or apartment.
3. A partnership with the Pennsylvania Housing Finance Agency to increase access to affordable, accessible housing units.
4. An initiative to improve quality assurance and improvement across all waivers.
5. A Cash and Counseling initiative to allow consumers to exercise more control over their services, including an individual budget that the consumer can manage directly.
6. A partnership with the Pennsylvania Department of Labor and Industry to improve direct support worker recruitment and retention.
7. Two pilot Aging and Disability Resource Centers that provide information on the variety of supports older adults and people with disabilities may need, including long-term support, vocational rehabilitation, housing, and transportation.

Office of Child Development

DPW combined several programs for children age 5 and younger into a new agency in 2005, the Office of Child Development. This office includes a unique Medicaid HCBS waiver that provides habilitation services for children under age three with significant developmental delays. In addition, the Office of Child Development administers state-funded early intervention services, licenses child care facilities, administers child care subsidies for low-income families, and promotes promising early childhood education practices. Before this change, the Office of Mental Retardation operated the waiver and other early intervention supports. The Office of Income Maintenance, which determines financial eligibility for Medicaid, SSI, Food Stamps, and other programs, administered child care subsidies.[20]

To encourage further integration of early childhood services, the Governor appointed a single person as both Deputy Secretary of the Office of Child Development and as policy director in the Pennsylvania Department of Education. This dual appointment is intended to increase coordination between the two

[20] Commonwealth of Pennsylvania *Governor's Executive Budget 2005-2006* February 8, 2005.

agencies. In addition to the many supports it provides for school-age children, the education system administers the early intervention program for children age three to five.

Long Term Living Organizational Structure

Governor Rendell changed the management structure for long-term supports for older adults and people with physical disabilities in 2006. The administration established a forum for senior administration officials to focus on long-term care, and consolidated several programs into a new agency focused on long-term supports. Chart 4 shows the resulting organizational structure for the state agencies that administer Medicaid institutional and HCBS waiver programs.

First, the Governor established a Long Term Living (LTL) Council with the senior officials listed below.

Long Term Living Council Members

- The Secretary of the Department on Aging;
- The Secretary of the Department of Public Welfare;
- The Budget Secretary;
- The Secretary of Policy;
- The Governor's Deputy Chief of Staff; and
- The Executive Director of the Office of Health Care Reform.

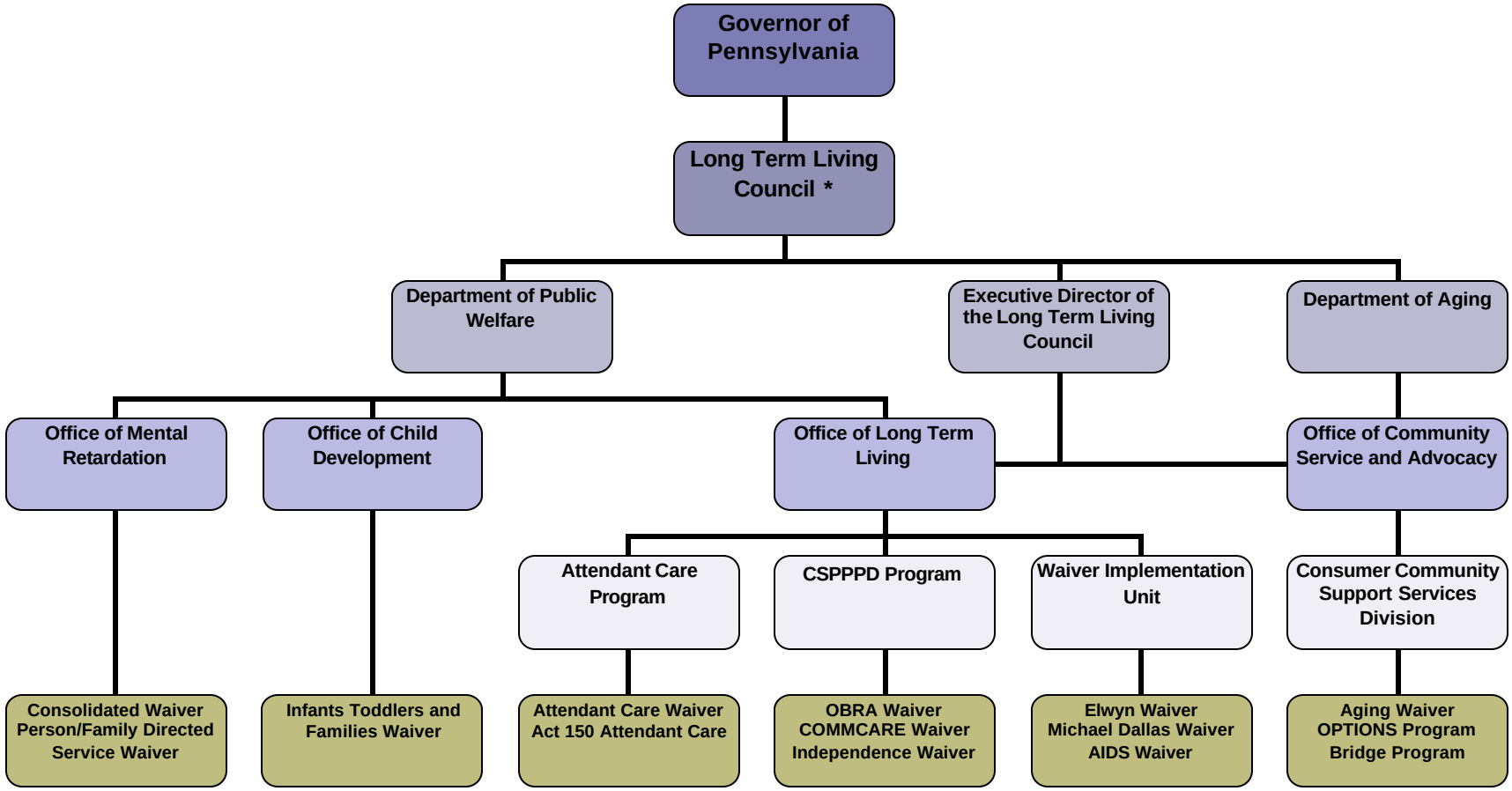
The Budget Secretary is involved because of the impact long-term care has on the Commonwealth's budget. In State Fiscal Year 2005-06, for example, Pennsylvania exceeded the appropriation for its long-term care budget. This budget includes Medicaid nursing facility care, the HCBS waiver for older adults, and two smaller programs. A reduction in nursing facility utilization was projected as the Commonwealth expanded HCBS. However, nursing facility utilization remained constant and anticipated budget savings were not realized. Nursing facility rates could not be reduced because the rate setting methodology is established in regulation. Rather than reduce growth of the Aging Waiver, the Administration requested and received a $128 million supplemental appropriation from the legislature.[21] This experience increased the involvement of the Governor's Budget Office in long-term care issues.

The LTL Council currently meets bi-weekly to discuss and coordinate long-term care issues across state government. These regular meetings provide a forum for making clear policy decisions, particularly when the decision affects more than one agency or has budgetary implications. A new staff position, the Executive Director of the LTL Council, reports directly to the Council and has overall management responsibility for the coordination of long-term care policy and operations.

The Executive Director's role increased a few months later when the Governor established a dual reporting relationship for agencies within DPW and PDA that serve older adults and people with physical disabilities. Assistant Secretaries for these agencies now report primarily to the Executive Director of the LTL Council, in addition to their cabinet Secretaries. The Secretaries generally exercise their authority through their membership on the Long Term Living Council.

[21] The General Assembly of Pennsylvania *Session of 2005, House Bill No. 815: Report of the Committee of Conference.*

Chart 4. Organizational Chart for Medicaid Home and Community Based Waiver Administrative Agencies



Note: The Long Term Living Council holds regular meetings to coordinate state policy on long-term supports for older adults and people with physical disabilities. Members are two Cabinet Secretaries-the Secretary of Public Welfare and the Secretary of Aging-and four leaders from Governor's Office – the Secretary of Budget, the Secretary of Policy, the Governor's Deputy Chief of Staff, and the Director of the Governor's Office of Health Care Reform.

Source: Information provided by Governor's Office of Health Care Reform, Pennsylvania Department of Aging and Pennsylvania Department of Public Welfare

At the same time, the administration established a new agency in DPW focused on long-term supports. Previously, a bureau of DPW's Medicaid agency managed nursing facility policy, had financial responsibility for the Aging Waiver, and managed four small Medicaid programs that provide HCBS.[22] This bureau also provided quality oversight for all of Pennsylvania's 11 Medicaid HCBS waivers. The new Office of Long Term Living in DPW combines this bureau with the agency that administered four Medicaid HCBS waivers for adults with physical disabilities.

Together, the above changes create a single management structure for long-term supports for older adults and adults with physical disabilities. The Executive Director of Long Term Living Council has management responsibility over both community and institutional services. As Pennsylvania implements new policies sparked by the increased focus on long-term care, coordination among the several long-term support programs is likely to improve. The Long Term Living Council and its Executive Director, however, are viewed as temporary organizational structures which are likely to change as the administration pursues further systems change.

Legislative Involvement

In most years, the Pennsylvania General Assembly has limited involvement in the long-term care system. Systems change has generally been initiated through the Governor in the current and previous administrations, with the legislature often approving requested funding increases for community supports. The statutes related to long-term supports provide a framework for state and county administration, allowing a degree of flexibility as long as program budgets are met.

The legislature was more active in 2006, responding to proposed nursing facility reimbursement changes. The administration requested and received legislative authority in 2005 to change the Medicaid nursing facility reimbursement regulations.[23] DPW then proposed regulations that would have lowered the nursing facility expenditure increase in State Fiscal Year 2006-07 from eight-to-ten percent to four percent. In 2006, legislators from both parties and in both houses were concerned the changes were too dramatic. Both houses passed a bill to prohibit reimbursement changes.[24] After the Governor vetoed the legislation, DPW and the nursing facility industry reached a compromise on a new formula.

The legislature has approved many system reform efforts, such as the closures of state institutions and the expansion of HCBS, through the appropriations process. Each year, the program departments develop budget estimates by projecting utilization and expenditures given current policies and by estimating the impact of proposed changes. The Governor's Budget Office then determines the total amount to be proposed for each program as part of the Governor's Executive Budget. The Commonwealth's legislature uses this proposed budget as a basis for appropriations legislation. In recent years, the legislature has made few changes regarding the long-term supports budget.

Four long-standing laws have particularly shaped the long-term support system. Three statutes established state-funded services that became the basis for the largest HCBS programs in Pennsylvania. First, the 1966 Mental Health and Mental Retardation (MHMR) Act established County MHMR Programs and two state-funded grants for community services: one targeting people with mental retardation and one for mental health services. Second, 1971 legislation authorizing the Commonwealth's lottery

[22] These programs are three Medicaid HCBS waiver and the Long Term Care Capitation Assistance Program, Pennsylvania's name for the national Program for All-Inclusive Care for the Elderly.
[23] The General Assembly of Pennsylvania *Session of 2005, House Bill No. 1168: Report of the Committee of Conference.*
[24] Rotstein, Gary "Nursing Homes, Rendell Feud Over Funds" *Pittsburgh Post-Gazette* May 29, 2006.

required proceeds to benefit older adults. The Pennsylvania Lottery provides hundreds of millions of dollars per year in funding for HCBS, transportation, and prescription drug programs. Third, a 1986 law authorized the Attendant Care Program for people with physical disabilities.

A fourth statute prohibits personal care homes, a licensure for community residential facilities serving older adults and people with disabilities, from serving people who need nursing facility services. It is part of the 1967 law that established the Public Welfare Code and covered a variety of human services.[25] This statute effectively prohibits funding assisted living through a Medicaid waiver, which is the most common funding mechanism for assisted living.[26] As described on page 32, DPW can waive personal care home requirements under certain circumstances,[27] and there are a few instances where this requirement is waived and a Medicaid waiver supports personal care home residents.

Consumer Involvement

Pennsylvania provides several opportunities for people who use long-term supports, their family members, advocates, and other stakeholders to participate in policy decisions. Both the Department of Public Welfare and the Department of Aging have department-level advisory committees or councils with sizeable consumer representation. People age 60 and older are a majority of the Council on Aging that advises PDA.[28] People with disabilities are a large number, if not the majority, of DPW's Stakeholders Planning Team, which examines HCBS for all individuals. In addition, the agencies within DPW that manage long-term support programs have broad stakeholder advisory committees that include people with disabilities, advocates, providers, and local administrative agencies. DPW has also added consumers and advocates to the subcommittee of the Medical Assistance Advisory Committee that focuses on long-term care.

The role of consumers and advocates has varied over time, and also among different agencies and stakeholder groups. In some cases, people with disabilities and family members have been particularly influential. For example, consumers and family members were instrumental in setting a 1991 vision for the mental retardation system called *Everyday Lives* and in helping the Commonwealth move toward that vision with increased HCBS options.[29]

Consumers and family members also are involved in short-term task forces to plan and/or implement new initiatives. For example, DPW convened an Autism Task Force in 2004, which made several recommendations to improve services for people with autism. DPW has hired staff, including members of this task force, to focus specifically on improving supports for people with autism.[30] Consumers and advocates are currently part of workgroups within OMR that are planning system changes to increase standardization among the County MH/MR Programs. Similarly, people with mental illness are part of workgroups to improve mental health services provided under the Medicaid rehabilitation benefit.[31]

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[25] Pennsylvania Department of the Auditor General *A performance Audit of the Department of Public Welfare's Oversight of Personal Care Homes in Pennsylvania* October 2001.
[26] Mollica, Robert and Johnson Lamarche, Heather *State Residential Care and Assisted Living Policy: 2004* National Academy of State Health Policy: March 31, 2005.
[27] Pennsylvania Administrative Code, Title 55, Section 2600.19.
[28] Pennsylvania Department of Aging "Council on Aging" August 24, 2001.
[29] Mullen, Dorothy; Eiken, Steve; Steigman, Daria. "Promising Practices in Long Term Care Systems Reform: Pennsylvania's Transformation of Supports for People w ith Mental Retardation" March 3, 2003.
[30] Department of Public Welfare *Autism Task Force: Final Report* December 2004.
[31] Department of Public Welfare "Medicaid Rehabilitation Benefit" February 1, 2006.

Section III. Services for Older Adults

Pennsylvania's service infrastructure for older adults illustrates the legacy of state-funded services and local control identified on page 6. The state lottery funds services for the majority of consumers who receive publicly funded home and community-based services (HCBS), although Medicaid's role in the financing of community-based services is increasing. County-based Area Agencies on Aging (AAAs) assess eligibility for all publicly funded supports and provide care coordination for most participants.

The Commonwealth has established much of the infrastructure that has been demonstrated to be effective in rebalancing long-term care systems, such as a unified institutional and community services budget, a single point of entry system, and tight controls over nursing facility supply. Key system components remain missing, however, such as community residential alternatives to nursing facilities and a single state administrative agency for institutional and community services.

Programs and Services

HCBS Programs

Over 100,000 people received HCBS in SFY 2004-05 (See Table 3 for number of people served by program).[1] Most of these people's services were funded by the Pennsylvania Lottery. The largest program, OPTIONS, provides case management, personal care, home delivered meals, medical supplies and equipment, adult day care, and other services to low and moderate-income people age 60 and older who do not qualify for Medicaid-financed long-term care. The maximum benefit is $625 per month.[2] Most OPTIONS participants do not meet clinical criteria for nursing facility care.[3] About 16,000 OPTIONS participants meet the clinical eligibility criteria, but have too many assets or too much income for Medicaid.[4] The most frequently used services are personal care, homemaker and chore services (called home support), and specialized medical equipment and supplies.[5]

Two other programs are funded in part by the lottery. The Bridge Program provides a higher level of service to low-income older adults with assets between the Medicaid eligibility threshold ($8,000 in Pennsylvania because of a $6,000 asset disregard) and $40,000. Consumers pay half of the service cost until they spend down to Medicaid eligibility. This program was closed to new consumers effective July 2005 and is being phased out.[6] The Family Caregiver Support Program pays up to $200 per month for low and moderate-income caregivers of older adults to purchase services or items not covered by health

[1] Pennsylvania defines older adults as people age 60 or older for long-term care programs.
[2] Pennsylvania Department on Aging "OPTIONS Program: Community Based Long Term Care" February 28, 2003.
[3] The Pennsylvania Department of Aging's *Home and Community Based Services Manual* defines nursing facility clinical eligibility criteria. A person must have "a medical diagnosis/illness or condition, which creates medical needs that require care and service, which:

- Are ordered by, or provided under the direction of a physician
- Are needed to be given on a regular basis and provided by or under the supervision of a skilled medical professional, or
- Because of a medical or physical disability, the individual requires nursing and related health and medical services in the context of a planned program of health care and management."

[4] Data provided by Pennsylvania Department on Aging.
[5] Pennsylvania Department on Aging "Program Facts" Undated.
[6] Pennsylvania Department on Aging *Aging Program Directive #05-01-08* August 22, 2005.

insurance, including respite care.[7] The National Family Caregiver Support Program provides almost half of this program's budget.[8]

The most significant Medicaid HCBS program is the Aging Waiver. This waiver offers the services available in OPTIONS, but without a monthly cost limit. Two-thirds of waiver consumers use personal care. Other common services are home delivered meals, extended home health care, specialized medical equipment and supplies, and personal emergency response system.[9] The other Medicaid HCBS option for older adults is the Long Term Care Capitated Assistance Program (LTCCAP).[10] This program includes seven sites that offer integrated service delivery of Medicare and Medicaid services, with a prominent role for adult day health care.

A few older adults receive services from other HCBS waivers. If people join a waiver before their 60th birthday, they may continue in their existing program to avoid a disruption in services, as long as they need the services and meet the program's criteria. They may also switch to the Aging Waiver or the LTCCAP program if they need a service in those programs that is unavailable in their current waiver, such as home delivered meals or adult day health care.

Table 3. Long-Term Care Programs for Older Adults: Participants in State Fiscal Year 2004-05 and Average Annual Growth since SFY 2001-02

Programs	Persons Served, SFY 2004-05	Average Annual Growth Rate
Aging Waiver	20,495	30%
Long-Term Care Capitated Assistance Program (national PACE model)	937	22%
Nursing Facilities	81,707	0%
Total Medicaid	**103,139**	**5%**
Bridge	965	1%
Family Caregiver Support	5,053	-11%
Options	85,443	-3%
SSI State Supplement - Personal Care Homes*	10,756	-1%
SSI State Supplement - Domiciliary Care Homes*	1,235	-2%
Total Non-Medicaid	**103,452**	**- 4%**
Total	**206,591**	**0%**

* SSI State Supplement data for people in personal care homes and domiciliary care homes include residents under age 60.

Sources:
Most data are from unpublished reports by the Pennsylvania Department of Aging and Pennsylvania Department of Public Welfare
2001-02 Aging Waiver data are from the CMS Form 372 Report for State Fiscal Year 2002.
Family Caregiver Support data are from Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.

[7] Medstat "Promising Practices in Home and Community-Based Services: Pennsylvania – Resource Counseling and Financial Assistance for Informal Caregivers" December 28, 2004.
[8] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[9] CMS Form 372 Report for State Fiscal Year 2002 for the Aging Waiver.
[10] LTCCAP is the Commonwealth's name for the national Program of All-Inclusive Care for the Elderly (PACE).

While Pennsylvania offers a full range of in-home and adult day services, the Commonwealth does not offer community residential services under Medicaid. The Commonwealth does support thousands of people in residential facilities, however. The enhanced state supplement to Supplemental Security Income (SSI) provides about $400 per month for SSI participants living in personal care homes and domiciliary care homes.[11] Personal care homes range from traditional board and care homes that provide a minimal amount of personal assistance to assisted living facilities that offer a wider range of supports. Domiciliary care homes provide a homelike living environment and supports, usually for three or fewer people per home. Most of the SSI payment and the state supplement pay the provider for the housing and supports provided. The supplement also includes a personal needs allowance for the consumer's expenditures. Older adults are about 60 percent of SSI supplement recipients in personal care homes and approximately one-third of SSI supplement recipients in domiciliary care homes.

Non-HCBS Supports

In addition to community long-term care services, older Pennsylvanians use a variety of supports that are often vital for community living. Many older adult HCBS participants receive the following supports from the sources mentioned below.

Common Non-HCBS Supports and Programs for Older Adults

- Health insurance from Medicare;
- Congregate dining, nutrition counseling, senior center activities, and other services from Area Agencies on Aging;
- Free fixed-route transit rides from the Pennsylvania Free Transit Program
- Discount door-to-door transportation from the Pennsylvania Shared Ride Program;
- Prescription drug assistance from Medicare Part D, supplemented by the Pharmaceutical Assistance Contract for the Elderly;
- Grocery payments from the Food Stamp Program;
- Utility bill payments and weatherization assistance from the Low-Income Home Energy Assistance Program; and
- Housing assistance from the local Public Housing Authority.

Appendix A presents data for these programs and for non-HCBS programs that support other population groups.

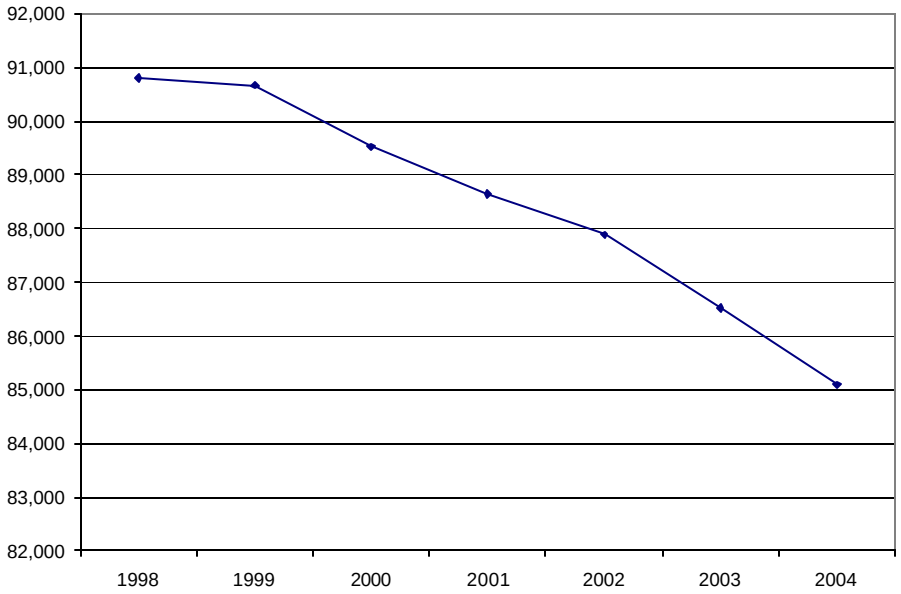
Demographic and Utilization Trends

Pennsylvania is an aging state, as described on page 1. The Commonwealth ranks third among the states in proportion of people age 65 or older. The population age 85 and older has been growing rapidly since 1990 and will continue to grow until 2010. Given these demographic trends, the demand for long-term care among seniors has grown significantly and will continue to grow over the next five years.

[11] U.S. Social Security Administration "Supplemental Security Income (SSI) In Pennsylvania" January 2006.

Although the population has aged, the state has been successful in reducing nursing facility beds. Several facilities have closed and the state has approved few new beds (See Chart 5).[12] This reduction in nursing facilities helped Pennsylvania achieve a nursing facility utilization rate that was slightly below the national average in 2003. Medicaid expenditures for nursing home care are still above average, even when controlling for the number of older adults, due to the state's relatively high nursing home reimbursement. Like other northeastern states, Pennsylvania pays relatively high Medicaid rates for nursing facility care.

Chart 5. Medicaid-Certified Nursing Facility Beds in Pennsylvania, 1998-2004



Source: Data provided by the Pennsylvania Department of Public Welfare.

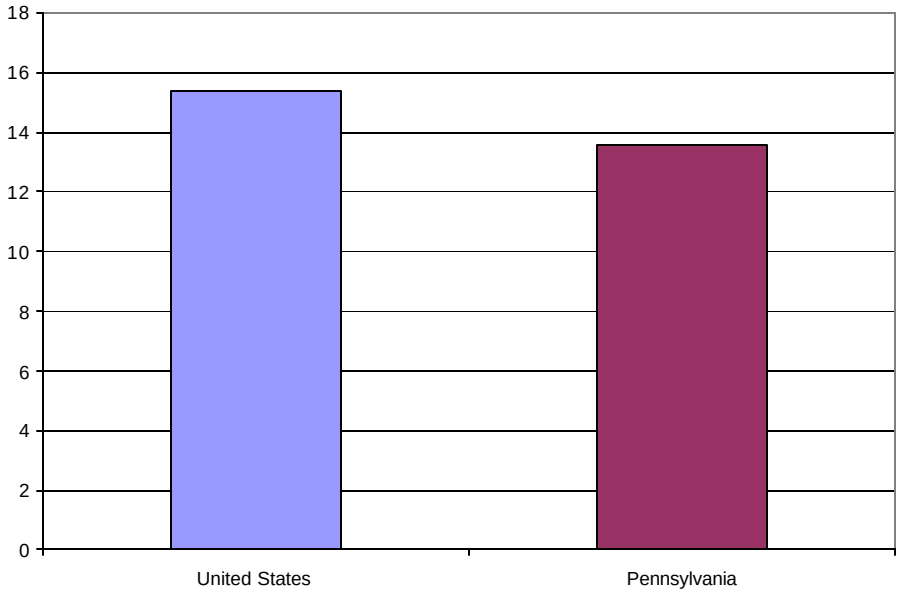
As mentioned on pages 3 and 4, the Commonwealth spends less than the national average for overall HCBS expenditures for older adults and people with physical disabilities.[13] While Medicaid HCBS waiver participation and funding have grown rapidly in recent years, the number of HCBS waiver participants per 1,000 elderly is still below average (See Chart 6). In addition, most other states offer personal care as a Medicaid State Plan service, which is not available in the Commonwealth. However, Pennsylvania serves a much larger number of people with state-funded services than other states.[14] As a result, Pennsylvania may serve a relatively high proportion of seniors overall.

[12] Data provided by the Department of Public Welfare.

[13] State comparison data is not available specifically for older adults because most states offer the same programs to both older adults and people with physical disabilities.

[14] Summer, Laura and Ihara, Emily *State-Funded Home and Community-Based Service Programs for Older People* AARP: 2004 and Kitchener, Martin; Willmott, Micky; and Harrington, Charlene "Home & Community-Based Services: State-Only Funded Programs" University of California - San Francisco: December 2004.

Chart 6. Medicaid HCBS Waivers for Older Adults and People with Physical Disabilities: Participants per 1,000 People Age 65 and Older



Data from 2005 were used for Pennsylvania's waivers. For other states, data were for the most recent year available, which was 2003 for most waivers but 2002 or 2004 for others.

Sources:

Waivers serving these populations were identified in Eiken, Steve; Burwell, Brian; and Selig, Becky "Medicaid HCBS Waiver Expenditures, FY 2000 through FY 2005" Thomson Medstat: July 6, 2006.
Pennsylvania data was obtained from the Pennsylvania Department of Public Welfare, Pennsylvania Department of Aging, and CMS Form 372 Reports.
Data from other states were obtained from National Association of State Medicaid Directors "1915(c) Home and Community Based Services Waivers – By State" November 2004, and Kitchener, Martin; Ng, Terence; and Harrington, Charlene "Medicaid 1915(c) Home and Community-Based Services Programs: Data Update" Kaiser Family Foundation: July 2005
Population estimates were from U.S. Census Bureau "Annual Estimates of the Population for the United States and States, and for Puerto Rico: April 1, 2000 to July 1, 2004" Undated.

Components Associated with Rebalancing

Streamlined HCBS Administration

Pennsylvania does not have a single state agency that administers and coordinates long-term supports for older adults. Pennsylvania has long divided long-term care administration between the Department of Public Welfare (DPW) and the Department of Aging (PDA). However, the state has established some structural features that streamline long-term support administration, and recent organizational changes have moved the state closer to a consolidated state agency.

Traditionally, the State Medicaid Agency, DPW, managed nursing home policy and PDA managed lottery-funded HCBS for older adults, which were the only HCBS programs. Pennsylvania established the Aging Waiver in 1995, and responsibility for this waiver has been split between DPW and PDA. DPW has budgetary and policy responsibility and PDA is responsible for day-to-day administration.

This split allowed two positive features. First, DPW has a common budget for nursing facility and HCBS for older adults. This budget also contains the Aging Waiver and LTCCAP. This combined budget is a

single line item in both the Governor's budget and the legislature's appropriations bill. If nursing facility expenditures decline more quickly than expected, the state can increase HCBS funding. Second, PDA continues to administer all HCBS for older adults, so it can coordinate policies and monitoring of AAAs for both state-funded services and Medicaid-funded services. However, this split of fiscal and administrative authority created blurred lines of responsibility. PDA was not accountable for the budgetary impact of policy decisions, and DPW was not responsible for programmatic changes to respond to budgetary constraints.

The new duties of the Executive Director of the Long Term Living Council, described on pages 10-12, may move the Commonwealth toward a consolidated long-term care agency. In 2006, The Governor established a dual reporting structure for these agencies to improve coordination and ensure both departments make key decisions together. The units within DPW and PDA related to nursing facilities and HCBS for older adults and people with physical disabilities now have a dual reporting relationship. In addition to their Cabinet secretaries, they report to the Executive Director of the Long Term Living Council. The Long Term Living Council includes the DPW and PDA Secretaries and other senior leadership with a role in long-term care. The Executive Director reports to this council and has overall responsibility for the management and coordination of long-term care policy and operations.

Single Access Points

County-based Area Agencies on Aging (AAAs) serve as a single entry point for older adults receiving publicly funded care. Staff at the AAAs conduct the initial nursing facility level of care assessments. Pennsylvania requires this assessment for Medicaid-funded nursing facility services, the LTCCAP program, and for Medicaid or lottery-funded HCBS. The assessment is also required for receipt of the SSI state supplement for personal care homes or domiciliary care homes – in this case the person must not meet nursing facility clinical criteria to receive the benefit. The AAAs are therefore the single point of contact to access both state-funded and Medicaid-funded long-term supports.

The AAAs also provide case management for the Aging Waiver, lottery-funded HCBS, and other Aging Network services. This arrangement connects people to services funded by the Older Americans Act, such as congregate meals, advocacy, health promotion, and volunteer services. It also allows consumers to work with the same agency regardless of financial status.

In ten counties, Pennsylvania is piloting an expedited eligibility program as part of an initiative called Community Choice. This initiative, led by the Governor's Office of Health Care Reform (OHCR) combined expedited eligibility, an outreach campaign, and a change in financial eligibility requirements to reduce barriers to using HCBS.[15] The goal was to increase HCBS utilization and consequently reduce nursing facility demand.

Table 4 shows differences between the Community Choice process and the standard process. In each county, the local AAA, Medicaid financial eligibility determination office, and the enrollment agencies for waivers for people with physical disabilities jointly established a process for expedited eligibility. People can receive HCBS within 72 hours of application when necessary. The expedited eligibility process appeared to prevent some nursing facility admissions and to make hospital discharge to the community a viable option. However, nursing facility utilization did not decrease in these pilot counties, and actually

[15] The financial eligibility change, a disregard of $6,000 in assets that effectively raised the asset limit to $8,000, was made statewide through a Medicaid State Plan amendment.

increased in some counties. The outreach campaign may have tapped some of the unmet need indicated by Pennsylvania's rapidly aging population.

Table 4. Differences between Standard HCBS Waiver Enrollment Process and Original Community Choice Process

	Standard Process	Community Choice
Intake availability	Normal working hours	24 hours / 7 days a week
AAA assessment deadline	10 working days	24-72 hours if circumstances require quick services to prevent unnecessary institutionalization Otherwise, 10 working days
CAO determination	30 days based on documentation of income and assets. Denials possible for lack of documentation.	24 hours if circumstances require quick services to prevent unnecessary institutionalization, based on self-reported data collected by AAA assessor. CAO verifies financial information during the next 60 days. The consumer is responsible for services if the documentation shows the consumer is not eligible.
Physician determination	A physician certification form, MA-51, is required before the AAA assesses NF clinical eligibility	A prescription or the MA-51 form is acceptable. Physician certification can occur after the assessment, but must occur before services begin.

Source: Information provided by the Pennsylvania Governor's Office of Health Care Reform.

Institution Supply Controls

Since 1998, Pennsylvania has controlled nursing facility bed supply using a Medicaid Participation Review Process. Any Medicaid-enrolled provider seeking to add beds or build a new facility must apply to DPW, the State Medicaid agency. DPW reviews expansion requests on a case-by-case basis.[16] Between 1999 and 2005, only seven of 88 requests were approved.[17] Since 1998, the number of Medicaid-certified nursing home beds has declined by approximately one thousand beds per year as facilities have closed beds and few replacement beds have been approved.[18] DPW established the review process two years after Pennsylvania ended its Certificate of Need program.

A second initiative specifically targeted county-owned nursing facilities. The County Commissioners Association of Pennsylvania Program for Alternative Community Care (CCAP-PACC) provided grants for counties interested in reducing licensed bed capacity. Counties could convert units or entire facilities to other purposes, such as assisted living units, adult day health care facilities, and outpatient therapy, and respite. Counties also received funding for 1.5 Aging Waiver slots for every bed removed from licensure. Counties have eliminated 1,341 beds under this program since 1999.[19]

[16] Pennsylvania Department of Public Welfare, "MA Participation Review Process" January 12, 1998.
[17] Pennsylvania Department of Public Welfare, "Participation Exception Review Process" August 8, 2006.
[18] Data provided by Pennsylvania Department of Public Welfare.
[19] Data provided by Pennsylvania Department of Public Welfare.

Transition from Institutions

The Aging Waiver offers community transition services, which enables Medicaid to pay for much of the up-front costs necessary to help someone move from a nursing facility to a home or apartment. More information is presented on page 31 in the context of services for people with physical disabilities because many transitioning consumers were under age 60.

Continuum of Residential Options

As mentioned above, older Pennsylvanians cannot access publicly funded community residential alternatives, where people live in facilities operated by the service provider. This service gap is particularly important for persons who are eligible for nursing facility services and do not have an in-home informal caregiver, but who do not require the intensity of nursing care and supervision provided in a nursing home setting.

A state law prevents the Commonwealth from using HCBS waivers for assisted living. Assisted living providers are licensed as personal care homes, and state law prohibits these facilities from serving people who qualify for nursing facility services. This prohibition is difficult to enforce in the private market because no one assesses privately-funded residents. However, it prevents the state from using Medicaid HCBS waivers to fund assisted living services.[20] The other type of community residential facility that serves older adults, domiciliary care homes, can theoretically provide waiver services. However, the waiver does not include a residential service to pay for services in these homes. Services for each resident must be billed on an hourly basis and tracking each hour can be a challenge, especially for these small settings.

Local providers and housing agencies have worked together to integrate housing and services using the Program for All-Inclusive Care for the Elderly model. Four sites are located in senior public housing buildings. For people living in that complex, the on-site presence of a provider offering adult day health and in-home services is similar to an assisted living model. These sites are open to the larger community as well.

Building HCBS Infrastructure

Pennsylvania has long used block grants to local AAAs to develop infrastructure for community supports. In recent years, the Commonwealth has also pursued several initiatives specifically to improve the recruitment and retention of direct support workers in all settings, from nursing facilities to in-home attendants. These tools for infrastructure development are particularly important as Pennsylvania's population continues to age, increasing demand for services.

The Aging Block Grant includes the OPTIONS program and funding from the federal Older Americans Act. Pennsylvania distributes block grant funds to each AAA based on a formula that considers the overall number of older adults and the number of disadvantaged seniors (i.e., in poverty, in ethnic or racial minority groups, and in rural areas).[21] AAAs have flexibility to use the grant for services and other expenditures, including developing new services, within state and federal guidelines. PDA occasionally awards additional grants specific to infrastructure development, such as the Direct Care Worker grants

[20] An exception is a Philadelphia-area pilot project that uses Aging Waiver funds to serve personal care home residents. This pilot does not use an assisted living model, but pays for a home care provider to provide services. The Department of Public Welfare waived the prohibition against serving nursing home-eligible residents for this pilot.
[21] Pennsylvania Department of Aging "Interstate Funding Formula" October 22, 2004

described below. Also, in SFY 2006-07 the Department will award $4 million in grants to senior centers for capital improvements and capacity building projects.[22]

Pennsylvania has provided over $8 million since 2001 for local initiatives to improve direct support worker recruitment and retention. PDA distributed two sets of grants, in SFY 2001-02 and SFY 2006-07, through the AAAs. AAAs determined local projects in consultation with provider agencies and workers. The Intra-Governmental Council on Long-Term Care – an advisory group for long-term care that includes Cabinet officials, state legislators, and Governor-appointed stakeholders – awarded 12 grants in SFY 2003-04. The projects funded by the three grant programs included:

Projects Funded by Pennsylvania's Grants for Direct Support Worker Recruitment and Retention

- Compensation increases through bonuses and benefits;
- Training initiatives for workers and their supervisors;
- Mentorship initiatives where more experienced workers support new workers;
- Media campaigns to promote the profession; and
- Local direct support worker associations.[23]

In addition, a Pennsylvania non-profit is working with provider agencies and workers across the state as part of the Better Jobs Better Care program, a partnership between The Robert Wood Johnson Foundation and The Atlantic Philanthropies. The Center for Advocacy for the Rights and Interests of the Elderly received the grant and established a separate non-profit organization solely focused on direct support workers, Better Jobs Better Care – Pennsylvania. This organization is working with 27 providers to change their organizational culture to be more supportive of direct support workers. It is also developing a Universal Core Curriculum for training workers in all settings that serve older adults and supporting direct support workers in establishing a statewide association.[24]

Participant Direction

Older adults are able to employ their direct support worker in the two largest HCBS programs: the Aging Waiver and the OPTIONS program. However, the option offered by the state has limited flexibility – the only service that can be purchased directly by consumers is personal care and consumers may not negotiate wages or establish an individual budget. Consumer direction is not widely used. A 2004 survey of participants and provider found that most consumers were aware of this option during service planning, but that providers in some counties did not inform people of the ability to hire and supervise their own attendant.[25] Pennsylvania plans to expand participant-direction options under the Cash and Counseling initiative led by the Governor's Office of Health Care Reform.

[22] Dowd Eisenhower, Nora "Senior Community Center Grant Program for FY 2006-07" August 9, 2006
[23] Funk, Ellen H. *Direct Care Worker Association and Demonstration Grants: Final Report* Philadelphia Corporation for Aging: March 2005 and Pennsylvania Department of Aging "Direct Care Worker Initiative Plus" February 14, 2006.
[24] Better Jobs Better Care – Pennsylvania "About BJBC-PA" Undated.
[25] Pennsylvania Department of Aging *Consumer Direction Report* February 2005.

Quality Management

The AAAs are responsible for most quality assurance activities for the HCBS programs, with oversight from PDA and DPW. AAAs are required to conduct on-site record reviews for each provider, and are encouraged to provide additional quality monitoring. AAAs also conduct consumer satisfaction surveys each year, though a standard consumer survey is not used.[26] This means Pennsylvania cannot compare consumer feedback across counties.

Variation among the 52 AAAs is a significant challenge as Pennsylvania pursues rebalancing. The AAAs vary significantly in their program management and in nursing facility and HCBS utilization. In recent years, PDA has increased efforts to ensure geographic consistency through more frequent monitoring visits and paper reviews of assessments and service plans. The Commonwealth is also exercising more oversight over service plan development. In January 2006, PDA required state-level prior authorization for service plans with daily expenditures above $55, which will provide particular focus on ensuring consistency and appropriate services for consumers with higher expenditures.[27] The requirement followed two years of double-digit increases in per capita expenditures for the PDA waiver.

As the State Medicaid Agency, DPW monitors the Aging Waiver to ensure it meets federal and state requirements. In recent years, DPW's monitoring has mimicked a protocol CMS used for reviewing HCBS Waivers.[28] DPW is changing its oversight mechanism to match CMS expectations that states present systematic evidence that the waiver requirements are met.

Summary

The Commonwealth has a number of positive features to its system of long term services for older people. Three important features are the single line-item budget for Medicaid-funded nursing home and HCBS services, the single entry point through county-based AAAs, and the state's successful efforts to control nursing facility supply. In addition, the expedited eligibility process in the ten Community Choice pilot counties is a positive development for people who need access to HCBS services immediately.

However, significant barriers to a well-balanced system remain. For example, the lack of community residential services for people with severe disabilities makes it more difficult for these people to avoid institutionalization. Also, HCBS expenditures are below the national average even after years of rapid growth. This limited funding supports a large number of people at different levels of need, rather than targeting supports to people at risk of nursing home placement.

[26] Pennsylvania Department of Aging *Home and Community Based Services Procedures Manual* Updated February 8, 2005.
[27] Pennsylvania Department of Aging *Aging Program Directive 06-01-03* April 28, 2006.
[28] Centers for Medicare & Medicaid Services *CMS Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs* December 20, 2000.

Section IV. Services for People with Physical Disabilities

The long-term support system for adults with physical disabilities in Pennsylvania is particularly fragmented. Two major programs provide home and community-based services (HCBS), each with its own functional eligibility criteria and service infrastructure. Three additional Medicaid HCBS waivers target people with particular conditions such as acquired immunodeficiency syndrome (AIDS). As described on page 6, this complex array of HCBS programs does not provide services to all who qualify for institutional services.

Pennsylvania has developed important elements of a rebalanced system in recent years, however. A statewide nursing facility transition has helped over 400 long-term residents move to the community in only two years. Local and state housing authorities and long-term support agencies are working together to improve housing opportunities for people with disabilities. In addition, the new Office of Long Term Living (OLTL), described on pages 10-12, is now the single state agency for all the long-term support programs for this population. OLTL may eventually reduce the system's fragmentation.

Programs and Services

HCBS Programs

Two HCBS programs fund most supports for adults with physical disabilities: the Attendant Care Program and the Community Services Program for People with Physical Disabilities (CSPPPD). As the name suggests, the Attendant Care Program offers only a single hands-on service: attendant care, which provides assistance with activities of daily living. Supports coordination and personal emergency response systems are also available. Attendant care is available for mentally alert adults with physical disabilities under both an HCBS waiver and a state-funded program.[29] Under the state-funded program, participants pay a premium based on a sliding fee scale.

CSPPPD serves people who have more needs than the Attendant Care Program can meet. It includes three Medicaid HCBS Waivers. The Independence Waiver serves a broad population of people with physical disabilities. Almost all waiver participants receive personal assistance, a service similar to attendant care. Other common services are support coordination, personal emergency response systems (PERS), respite, and community integration services, which assists people in self-help, socialization, and adaptive skills through cueing, modeling behavior, and supervision.[30]

The COMMCARE Waiver serves people who have suffered traumatic brain injuries. It offers the same services as the Independence Waiver and offers additional services including habilitation and cognitive therapy. The most common hands-on service is personal assistance, used by 56% of consumers in 2004. Other common services are community integration, respite, and behavioral, physical, occupational and speech therapies.[31] The therapies are also available in the Medicaid State Plan, but the CSPPPD waivers allow people to receive a higher level of service than is available under the regular State Plan.

[29] Pennsylvania Department of Public Welfare "Attendant Care" December 9, 2004.
[30] Independence Waiver CMS Form 372 Report for July 1, 2002 - June 30, 2003 and Independence Waiver Application, March 15, 2006.
[31] COMMCARE Waiver CMS Form 372 for July 1, 2003 - June 30, 2004.

The OBRA Waiver serves adults with physical, developmental disabilities, i.e., disabilities that affect physical functioning and were apparent before age 22. The service package and common services are similar to the Independence Waiver. This waiver started to help implement federal requirements from the 1987 Omnibus Budget Reconciliation Act (OBRA). This law requires states to assess nursing facility residents for mental illness and developmental disabilities, and to ensure residents receive appropriate services.[32] Other programs served people with mental illness and mental retardation, but no services were available for people with other related conditions.[33]

The OBRA Waiver is the only waiver for physical disabilities that does not require people to meet nursing facility level of care criteria. Participants must meet criteria for an Intermediate Care Facility for people with Other Related Conditions (ICF/ORC). The criteria are similar to requirements for an Intermediate Care Facility for people with mental retardation (ICF/MR), except a diagnosis of mental retardation is not required.[34] Pennsylvania established three private ICF/ORC at the same time it established the OBRA Waiver. These institutions provide a viable institutional choice for OBRA Waiver consumers, which was required for federal waiver approval. Only two ICF/ORC remain, serving 14 individuals.

When starting the OBRA Waiver, Pennsylvania established a small, state-funded appropriation for specialized services for nursing facility residents with developmental disabilities other than mental retardation. The Commonwealth still provides $120,000 per year for services including supports coordination, peer support, and independent living skills training. At first, the OBRA Waiver only served former nursing facility residents. The waiver was amended in the late 1990s to serve all qualified individuals.

In addition to the Attendant Care and CSPPPD programs, three small waivers were designed for specific populations and together serve about 300 people:

- The AIDS Waiver provides nutritional supplements and counseling and homemaker services for people with human immunodeficiency virus or acquired immunodeficiency syndrome (HIV/AIDS);[35]
- The Michael Dallas Waiver provides private duty nursing and other services for people who require technology to sustain life or replace a vital bodily function;[36] and
- The Elwyn Waiver provides assisted living to people in Delaware County who are deaf or hard of hearing and who require a nursing facility level of care.[37]

Finally, Pennsylvania supports thousands of personal care home residents – including an unknown number of people with physical disabilities – through an enhanced state supplement to Supplemental Security Income (SSI) described on page 16.

The programs described above serve many people with disabilities but also leave gaps in coverage. Some individuals do not have access to valuable services. For example, the COMMCARE Waiver only

[32] This process is called Preadmission Screening & Annual Resident Review (PASARR) and is required for people initially entering a nursing facility and at least once a year for continuing residents.
[33] The OBRA Waiver does not cover all developmental disabilities other than mental retardation. Some individuals with developmental disabilities are not eligible for home and community-based services, as discussed on page 33.
[34] ICF/ORC level of care criteria is defined as substantial functional limitations in three of six categories: mobility, self care, communication, self-direction, capacity for independent living, and learning.
[35] AIDS Waiver CMS Form 372 for April 1, 2002 - March 31, 2003.
[36] Michael Dallas Waiver CMS Form 372 for July 1, 2003 - June 30, 2004.
[37] Elwyn Waiver CMS Form 372 for October 1, 2003 - September 30, 2004. The Elwyn Waiver was established when Elwyn, Incorporated closed its nursing facility for deaf and hard of hearing individuals and opened an assisted living facility. This facility is the only provider in the suburban Philadelphia service area that meets the waiver's provider standards.

serves people with brain injuries caused by external force or trauma. People who acquired brain injuries in other ways, such as congenital conditions, are not eligible for the specialized services in this waiver. They are only eligible for the Independence Waiver.

Other individuals qualify for nursing facility care but not for HCBS. Each waiver has functional eligibility beyond meeting nursing facility level of care criteria.[38] The waiver that serves the broadest population, the Independence Waiver, requires participants have substantial functional limitations in three of six categories: mobility, self care, communication, self-direction, capacity for independent living, and learning. A small number of individuals reportedly meet nursing facility criteria but do not have enough types of functional limitations.[39]

Table 5. HCBS Programs for People with Physical Disabilities: Participants in SFY 2004-05 and Average Annual Growth Rate since SFY 2001-02

Programs	Persons Served, SFY 2004-05	Average Annual Growth Rate
AIDS Waiver*	99	8%
Attendant Care	3,968	14%
COMMCARE Waiver**	152	230%
Elwyn Waiver***	41	-2%
ICF/ORC	14	-14%
Independence Waiver	1,233	49%
Michael Dallas Waiver***	66	11%
OBRA Waiver	759	31%
Total Medicaid	**6,332**	**20%**
Act 150 Attendant Care	2,268	1%
Total Non-Medicaid	**2,268**	**1%**
Total	**8,600**	**14%**

* AIDS Waiver data are for SFY 2002-03, the latest year reported.
** The COMMCARE Waiver started in SFY 2002-03. Average growth rate is calculated from that year.
*** Michael Dallas and Elwyn Waiver data are for SFY 2003-04, the latest year reported.

Sources:
2001-02 and 2002-03 Waiver data are from CMS Form 372 Reports.
2004-05 Waiver data and Act 150 data are from unpublished reports by Pennsylvania Department of Public Welfare.

In addition, anecdotal evidence and a review of eligibility guidelines suggest people with both a mental illness and physical disability face challenges obtaining a combination of HCBS to address physical disabilities and community mental health supports.[40] Like most HCBS waivers, Pennsylvania's waivers do not serve people whose functional impairments are primarily caused by mental illness. To identify Independence Waiver applicants with a primary mental health diagnosis, special justification is required in

[38] The Pennsylvania Department of Aging's *Home and Community Based Services Manual* defines nursing facility clinical eligibility criteria. A person must have "a medical diagnosis/illness or condition, which creates medical needs that require care and service, which:

- Are ordered by, or provided under the direction of a physician;
- Are needed to be given on a regular basis and provided by or under the supervision of a skilled medical professional; or
- Because of a medical or physical disability, the individual requires nursing and related health and medical services in the context of a planned program of health care and management."

[39] Pennsylvania Department of Public Welfare, Home and Community-Based Services Stakeholders Planning Team *Recommendations to the Rendell Administration* December 13, 2002; and Pennsylvania Inter-Governmental Council on Long-Term Care *Home and Community-Based Services Barriers Elimination Workgroup Report* March 2002.

[40] Eiken, Steve and Heestand, Alexandra "Pennsylvania Transition to Home (PATH): Pennsylvania's Nursing Home Transition Program" Thomson Medstat: December 22, 2003.

several circumstances such as psychiatric hospitalizations in the last two years, a diagnosis of serious mental illness, evidence of hallucinations, or "an episode of significant disruption to the normal living situation" that required intervention.[41] These questions may be interpreted to exclude other individuals with mental illness or challenging behaviors.

Non-HCBS Programs

Adults with physical disabilities often need to piece together many different supports to live independently in the community. HCBS participants may also receive the following supports from the following sources.

Common Non-HCBS Supports and Programs for People with Physical Disabilities

- Income support from Social Security Disability Insurance or Supplemental Security Income;
- Health insurance from Medicare (or Medicaid if the person does not qualify for Medicare);
- Paratransit services;
- Loans and grants for home modification from the Department of Community and Economic Development's Pennsylvania Access Program;
- Employment training and supports from the Vocational Rehabilitation Program;
- Grocery payment from the Food Stamp Program;
- Utility bill payment and weatherization assistance from the Low-Income Home Energy Assistance Program; and
- Housing assistance from the local Public Housing Authority.

Appendix A presents data for these programs and non-HCBS programs that support other population groups. Additional programs serve people with no health insurance and with specific conditions such as traumatic brain injury, HIV/AIDS, and chronic renal disease.

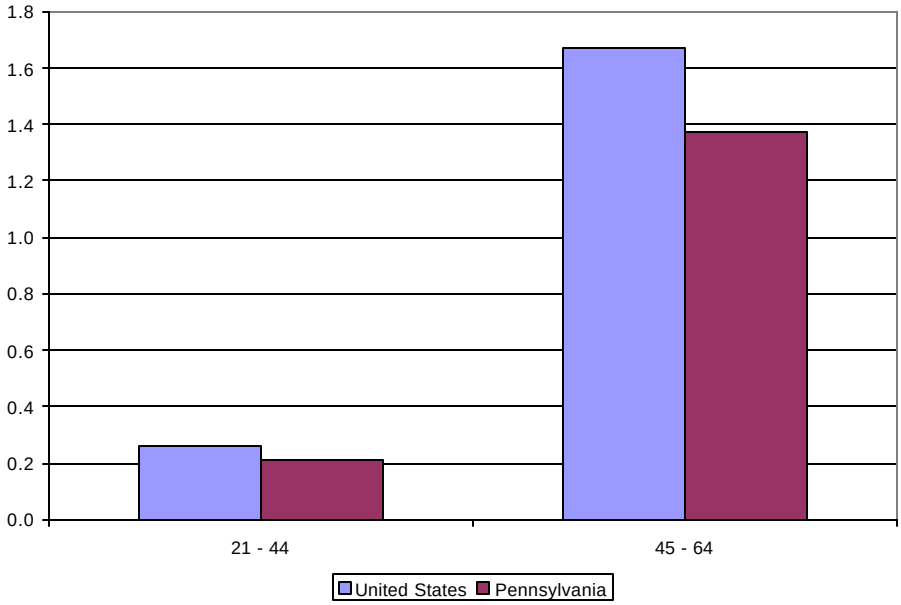
Demographic and Utilization Trends

As described in Chart 2 in the Background Section, the Commonwealth has a relatively high incidence of disability among its under 65 population. Despite this high rate of disability, Pennsylvania's Medicaid nursing facility utilization for adults under age 65 is 18% below the national average.[42]

As shown in Table 5, more people with physical disabilities have received HCBS in recent years. The combination of increasing HCBS and low nursing facility utilization do not necessarily indicate a well-balanced system, however. As discussed in the Older Adults section, overall HCBS spending and Medicaid HCBS waiver utilization are below average for the older adults and people with physical disabilities.[43] It is possible HCBS utilization for working-age adults is also below average, but this is not possible to verify due to limitations in national data.

[41] Pennsylvania Department of Public Welfare "OSP/OBRA Waiver Eligibility Worksheet" Undated.
[42] Medstat analysis of data from Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart.
[43] State comparison data is not available specifically for programs serving people with physical disabilities because most states offer the same programs to both older adults and people with physical disabilities.

Chart 7. Medicaid Nursing Facility Residents per 1,000 State Population in Working-Age Adult Cohorts: Daily Average in Federal Fiscal Year 2003



Source: Medstat analysis of data from Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart.

Comparisons are possible for three HCBS waivers that target people with specific diagnoses: the COMMCARE Waiver, the HIV/AIDS Waiver, and the Michael Dallas Waiver. Pennsylvania serves a small number of people, relative to state population, for each waiver. Using the latest national data available for Medicaid HCBS waiver programs, Pennsylvania was in the bottom three for each type of waiver.

Table 6. Medicaid HCBS Waivers Targeting Selected Conditions, Participants per 100,000 State Population

Target Population	Number of States with Available Data	Median State	Pennsylvania	Rank
Brain Injury	20	4.9	1.2	18th
Technology Dependent	16	2.5	0.5	16th
HIV/AIDS	15	3.7	0.8	14th

Data are for the most recent year available, which was 2003 for most waivers but 2002 or 2004 for others. Data from 2005 were used for Pennsylvania's waiver serving people with brain injuries.

Sources:
A list of waivers by target population is from Eiken, Steve; Burwell, Brian; and Walker, Eileen "Medicaid HCBS Waiver Expenditures, FY 1999 through FY 2004" Medstat: May 9, 2005.
Data from other states are from National Association of State Medicaid Directors "1915(c) Home and Community Based Services Waivers – By State" November 2004, and Kitchener, Martin; Ng, Terence; and Harrington, Charlene "Medicaid 1915(c) Home and Community-Based Services Programs: Data Update" July 2005.
Pennsylvania data are from the Pennsylvania Department of Public Welfare and CMS Form 372 Reports.
Population estimates are from U.S. Census Bureau "Annual Estimates of the Population for the United States and States, and for Puerto Rico: April 1, 2000 to July 1, 2004" Undated.

Components Associated with Rebalancing

Streamlined HCBS Administration

Earlier this year, Pennsylvania established the Office of Long Term Living (OLTL) within the Department of Public Welfare (DPW). OLTL includes Medicaid nursing facility policy and HCBS supports for people with physical disabilities. These functions were previously split into two agencies. A bureau of the Medicaid agency managed nursing facility policy and the waivers that serve technology-dependent individuals, people with HIV/AIDS, and deaf or hard of hearing individuals. The Attendant Care Program and CSPPPD were part of the Office of Social Programs (OSP). OSP housed several programs that did not fit the mission of DPW agencies – including programs for homeless individuals, domestic violence survivors, and refugees – until it was gradually dismantled during the Rendell administration.

While both Attendant Care and CSPPPD were part of OSP, these programs have long had separate state management and their own policies and procedures. However, Attendant Care and CSPPPD often coordinated implementation of new initiatives such as the nursing facility transition program and the Community Choice Initiative. The programs each have their own line item in the Governor's budget and in appropriations legislation. Unlike the common long-term care budget for older adults, if nursing facility costs for people under age 60 decrease, the savings are not automatically available for community-based programs.

Single Access Point

Pennsylvania has several different entry points for community supports, but has taken significant steps to improve access. Table 7 describes assessment and support coordination agencies for each program. CSPPPD contracts with three regional agencies to assess and enroll consumers and provide support coordination. The Attendant Care Program contracts with 15 assessment and enrollment agencies, each with a separate service area. These agencies and ten others offer support coordination. A majority of agencies for both programs are centers for independent living and branches of United Cerebral Palsy. The state administrative unit that manages three smaller waivers, the Waiver Implementation Unit, directly enrolls people in the HIV/AIDS and Michael Dallas waivers based on a review of a physician's certification of waiver eligibility. The local Area Agency on Aging is the access point for the Elwyn Waiver, which operates in only one county.

The above agencies access program eligibility. An additional nursing facility level of care assessment by is necessary for all these waivers except the OBRA Waiver, which serves people at an Intermediate Care Facility. Area Agencies on Aging assess nursing facility clinical eligibility, and therefore serve as an entry point.[44] Thus, many applicants have two assessments: AAAs assess nursing facility criteria and the local enrollment agencies assess program functional eligibility. The enrollment agencies use shorter assessments that contain questions specifically related to program criteria. The additional assessment does not appear to delay services for eligible individuals, because the assessment meeting also informs service planning. Some AAAs and enrollment agencies schedule their assessments together so the consumer is subject to only one assessment. In other areas, the agency that first learns about the person conducts the first assessment, and then passes this information to the other agency. Once a person joins a waiver, the local enrollment agency conducts reassessments of nursing facility clinical eligibility annually, or more frequently if a person's circumstances warrant a reassessment.

[44] HCBS applicants with physical disabilities do not need Area Agencies on Aging assessments in two circumstances. The state-funded attendant care program does not require people meet nursing facility level of care. Also, a minority of HIV/AIDS Waiver participants require a hospital level of care, which is certified by the physician and subject to state approval.

Table 7. Assessment Agencies for HCBS Programs Serving Adults with Physical Disabilities		
HCBS Program	**Initial Level of Care Determination**	**Program Eligibility Determination and Reassessments**
Attendant Care	Local Area Agency on Aging (AAA) and physician certification of level of care*	One of 15 regional enrollment agencies
COMMCARE	AAA and physician certification of level of care	One of three regional enrollment agencies, subject to OLTL CSPPPD review
Elwyn	AAA and physician certification of level of care	AAA
HIV/AIDS	AAA** and physician certification of level of care	OLTL Waiver Implementation Unit reviews physician certification form
Independence	AAA and physician certification of level of care	One of three regional enrollment agencies, subject to OLTL CSPPPD review
Michael Dallas	AAA and physician certification of level of care	OLTL Waiver Implementation Unit reviews physician certification form
OBRA Waiver	One of three regional enrollment agencies, subject to OLTL CSPPPD review	One of three regional enrollment agencies, subject to OLTL CSPPPD review

* AAAs do not conduct level of care assessments for state-funded attendant care participants. Nursing facility level of care is not required for the state-funded Act 150 program.

** A few HIV/AIDS participants qualify at a hospital level of care. Physicians certify hospital level of care on a form that is reviewed by OLTL Waiver Implementation Unit.

Sources: Information provided by Pennsylvania Departments of Aging and Public Welfare.

The multiple entry points can create confusion for consumers, especially for the two waivers serving a broad population of adults with physical disabilities: the Attendant Care and Independence waivers. In most areas of the state, different agencies enroll people in these waivers. Since the Independence Waiver offers more services than Attendant Care, the local enrollment agencies triage applicants for the two waivers. Attendant Care agencies often refer people to the Independence Waiver if they need additional services such as a home modification or respite. Similarly, if an Independence Waiver applicant only needs attendant care, he or she is referred to the other waiver.

To help people access services, the Department of Public Welfare developed an online application system for all of its programs. The Commonwealth of Pennsylvania Access to Social Services (COMPASS) enables a person to start the enrollment process no matter which agency they approach, ensuring there no wrong door to access services. For example, if a person asks a private home health or social service agency about services, that agency can help the consumer apply through COMPASS. People complete an application and send it to the program's enrollment agency, which then calls the consumer to schedule an assessment. In addition to many HCBS programs, the social services included in the COMPASS website include Medicaid and state-funded health insurance, food stamp benefits, free or reduced price school meals, home energy assistance, cash assistance, and institutional long-term care. [45]

People with physical disabilities in ten counties can access HCBS more quickly through the Community Choice initiative described on pages 19 and 20. This initiative includes an expedited eligibility process,

[45] Commonwealth of Pennsylvania Access to Social Services "About COMPASS" Undated.

an outreach campaign, and a change in financial eligibility requirements to reduce barriers to using HCBS.[46]

Controlling Institution Supply

Like many states, Pennsylvania has been rebalancing its system by reducing institutionalization as well as by expanding HCBS. Pennsylvania has had some success in reducing the supply of nursing facilities, using the supply controls described on page 20.

Transition from Institutions

Pennsylvania has established a statewide nursing home transition program with dedicated state funding as well as federal support from a Nursing Facility Transition Grant. Since the program went statewide in January 2005, the project has helped 400 nursing home residents move to houses and apartments.[47] Almost all residents had long-term stays, defined as 90 days or longer. Many transitioning residents were under age 60.[48]

The Governor's Office of Health Care Reform (OHCR) provides grants to 30 local collaborations of AAAs and agencies that serve adults with physical disabilities, including many centers for independent living (CILs) and branches of United Cerebral Palsy. OHCR also provides training and technical assistance regarding nursing home transition. The grants were intended to pay for a full-time equivalent of staff focused on helping nursing facility residents move to the community. In many communities, the collaborative sent all funds to the provider for people under age 60, so this provider could hire a full-time person devoted to nursing home transition. These providers, particularly the CILs, often had prior experience coordinating nursing home transitions. The grants allowed them to expand their efforts.

In addition, a pilot initiative targets higher functioning residents in six counties with the highest proportions of low-acuity residents according to data from the Minimum Data Set (MDS) assessment. Utilization review nurses interview high functioning residents and estimate the supports necessary for transition. Local AAAs then prioritize transition assistance to first assist people who need the least support. Utilization review nurses were selected for this task because they already work regularly with nursing facilities, reviewing the appropriateness of data on the MDS assessment that influences nursing facility payment.

All waivers for people with physical disabilities except the Elwyn Waiver pay for up to $4,000 in community transition services. The service definition includes most transition supports allowed under Medicaid HCBS waivers, including assistive technology and many things a person may need for a new apartment such as furniture, security deposits, moving expenses, utility set-up fees, cookware, linens, and other household supplies.

[46] The financial eligibility change, a disregard of $6,000 in assets that effectively raised the asset limit to $8,000, was made statewide through a Medicaid State Plan amendment.
[47] Vitez, Michael "Homeward Bound: in Reverse Trend, People Move from Nursing Homes to Live on Their Own" *Philadelphia Inquirer* May 3, 2006.
[48] Data provided by the Governor's Office of Health Care Reform.

Continuum of Residential Options

Pennsylvania offers few options for people with physical disabilities where people who live in facilities operated by their service provider. Residential options are limited because state law does not allow personal care homes – the most common type of residential facility serving people with physical disabilities – to serve people who need nursing facility services. The Department of Public Welfare can waive a personal care home requirement if residents will benefit and if "there is an alternative for providing an equivalent level of health, safety, and well-being protection."[49] There are a few instances where DPW has allowed a personal care home to serve nursing facility eligible people, with funding from a Medicaid waiver.

Two HCBS waivers provide residential supports to nursing facility eligible individuals. The Elwyn Waiver is the only program provides a per diem reimbursement for a 24-hour secure environment, personal care, transportation, and other services. This waiver covers assisted living for about 40 people who are deaf or hard of hearing. The COMMCARE Waiver for people with traumatic brain injuries includes people who live in small group settings operated by a provider. The provider bills services on an hourly rate for each person served. For example, if one direct support worker spends an eight-hour work day supporting three people, the provider bills 2.75 hours for two residents and 2.5 hours for the third.

The OBRA Waiver also serves individuals who live in personal care homes. The OBRA Waiver serves people at an Intermediate Care Facility for people with Other Related Conditions (ICF/ORC) level of care, rather than nursing facility level of care. As a result, personal care homes can serve OBRA consumers. Like the COMMCARE Waiver, the OBRA Waiver pays for services on an hourly basis.

Advocates for people with physical disabilities have not called for more assisted living or other group settings. Instead, they have worked to expand access to apartments and single family homes that are affordable and accessible. A recent success is a partnership between the Governor's Office of Health Care Reform (OHCR), DPW, and the Pennsylvania Housing Finance Agency (PHFA) to improve the availability of accessible subsidized housing units. In recent years, PHFA has developed an affordable housing locator that enables people to search for any affordable housing in the state, including accessible units. PHFA also provides 90 days advance notice to OHCR when a new property with accessible units is ready to lease. OHCR in turn passes the information to centers for independent living and other organizations that work directly with people who need accessible units.

Building HCBS Infrastructure

Publicly funded supports for people with physical disabilities are relatively new to Pennsylvania. While programs for other populations started in the 1960s and 1970s, the Attendant Care Program started as a state-funded program in the mid-1980s. The OBRA Waiver started in 1990, with other waivers added in subsequent years.[50] To develop a provider base for people with physical disabilities, the state has worked with non-profit organizations that had a history of serving people with disabilities with other private and public funds. The three CSPPPD enrollment agencies, for example, are two centers for independent living (CILs) and an organization that started as a chapter of United Cerebral Palsy (UCP) before becoming a separate non-profit agency. CILs and branches of UCP are also a majority of Attendant Care providers.

[49] Pennsylvania Administrative Code, Title 55, Section 2600.19.
[50] Pennsylvania Department of Public Welfare "Home and Community-Based Services Waiver Profiles" May 2002.

CSPPPD also established three regional administrative entities that conduct outreach to recruit providers. These private, non-profit entities also help providers navigate the Medicaid contracting process and train providers regarding the billing information system. The administrative entities have limited provider recruitment capacity, however. Each has fewer than ten staff for provider recruitment and other delegated functions of the State Medicaid Agency, such as review of individual service plans.

People with physical disabilities have also benefited from the workforce development initiatives described in the Older Adults section. The workers targeted in these initiatives serve people with physical disabilities as well as older adults.

Participant Direction

Employing one's own attendant is a commonly-used option in the three largest waivers: Attendant Care, Independence, and OBRA. Employing an attendant is also available, but not as common, in the waivers for people with a traumatic brain injury and for technology-dependent individuals.

The option is fairly limited in its design. People are able to employ an attendant, but individual budgets are not available. Participants also cannot negotiate wages with workers. Further, people who need or want to designate a representative to direct their supports have limited options. Attendant Care participants cannot designate a representative. Independence and OBRA Waiver consumers can only designate a representative who already has power of attorney. Finally, consumer-employed assistants are primarily available only for one service, called attendant care or personal assistance depending on the waiver. This service provides basic assistance with activities of daily living, and can include certain health maintenance tasks such as bowel and bladder routines and wound care. Independence and OBRA Waiver participants can also hire their own respite staff.[51]

The same agencies that provide the respite, personal assistance, and attendant care services also assist people in directing their own supports. Providers withhold income, payroll, and unemployment taxes and educate consumers regarding the rights and responsibilities of self direction. These agencies are also responsible for having back-up support available if an attendant is not available. The use of the same agencies for both the agency model and the self-directed model presents a possible conflict of interest, where providers are in a position to encourage one model or another. For the OBRA and Independence Waivers, Pennsylvania is establishing a separate waiver service for financial management services to address this potential conflict of interest.

Quality Management

Two key quality monitoring features for the largest programs, Attendant Care and CSPPPD, are written consumer surveys and annual provider reviews. The surveys are mailed to consumers, who can respond anonymously or identify themselves if they need help with a particular issue. Surveys are used to measure consumer satisfaction and control; to enable consumers to identify particular problems with their services; and to provide feedback regarding the quality of services.

The Commonwealth's quality reviews focus on a sample of five percent of consumers, with a minimum of ten individuals for CSPPPD and five people for Attendant Care. Participants are interviewed, with permission, and their records are reviewed to evaluate whether the provider meets program standards.

[51] Pennsylvania Department of Public Welfare *Attendent Care Waiver Application* 2003 and Pennsylvania Department of Public Welfare *Independence Waiver Application* 2001.

The reviews focus on compliance with federal and state waiver requirements. Providers are required to develop corrective action plans when problems are identified.

CSPPPD provides additional oversight over enrollment and service plan development. The state conducts this oversight in partnership with three contracted "administrative entities," one for each regional enrollment agency.[52] Staff from both the administrative entity and DPW review each applicant's program eligibility assessment and service plan to verify eligibility and service appropriateness. CSPPPD also requires both levels of review for service plan changes.

DPW has developed quality management plans for both the Attendant Care and CSPPPD programs that analyze data from the above activities and from service authorization and claim payment data. The data analysis will inform quality improvement. The plans are part of a statewide, cross-disability quality assurance and improvement initiative.

Summary

The Pennsylvania system of long-term supports for people with disabilities has notable strengths. It has a smaller than average institutional population and its support for HCBS has risen dramatically in recent years. The statewide nursing facility transition program has achieved some success in helping people move from institutional care. Finally, the new Office of Long Term Living includes all long-term supports for people with physical disabilities, and presents an opportunity to reduce the system's fragmentation.

However, people with physical disabilities often face significant challenges in seeking community services. Multiple local administrative agencies can lead to confusion in whom to contact. The complex array of programs, each with its own functional or diagnosis-based criteria, limits access for some individuals. Also, important options such as the flexibility of an individual budget and community residential supports are not available.

[52] The administrative entities were once a unit of the enrollment agencies. These duties were separated in two regions due to one agency's poor performance and the other agency's decision to create a separate non-profit administrative entity.

Section V: Services for People with Mental Retardation

Unlike most states, Pennsylvania serves people with developmental disabilities through two different systems. This section describes the system designed specifically for people with a mental retardation diagnosis, which serves most individuals with developmental disabilities. The Community Services Program for People with Physical Disabilities (CSPPPD) program, described in the previous section, provides supports for people with developmental disabilities that affect physical function.

Some individuals with significant disabilities do not fit into either system and do not have access to home and community-based services (HCBS). The most significant gap is people with autism spectrum disorders.[53] Many people with autism qualify for services in the mental retardation system, but many others do not. Except for a 24-person pilot project in the OBRA Waiver, no HCBS are available for people with autism spectrum disorders who do not have mental retardation. The number of people diagnosed with these disorders has increased rapidly in recent years, making this gap more apparent. The Commonwealth is considering options to serve more people with autism spectrum disorders.

Pennsylvania has had considerable success in rebalancing supports for people with mental retardation. When controlling for state population, the number of Pennsylvanians with mental retardation receiving Medicaid HCBS waiver services is higher than in most states, and the number of state institution residents is below average. However, there is still progress to be made. Available community support options vary from county to county, reflecting the traditional role of county-based service administration.

Programs and Services

HCBS Programs

Community supports for people with mental retardation began 40 years ago, when the 1966 MH/MR Act required counties to establish mental health and mental retardation (MH/MR) programs and authorized state-funded grants for these programs. The MH/MR Act established Pennsylvania as a national leader in services for people with mental illness and mental retardation. Since the early 1980s, the state has used Medicaid HCBS Waivers to provide more intensive supports and to serve more people.[54]

Two waivers are currently available for people with mental retardation age three and older: the Consolidated Waiver and the Person/Family Directed Supports (P/FDS) Waiver.[55] The Consolidated Waiver is the largest waiver in Pennsylvania and offers residential services in small community settings. The P/FDS Waiver does not offer residential services and each consumer has an annual cost limit of $21,225. The two waivers share a common waiting list of over 23,000 individuals. This list includes people who are projected to need services up to ten years from now in order to avoid institutionalization. Only 3,000 of those on the waiting list are considered to have "emergency" needs – that is, they require services within one year.[56] The waiting list also includes people already served by the waiver who are projected to need additional services in the future.

[53] The autism spectrum includes autism, Asperger's disorder, and other pervasive developmental disabilities.
[54] Pennsylvania Department of Public Welfare "Home and Community-Based Services Waiver Profiles" May 2002.
[55] Most waiver participants are adults age 21 and older. According to the Department of Public Welfare, the Consolidated Waiver served 798 children under age 21 in State Fiscal Year 2004-05. The P/FDS Waiver served 943 people under age 21.
[56] Data provided by the Pennsylvania Department of Public Welfare.

The primary service for both waivers is habilitation, which helps people acquire, improve, and maintain self-help, socialization, and adaptive skills.[57] Habilitation is defined to include residential habilitation, day programs, educational services, pre-vocational services, and supported employment. Each waiver also offers a comprehensive array of therapies, respite, environmental modifications, and other services individuals may require for community living.[58]

In addition to the Medicaid waivers, the state-funded community mental retardation grants, also known as base funding, provides a small amount of flexible support for thousands of people who do not receive waiver services. County MH/MR programs must match one dollar for every nine in grant funds. A common benefit is the Family Support Services program, which provides up to $1,200 per year so families can pay for respite care and other expenditures to help the family care for the individual with mental retardation.

Table 8. Long-Term Support Programs for People with Mental Retardation: Participants in SFY 2004-05 and Average Annual Growth since SFY 2001-02

Programs	Persons Served, SFY 2004-05	Average Annual Growth Rate
Consolidated Waiver	13,821	1%
P/FDS Waiver	7,445	6%
ICF/MR	4,067	-2%
Total Medicaid	**25,333**	**2%**
Family Support Services	15,407	-1%
Total Non-Medicaid	**15,407**	**-1%**
Total	**40,740**	**1%**

Sources:
2001-02 Waiver data are from CMS Form 372 Reports.
2004-05 Waiver and Family Support Services data are from unpublished reports by Pennsylvania Department of Public Welfare.
ICF/MR data are from Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
2001-02 Family Support Services data are from Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.

Also, domiciliary care homes and personal care homes provide housing and support for individuals with mental retardation. Pennsylvania pays a few hundred dollars a month for these individuals through a state supplement to SSI described on page 16. Approximately one-third of domiciliary care home residents have MR; no estimate is available for personal care homes. Residents of either type of facility are eligible for any of the above waivers if they meet program criteria.

Non-HCBS Programs

In addition to supports from HCBS programs, informal support from family members, usually parents, is particularly important. Families are the primary supports for most people who are on the waiting list for the waivers. Families continue to play a significant role after the person receives waiver supports. This is especially true for P/FDS Waiver consumers because this waiver builds services around the person's existing informal support. In addition to HCBS programs and informal support, people with mental retardation often also receive the services shown below.

[57] Consolidated Waiver CMS Form 372 Report and P/FDS Waiver CMS Form 372 Report, both for July 1, 2002 through June 30, 2003.
[58] Pennsylvania Department of Public Welfare *Mental Retardation Bulletin 00-06-04* January 31, 2006.

Common Non-HCBS Supports and Programs for People with Mental Retardation

- Income support from Supplemental Security Income;
- Health insurance from Medicaid;
- Paratransit services;
- Employment training and supports from the Vocational Rehabilitation Program;
- Grocery payment from the Food Stamp Program; and
- Housing assistance from the local Public Housing Authority.

Appendix A presents data for these programs and for non-HCBS programs that support other population groups.

Demographic and Utilization Trends

As noted on pages 4 and 5, Pennsylvania relies less on institutions for people with mental retardation than other states. The Commonwealth has been particularly successful in reducing the use of large state institutions. The proportion of state residents in these institutions was 14% lower than the national average in 2005. Meanwhile, Pennsylvania's HCBS utilization is 40% above average. Utilization of private ICF/MR, which are typically smaller and provide more community integration opportunities, is close to the national average.

Table 9 compares Pennsylvania and national institutionalization rates for people with mental retardation and other developmental disabilities. Almost all institution residents in Pennsylvania have mental retardation. Two facilities serve people with other developmental disabilities and have a capacity to serve 14 individuals.

Table 9. Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD): Residents per 100,000 State Population as of June 30, 2005

Institution Type	United States	Pennsylvania
Large State Institutions	13.6	11.7
Other ICF/MR	20.7	21.0
Total	**34.4**	**32.6**

* Large state institutions are defined as state-operated facilities with 16 or more beds that serve people with developmental disabilities.

Source:
Prouty, Robert; Smith, Gary; Lakin, K. Charlie; Bruiniks, Robert; Coucouvanis, Kathryn *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005* University of Minnesota: July 2006.

Components Associated with Rebalancing

Streamlined HCBS Administration

The Office of Mental Retardation (OMR), an agency within the Department of Public Welfare (DPW) administers both community and institutional services for people with mental retardation. OMR administers all Medicaid and state-funded supports. OMR also licenses community-based residential facilities. The Department of Health licenses ICF/MR.

A single agency can consider the impact of changes to HCBS policy on institutional services and vice versa. For example, when planning to close a state institution, OMR estimates how many institution residents will transfer to nearby institutions, move to private ICF/MR, or move to waiver-funded residential homes. OMR incorporates these estimates into its budget request, which has separate line items for state institutions, private ICF/MR, and community supports.

Single Access Point

Pennsylvania has effectively implemented a single access point for people with MR. The 1966 MH/MR Act established grants for counties to administer community supports on the local level. County MH/MR programs administer state-funded supports and the Medicaid HCBS waivers. They also administer Early Intervention services for children under age three.

County MH/MR programs assess eligibility for community and institutional services, including state institutions. Physician certification of level of care and a mental retardation diagnosis are also required. Because service availability depends on a person having mental retardation, families often pay for several IQ tests to increase the likelihood of a mental retardation diagnosis.

For HCBS waiver services, counties also complete the Priority and Urgency in Need for Services (PUNS) assessment. This assessment determines where the consumer fits in Pennsylvania's waiting list prioritization criteria. Applicants are categorized based on when services will be necessary to avoid institutionalization. Categories are:

Waiting List Prioritization Categories for Waivers Serving People with Mental Retardation

- Emergency (needs services within one year);
- Critical (need services within one to five years); and
- Planning (needs services more than five years from now).

Controlling Institution Supply

Like many states, Pennsylvania has two types of institutions for people with mental retardation: large state institutions that long were the only option for people with developmental disabilities and smaller private ICF/MR that tend to offer more opportunities for community integration. Pennsylvania has focused its rebalancing efforts on closing state institutions. During the past 30 years, Pennsylvania has closed 17 state institutions, including the Altoona State Center in early 2006. Closures initially occurred

under lawsuit settlements such as the 1977 landmark *Pennhurst State School and Hospital v. Haldeman*.[59] More recent closures have been voluntary. Five facilities remain that serve from 145 to 374 people.[60] In contrast, 158 of Pennsylvania's 180 private ICF/MR serve eight or fewer people.[61]

Transition from Institutions

Both state institutions and private ICF/MR are required to help residents improve functioning with a goal of moving to a more integrated setting. Pennsylvania has placed a high priority on transitioning people from the state's five mental retardation facilities. Several years ago, OMR developed a standard transition planning process for the state institutions.

The transition process is used during planned institutional closures and in separate individual transitions. Each person has an individual planning team including staff from the institution and the county MH/MR program, the person, and family and friends he or she selects. This team develops a plan for community supports and then a plan for transition, describing how the person and others will prepare for the move. For example, people often stay overnight at their new home to become more familiar with their community environment and ensure it is a good fit. People may also visit health care and long-term support providers to establish relationships with them.[62]

Continuum of Residential Options

Like many state systems for people with developmental disabilities, Pennsylvania's mental retardation system long has used small group homes of three to four people to provide a community option to institutional services. OMR licenses two types of facilities that provide room and board, habilitation, and personal supports to people with mental retardation (described below). For most residents, the Consolidated Waiver pays for the services people receive in these settings. Housing costs are funded by Supplemental Security Income (SSI) and state funds.

Licensed Community Residential Settings
Serving People with Mental Retardation

- ***Community Homes*** – serve three to ten people. Facilities established since 1996 are limited to four individuals per home.[63] The 3,223 licensed sites have a total capacity of 13,000 beds; and
- ***Family Homes*** – serve one or two people in a single-family home. Some family homes are owner occupied, while other family homes are owned and managed by agencies that recruit and compensate the families.[64] About 900 family living homes are licensed, with total capacity for 1,466 individuals.

[59] O'Shaughnessey, Carol, et al. *A CRS Review of 10 States: Home and Community-Based Services – States Seek to Change the Face of Long-Term Care: Pennsylvania* Congressional Research Service: April 1, 2003.
[60] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[61] Pennsylvania Department of Public Welfare "Human Services Provider On-Line Directory" November 12, 2005.
[62] Pennsylvania Department of Public Welfare *Guide to Supporting People Moving from State Centers Into Community* April 8, 2004.
[63] Pennsylvania Department of Public Welfare *Mental Retardation Bulletin 00-06-04* January 31, 2006.
[64] Pennsylvania Administrative Code Title 55, Chapter 6500.

Since the late 1990s, Pennsylvania has also increased options for people who do not need a small group setting. The Person/Family Directed Supports Waiver started in 1999 to serve people living with family members, and now serves over 7,000 individuals. In addition, the Consolidated Waiver offers a service called "Home Finding" that helps people currently in licensed settings find an apartment or a single family home.

Building HCBS Infrastructure

The MR system started developing its infrastructure for community supports forty years ago through the state-funded grant program. The grant funding included start-up capital for providers to establish community supports. Medicaid has played a steadily increasing role in HCBS since the Medicaid HCBS Waiver program started in the early 1980s and grew rapidly in the 1990s.[65]

While funding for community services continues to increase, the Commonwealth has focused on improving currently available services. For example, Pennsylvania established eight regional, non-profit Health Care Quality Units to improve the health of people with mental retardation. The organizations provide training and technical assistance to community support and medical providers to help both systems serve people with mental retardation and other health conditions. The Health Care Quality Units also collect and analyze health status data to inform systemic health improvement efforts.[66]

Pennsylvania is currently establishing a larger state role in managing supports to persons with mental retardation. This greater role is necessary because the Medicaid-funded programs are characterized by local control and flexibility. The type of services one receives and the amount of time one spends on a waiting list varies greatly among county MH/MR programs. Such variation among counties is expected in grant programs, which allow more local autonomy to address unique community needs. However, Medicaid is a benefit for particular qualifying individuals and confers certain rights to applicants and consumers that apply consistently across an entire state.

The Centers for Medicare and Medicaid Services (CMS) is requiring the Commonwealth to restructure its Medicaid-funded programs in accordance with Federal statutory and regulatory requirements before approving a renewal of the Consolidated Waiver. The four main assurances that need to be addressed are:

- Establishing the authority of the Commonwealth over the waiver program
- Assuring that plans of care meet the needs of waiver participants through the provision of necessary services
- Enrolling all qualified and willing providers to permit waiver participants to exercise free choice
- Implementing Commonwealth policies for the setting of payment rates

Participant Direction

Both HCBS waivers for people with mental retardation allow participants to direct some of their supports. People can hire their own individual providers for day habilitation, in-home respite, transportation, homemaker and chore services, environmental modifications, adaptive equipment, and several other services. Consumers can authorize a representative to manage their services. They also can negotiate

[65] Mullen, Dorothy; Eiken, Steve; and Steigman, Daria "Promising Practices in Long-Term Care Systems Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation" March 3, 2003.
[66] Ibid.

wages with individual providers, but individual budgets are not an option.[67] Participant direction is more common in the non-residential P/FDS Waiver, which was intended in part to create more opportunities for participants and families to direct their own supports.

Quality Management

Pennsylvania's mental retardation system collects a variety of data to inform quality improvement, including: consumer interviews; record reviews; health assessments for a sample of consumers; and reports from an information system that tracks certain program operations and gathers information from the above activities into a single source. These sources are described below. Drawing information from this large volume of data to inform quality improvement has been a challenge. OMR is refining its quality improvement plan to improve the process for using these data as part of the Commonwealth's statewide, cross-disability quality improvement initiative.

Volunteer review teams conduct the consumer interviews using a tool called Independent Monitoring for Quality (IM4Q). The volunteers – individuals with disabilities, family members, and other stakeholders without a link to the support providers being reviewed – interview selected participants and their families about the quality of supports within the context of their daily lives. Each county MH/MR program contracts for training and technical support for the volunteers. Pennsylvania's goal is to conduct an independent monitoring review for each participant in a community residential setting every three years. The IM4Q results inform the regional monitoring of counties described below. OMR has also developed quality improvement initiatives based on IM4Q results, such as developing brochures to inform participants and families about available employment assistance, which was underutilized.[68]

The Office of Mental Retardation's regional office staff conduct an annual monitoring visit for each county MH/MR program. The regional office randomly selects a five-percent sample of participants. Regional staff interview these participants and review their provider and county records for compliance. The monitoring team submits the final report to the county and, if necessary, the review team asks the county to develop a corrective action plan. To ensure quality issues are adequately addressed, the regional office reviews monitoring plans and may conduct a subsequent in-person visit to verify the corrective actions are in place.

Each year, eight regional Health Care Quality Units assess a sample of individuals with mental retardation to track the population's health status and access to medical services.[69] The assessments, called Health Risk Profiles (HRP), measure an individual's status regarding several physical and behavioral health risk factors. The participants, family members, and providers are notified if an individual's profile identifies areas that may require intervention. Health Risk Profile results are reviewed at the provider, county, and regional levels to inform quality improvement initiatives.

IM4Q interviewers, health risk assessors, and county monitors all enter their information into the Home and Community Services Information System (HCSIS). This system also contains more routine information about supports for people with mental retardation, including the assessment for service priority, service authorization information, and unusual incident reports and the results of investigations. OMR can use all of this information to inform quality improvement planning.

[67] Pennsylvania Department of Public Welfare *Mental Retardation Bulletin 00-06-04* January 31, 2006.
[68] Medstat "Pennsylvania's Independent Monitoring for Quality (IM4Q)" June 2003.
[69] The HCQUs also provide training and technical assistance to counties, MR providers, and health care providers to help them improve consumers': access to health services and health status.

Summary

Pennsylvania has made significant progress in rebalancing services for people with mental retardation. Pennsylvanians are more likely to receive HCBS and less likely to live in state institutions than people in other states with developmental disabilities. Three-fourths of state institutions have been closed since the 1970s.

However, the Commonwealth's system varies significantly by county and by diagnosis. Consumers' services often depend as much on where they live as they do on the consumer's needs, strengths, and informal support. In addition, the system only serves people with a diagnosis of mental retardation. Many people with developmental disabilities, but without mental retardation, cannot access services. People with autism spectrum disorders are particularly affected by this gap.

Section VI. Services for People with Mental Illness

Pennsylvania's system for adults with mental illness has seen significant changes in the past 10-15 years. The state hospital census is one-third the level it was in 1991. The community mental health system, including home and community-based services (HCBS), has expanded dramatically, thanks in part to Medicaid's growing role. The Commonwealth is providing more and higher quality service options, targeting growth toward services with evidence of effectiveness. Despite this progress, much work remains. The Commonwealth still serves more people in state institutions than most states, controlling for state population. While Pennsylvania's decentralized system has enabled some localities to pioneer innovative services, other counties have lagged behind.

Programs and Services

HCBS Programs and Supports

Medicaid has played an increasing role in the financing of community mental health services and is now the largest public funding source for mental health services in Pennsylvania.[70] Medicaid mental health services (listed below) are provided through two different delivery models. In 25 counties that include the largest metropolitan areas, Pennsylvania operates a mandatory Medicaid managed care program. Sixty-five percent of all Medicaid participants are served under this program, called HealthChoices. A behavioral health component called Behavioral HealthChoices provides services through separate contracts with plans specializing in mental health.[71] Statewide expansion of HealthChoices is planned, and a new four-county area is scheduled to start services in 2007.[72] In the remaining counties, the Commonwealth reimburses Medicaid services on a fee-for-service basis.

Medicaid Mental Health Benefits Offered in Pennsylvania

- Inpatient hospitalization;[73]
- Outpatient psychiatrist and psychologist services;
- Partial hospitalization, more intensive treatment for people who need more than typical outpatient visits;
- Prescription drugs;[74]
- Rehabilitation services;
- Crisis intervention, including hotlines, walk-in, and residential services; and
- Targeted case management to facilitate access to necessary health and social services.

[70] Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.
[71] Behavioral HealthChoices covers all Medicaid participants except people in institutions. While people dually eligible for Medicare and Medicare are exempt from the physical health portion of HealthChoices, they still participate in Behavioral HealthChoices because the Medicaid mental health system covers a broader range of services than Medicare. HealthChoices operates under a waiver of Medicaid rules that allows states to waive participants' right to freely choose service providers. These waivers are authorized by section 1915(b) of the Social Security Act.
[72] Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.
[73] Inpatient hospitalization does not include most state hospital admissions. Medicaid funds cannot be used for services in an "Institution of Mental Disease" (IMD) for people age 22-64. Pennsylvania's Medicaid benefit does include people under age 22 and

Community mental health grants are the other major public funding source for mental health services. The grants funds services that are not covered by the Medicaid program and support people who are not enrolled in Medicaid.[75] Like the state grants for people with mental retardation, community mental health grants are authorized by Pennsylvania's 1966 MH/MR Act. The grants are provided to county MH/MR programs, which can also use them for building capacity for innovative service models. The Commonwealth contributed almost 80 percent of community mental health grants funding in state fiscal year 2004-05. Counties are required to pay for 10 percent of grant-funded services. Federal funds – from federal community mental health grants and the social services block grant – provided the other 10 percent.

A third program promotes better linkages of mental health and substance abuse services. The Behavioral Health Services Initiative (BHSI) funds integrated services for uninsured people with co-occurring mental illness and substance abuse. Such integrated services are considered an Evidence-Based Practice by the federal Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to this initiative, Pennsylvania received a $3.9 million SAMHSA State Incentive Grant in 2003 to develop a permanent, statewide infrastructure for integrated treatment.[76] The Office of Mental Health and Substance Abuse Services (OMHSAS) operates this program in conjunction with the agency that administers substance abuse treatment grants, the Pennsylvania Department of Health, Bureau of Drug and Alcohol Programs.

In addition, domiciliary care homes and personal care homes provide housing and support for individuals with mental illness. Pennsylvania pays a few hundred dollars a month for these individuals through a state supplement to SSI described on page 16. Approximately one-third of domiciliary care home residents have a mental illness; no estimate is available for personal care homes.

Table 10. Community Mental Health Programs: Participants in SFY 2004-05 and Average Annual Growth Rate Since SFY 2001-02

Programs	Persons Served, SFY 2004-05	Average Annual Growth Rate
Medicaid	**256,020**	**n/a**
Community Mental Health Grants	120,245	n/a
Behavioral Health Services Initiative	31,553	n/a
State Institutions	2,251	-4%
Non-Medicaid	**154,049**	**n/a**
Total (not unduplicated)	**410,069**	**n/a**

Program-specific trend data were not available for community mental health services.

Source:
Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.

age 65 and older in IMDs, which include state institutions and certain other facilities with more than 16 beds that primarily provide mental health services.

[74] Prescription drugs are not part of the Behavioral HealthChoices mental health package. The plans that cover physical health services are responsible for all prescription drugs.

[75] Throughout the country, many people with serious mental illness may not be enrolled in Medicaid because their symptoms are not severe enough to meet SSI disability criteria, or they may face significant challenges navigating the disability determination system and providing sufficient documentation of the disability. (Eiken, Steve and Galantowicz, Sara *Improving Medicaid Access for People Experiencing Chronic Homelessness: State Examples* March 29, 2004).

[76] Stohl, Lana; Logsdon, Gloria; LeFlore, Bob; Brandt, Gordon; Cheek, Mattie *Pennsylvania Mental Health Block Grant Core Monitoring Report* U.S. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services: 2004.

Pennsylvania has been working with the county mental health programs to introduce service delivery innovations for several years. Like other mental health systems across the country, Pennsylvania is strongly encouraging a shift in its mental health system from a focus on symptom management to a recovery emphasis that encourages adults with serious mental illness to live fulfilling and productive lives. Recovery oriented services such as consumer-run drop-in centers and mutual support groups often involve people with mental illness learning from peers who are experiencing recovery.[77] These services are likely to increase as Pennsylvania implements several system changes identified in its 2004 Mental Health System Transformation Grant, including adding certified peer specialist services to Medicaid.[78]

Non-HCBS Supports

In addition to the broad range of HCBS available to Pennsylvanians with mental illness, medical and other services described below help support their efforts to live independently in the community.

Common Non-HCBS Supports and Programs for People with Mental Illness

- Medicare or Medicaid for health insurance coverage;
- Income support from SSDI, SSI or General Assistance;[79]
- Nutrition assistance from the Food Stamp program;
- State-funded prescription drug assistance from the Special Pharmaceutical Benefits Program for people with schizophrenia who are not on Medicaid;
- Substance abuse treatment, which is often integrated with mental health treatment; and
- Homeless assistance programs, including a state-funded program for temporary shelter and rental assistance, and several programs funded by the U.S. Department of Housing and Urban Development to provide a continuum of housing and supports (e.g., Emergency Shelter Grants, the Supportive Housing Program, and the Shelter Plus Care Program).

Appendix A describes these programs and non-HCBS programs that support other population groups.

Demographic and Utilization Trends

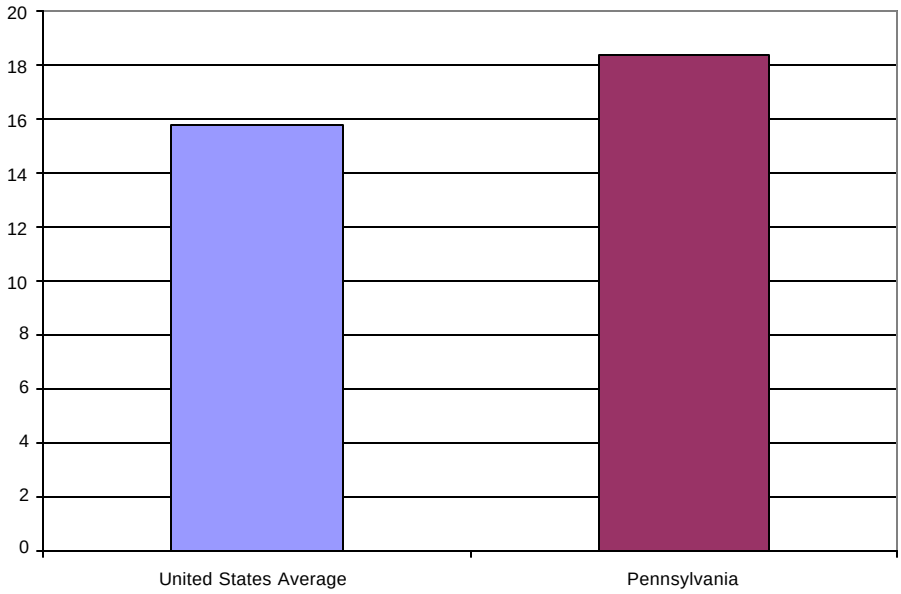
Pennsylvania's utilization rate for state institutions for people with mental illness in 2004 was above the national average, based upon the latest state comparison data available (See Chart 8 below). About four-fifths of the residents of state institutions were involuntarily committed, usually in a civil procedure.[80] Approximately half of the residents have a length of stay of more than two years. The institutional

[77] Ibid.
[78] Research Triangle Institute *Real Choice Systems Change Grants: Compendium, Fifth Edition* March 2006.
[79] General Assistance is a state-funded income support program for people with very low incomes who are unable to work but who do not meet requirements for SSI or Temporary Assistance to Needy Families (TANF), a federal and state program for families with children.
[80] NASMHPD Research Institute "State Profile Data and Reports" National Association of State Mental Health Program Directors: Undated.

population has declined dramatically since the 1990s, demonstrating the state's commitment to rebalancing. The total census for state institutions dropped from 4,934 in June 1995 to 2,251 people in June 2005, a 54% decrease over ten years.[81]

Throughout the 1990s and in the current decade, Pennsylvania has continually increased its support for community services. Expenditures for community-based services grew by an average of seven percent per year between State Fiscal Years 1994-95 and 2006-07. Medicaid has played an important role in this expansion, especially since Behavioral HealthChoices started in 1997.[82] The Commonwealth has added mental health services to the Medicaid State Plan and required plans participating in Behavioral HealthChoices to offer these supports as well. Managed care plans also must conduct outreach to ensure people know about and can access mental health supports. It is difficult to know how Pennsylvania compares nationally with respect to its HCBS for people with mental illness, as there are no data available that include both Medicaid and community mental health participants across a majority of states.

Chart 8. State Hospital Residents Per 100,000 in State Population on last day of State Fiscal Year (SFY) 2004



United States data includes 38 states that reported institutional population. Pennsylvania data include the nine state hospitals open at the time a state-operated nursing facility with special services for people with mental illness.

Sources:
NASMHPD Research Institute "State Profile Data and Reports: 2004" National Association of State Mental Health Program Directors: Undated. .
U.S. Census Bureau "State Single Year of Age and Sex Population Estimates: April 1, 2000 to July 1, 2004 – RESIDENT" March 10, 2005

[81] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[82] Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.

Components Associated with Rebalancing

Streamlined HCBS Administration

Pennsylvania has a single state agency responsible for the publicly funded mental health system. DPW's Office of Mental Health and Substance Abuse Services (OMHSAS) manages Medicaid and grant-funded supports and the state institutional budget. OMHSAS also manages Medicaid substance abuse treatment, which makes it easier to promote integrated treatment for people with co-occurring disorders. Having sole responsibility over all these funding streams enables the agency to allocate funds more efficiently among these programs.

Single Access Point

County MH/MR programs play a large role in the system and perform most of the functions of a single entry point. County government agencies allocate community mental health grant funds and contract with local providers for service delivery. They determine clinical eligibility for grant services and provide information and referral for mental health services regardless of payer. County programs also assess eligibility for state institution admission (except when it is court ordered) and ensure people know about other options that may be appropriate.

County programs do not determine eligibility for Medicaid-covered services, however. The county programs' role in Medicaid varies between Behavioral HealthChoices counties and fee-for-service counties. In the fee-for-service counties, consumers can approach any Medicaid provider directly for services. OMHSAS staff perform any prior authorization required for more intensive services. In managed care counties, county mental health programs play a large role in developing and operating the managed care plans. Counties have the right of first opportunity to develop their own risk plans and accept capitated payment for behavioral health services. However, most counties subcontract plan administration and risk to private managed care organizations.[83]

Institutional Supply Controls

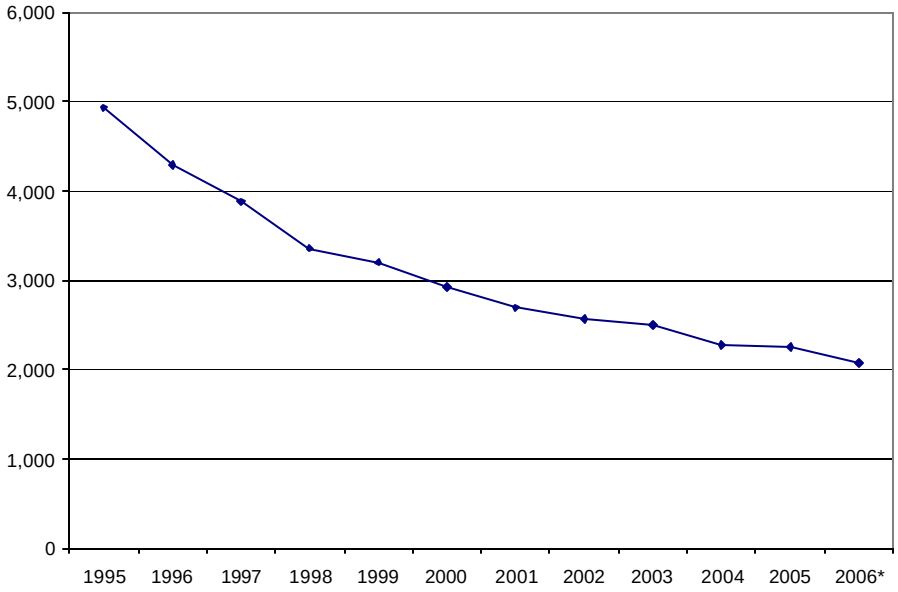
Pennsylvania reduced its supply of state institutions for people with mental illness, especially since the early 1990s. It has closed five of the 13 state-operated hospitals, and reduced capacity in others. Four closures occurred more than a decade ago.[84] The fifth closure, Harrisburg State Hospital, occurred during 2005 and 2006.

Key policies in the early 1990s encouraged rebalancing. During this time, Pennsylvania started the Community Hospital Integration Projects Program (CHIPP), which set aside funds for community supports when someone moves from a state institution. The Commonwealth also established a combined budget for community mental health grants and state institutions, so savings from reduced admissions would automatically be available for community supports. Also, county MH/MR programs assess the appropriateness of state hospital admissions, except when confinement is ordered by a court. Between SFY 1990-91 and 2004-05, the state hospital census dropped from 6,611 to 2,251, an average decline of

[83] Pennsylvania Department of Public Welfare "Behavioral HealthChoices" July 14, 2004.
[84] Pennsylvania Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2005-2006: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 10, 2005.

seven percent per year.[85] These figures do not include the impact of the closure of Harrisburg State Hospital in the past year.

Chart 9. Pennsylvania State Institution Residents as of June 30, 1995-2006



* 2006 data is projected.

Source:
Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.

Transition from Institutions

The recent closure of this Harrisburg State Hospital illustrates successes and challenges in the process of transitioning people from state institutions. A positive development was the higher-than-expected number of people who moved to community settings. The state originally estimated that about half of the hospital's 258 residents would move to the community and the other half would enter one of two nearby hospitals.[86] By March 2006, three-fourths of the hospital's residents had moved to community settings.[87] Other residents faced a longer-than-expected wait for their transition. The hospital officially closed in January, but 40 to 50 people remained on-site as of March 2006 pending a permanent community placement.[88]

[85] Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006 and Pennsylvania Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2005-2006: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 10, 2005.
[86] Pennsylvania Department of Public Welfare "Dept. of Public Welfare to Close Harrisburg State Hospital and Altoona Center as Part of Ongoing Effort to Improve Community-Based Care" January 6, 2005.
[87] Pennsylvania Department of Public Welfare "Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.
[88] The National Alliance on Mental Illness *Grading the States: A Report on America's Health Care System for Serious Mental Illness* March 1, 2006; and Pennsylvania Department of Public Welfare "The Governor's Recommended Budget Fiscal Year 2006-2007: Office of Mental Health and Substance Abuse Services Stakeholder Briefing" March 9, 2006.

The closure of Harrisburg State Hospital occurred over a period of a little more than a year. Each resident received an individual assessment involving consumer and family and clinical professionals to determine whether the person would move to the community or transfer to another state hospital. Hospital staff, OMHSAS, county MH/MR programs, and providers worked with consumers and families to identify and secure available community supports. The Office of Mental Retardation and the mental retardation units in county MH/MR programs were involved for ten percent of the residents who had dual diagnoses of mental retardation and mental illness.

Continuum of Residential Options

Pennsylvania offers multiple levels of housing and supports for adults with mental illness. According to a recent comparison of state mental health systems, Pennsylvania is one of many states with a shortage of supported housing for people with mental illness.[89] One challenge in increasing the supply of these options is that they are not eligible for Medicaid payment. People in smaller residential settings may qualify for and receive Medicaid services, but room and board and other basic living supports are not part of the Medicaid benefit.

Two supported housing settings are licensed specifically for mental health services. The most intensive and structured type of facility is Long-Term Structured Residences (LTSR), which was established to provide a community-based alternative to state hospitals. Currently, 28 LTSRs have the capacity to serve approximately 400 consumers,[90] but are not available in every area. LTSRs are available for people who qualify for psychiatric hospitalization but can be safely served in the less restrictive LTSR setting. Participants must be approved by the county MH/MR program administrator prior to admission.[91]

The other licensed setting, Community Residential Rehabilitation Services (CRRS) provides housing, personal care, and psychosocial rehabilitation to help people develop independent living and inter-personal skills. CRRS agencies promote independence and assist people in transitioning to more independent settings, in coordination with service planning and provider agencies. As of November 2005, 99 CRRS agencies, some with multiple sites, had the capacity to serve 2,615 people.[92]

Both types of licensed facilities are charged with promoting recovery and helping the person move to more independent settings, including mainstream homes and apartments. OMHSAS started a network of Local Housing Options Teams (LHOTs) to increase the number of housing units available for all people with disabilities and to increase the availability of housing with supportive services that enable people to live more independently.[93] LHOTs include staff from local disability service and advocacy organizations, including: county MH/MR programs; the Single County Authority that manages local drug and alcohol programs; Public Housing Authorities; centers for independent living; United Cerebral Palsy chapters; and other agencies and organizations

OMHSAS funds a technical assistance provider with housing expertise to work with local coalitions. Other state agencies, including the Governor's Office of Health Care Reform, are also working with LHOTs on housing issues for people with disabilities. The 31 LHOTs cover 46 of Pennsylvania's 67

[89] The National Alliance on Mental Illness *Grading the States: A Report on America's Health Care System for Serious Mental Illness* March 1, 2006.
[90] Pennsylvania Department of Public Welfare "Human Services Provider On-Line Directory" Updated November 12, 2005.
[91] Pennsylvania Administrative Code: Title 55, Chapter 5320.
[92] Pennsylvania Department of Public Welfare "Human Services Provider On-Line Directory" Updated November 12, 2005.
[93] Stohl, Lana; Logsdon, Gloria; LeFlore, Bob; Brandt, Gordon; Cheek, Mattie *Pennsylvania Mental Health Block Grant Core Monitoring Report* U.S. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services: 2004.

counties. In a March 2006 survey, the LHOTs reported that their efforts have assisted 1,136 households. About one-third of households included people who were homeless.[94]

Building HCBS Infrastructure

State and federal community mental health grants have been critical in developing service infrastructure over the past 40 years. For example, community mental health grants funded the new residential setting – LTSR – developed to serve people leaving state hospitals who require a more intensive level of care. Also, the Commonwealth has long offered a state-funded technical assistance program based in Penn State University to encourage local adoption of best practices.

The MH/MR Act that authorizes the grants requires counties to provide annual reports regarding uses of grant funds. Counties also must identify additional needs for the local mental health system. OMHSAS has revised the annual report form starting in 2002. County plans now include specific sections on county development of services focused on recovery.[95] Counties also list planned systems changes to move toward a recovery model and requests for new services that include the estimated cost. The reports link new service funding requests to systems change, to focus new funds toward promising or evidence-based services. OMHSAS reviews each plan with the county program and local consumers, families, advocates, and providers.[96]

OMHSAS also changed the timing of the annual county reports to link them more directly to funding decisions. County plans are timed so they can inform OMHSAS' budget request for the upcoming budget year. OMHSAS can therefore identify what the Commonwealth will purchase if it invests more money in community mental health.

The Medicaid managed care model provides another opportunity for counties to develop infrastructure. The state allows HealthChoices counties to reinvest the state share of any cost savings into expanded non-Medicaid services. For example, if the plan is successful in reducing inpatient psychiatric days, it may develop a consumer-run drop-in center or more mutual support group options. Counties must develop a HealthChoices reinvestment plan for establishing new or expanded services and the Commonwealth must approve the plan.[97]

Participant Direction

As in many states, participant-direction options for mental health services are limited in Pennsylvania. Participant-directed supports were not among the most common recovery-oriented services that counties plan to add, according to a summary of the most recent county MH/MR program plans for mental health.[98]

Quality Management

The Commonwealth increased quality measurement and monitoring with the implementation of Behavioral HealthChoices. The arrival of managed care came with concerns about the ability to access

[94] Data provided by the Governor's Office of Health Care Reform and Diana T. Myers (technical assistance provider for LHOTs).
[95] Examples of recovery-oriented services covered by some counties include respite, consumer-run drop-in centers, mutual support groups, and peer mentoring.
[96] Pennsylvania Department of Public Welfare "Annual County Plan Report FY 2005-2006" January 25, 2005.
[97] Stohl, Lana; Logsdon, Gloria; LeFlore, Bob; Brandt, Gordon; Cheek, Mattie *Pennsylvania Mental Health Block Grant Core Monitoring Report* U.S. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services: 2004.
[98] Pennsylvania Department of Public Welfare "Annual County Plan Report FY 2005-2006" January 25, 2005.

appropriate and effective services. Behavioral HealthChoices plans must produce quarterly reports measuring a limited set of measures shown below.

Quality Measures Included in Behavioral HealthChoices Quarterly Reports

- The proportion of all Medicaid participants who use mental health services (a.k.a. the penetration rate);
- The number of involuntary hospital admissions;
- The percentage of people discharged from an acute psychiatric hospital bed who are readmitted within 30 days; and
- A summary of complaints, denials, and grievances.

The report compares results in HealthChoices counties to state and national averages and to performance standards set by the state.[99]

For the community mental health system as a whole, the Commonwealth developed a set of consumer outcome measures that counties report quarterly. Indicators of positive system performance include less use of restrictive settings such as out-of-home placements; less homelessness; increased school attendance; increased employment; reduced indicators of criminal activity; increased consumer and family satisfaction; and implementation of continuous quality improvement initiatives.[100]

Summary

Pennsylvania has been aggressively tackling its relatively high rate of institutionalization of people with mental illness. Over the past 15 years, it has dramatically reduced the number of people in large state hospitals and invested in community-based services for people with mental illness. It has also expanded residential services and supported housing options to provide alternatives to institutions and support recovery.

The Commonwealth's tradition of local control and resulting county variation presents a significant challenge, however. The linking of new community mental health grant funds to particular new services, including recovery-oriented services, will further encourage counties to develop these supports so they are eventually available statewide. The planned statewide expansion of Behavioral HealthChoices would further reduce county differences by creating a common Medicaid infrastructure, and common Medicaid quality standards, across the entire state.

[99] Pennsylvania Department of Public Welfare *HealthChoices Behavioral Health Program Quarterly Monitoring Report: First Quarter 2005* November 1, 2005.
[100] Pennsylvania Department of Public Welfare *HealthChoices Behavioral Health Program: Program Standards and Requirements - Primary Contractor - County* July 10, 2003.

Section VII. Services for Children

Children with disabilities in Pennsylvania have federally mandated entitlements to long-term supports that help to reduce the gaps in services experienced by some adults. The public education system has important obligations for all children with disabilities. Medicaid must provide a broader array of supports for children with special needs, including services not offered to adults. For some population groups, the same state and local agencies administer services for both children and adults. Other individuals must get acquainted with a new case management and service system when reaching adulthood.

Pennsylvania serves far fewer children than most states in the most restrictive settings, such as state institutions. Comparison data regarding other home and community-based services (HCBS) are not available, making it difficult to assess the Commonwealth's progress toward serving children in the community.

Programs and Services

HCBS Programs

Medicaid and special education are the two largest programs providing long-term supports for children with disabilities. Most children with severe disabilities are eligible for both programs regardless of their family's financial status. Pennsylvania's Medicaid program has no resource requirement and bases financial eligibility on the child's income, not the parents' income, for children under age 21 that meet SSI disability criteria.[101]

Education services help children with disabilities from kindergarten to age 22 learn in the least restrictive environment. These services are a universal benefit mandated under the federal Individuals with Disabilities Education Act (IDEA). The education system also manages federal and state-funded early intervention grants for children age three to five. These supports can range from changes in instruction technique in a mainstream classroom, to personal assistants helping students with activities of daily living, to a variety of therapies to improve function and develop skills.

Education and Medicaid services are usually separate, but can overlap when Medicaid pays for services provided in schools.[102] Within Medicaid, children and youth with disabilities may receive long-term supports from three service systems:

- The physical health care system provides medical and rehabilitative services to children with physical disabilities.
- The mental health system provides clinical and rehabilitative services to children with severe emotional disturbances or whose disabilities affect behaviors (e.g., children with autism or a brain injury).
- The mental retardation system offers Medicaid HCBS waivers described on pages 35 and 36. Waiver services are available to children as young as age three, although children are only eight percent of all consumers in these waivers.

[101] The state set more liberal financial eligibility criteria within limits specified in section 1902(r)(2) of the Social Security Act.

[102] Medicaid may pay for services provided by school districts and their providers if the child is a Medicaid participant, the provider is enrolled in Medicaid for that service, the care is medically necessary, and other conditions of Medicaid reimbursement are met.

The physical and mental health systems must provide an array of medical and therapeutic services under Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. EPSDT requires states to cover all Medicaid services listed in section 1905(a) of the Social Security Act, regardless of whether those services are also covered under the regular Medicaid state plan. States can only deny these services if they are not medically necessary or if they are experimental. EPSDT services include: nursing; home health aide; personal care; physical, occupational, speech and behavioral therapies; and durable medical equipment.

Although Medicaid benefits to children with disabilities are substantial, these benefits tend to be medically-oriented. Fewer than 100 children use intensive home health services for several hours a day on an ongoing basis.[103] The direct support staff typically are licensed nurses and home health aides. Personal care is not commonly used, but this service could provide increased flexibility and control for families. It could also be a more cost-effective option than the home health aide service, and give children experience with the primary service in the waivers for adults with physical disabilities.

Table 11. Community Services Programs for Children Age 21 and Younger: Participants in SFY 2004-05 and Average Annual Growth Rate since SFY 2001-02

Programs	Persons Served, SFY 2004-05	Average Annual Growth Rate
Medicaid	**n/a**	**n/a**
Special Education	268,000	5%
Community Mental Health Systems (estimate, including Medicaid)	60,000	n/a
Early Intervention – infants and toddlers	26,458*	10%
Early Intervention – pre-school	36,790	8%**
Total Non-Medicaid (not unduplicated)	**410,069**	**n/a**
Total	**n/a**	**n/a**

Data regarding the number of Medicaid participants with disabilities was not available.
* The figure for "Early Intervention – infants and toddlers" includes 3,903 children served under the Infants, Toddlers, and Families Waiver.
** Average growth rate is calculated from SFY 2002-03.

Sources:
Special education data were from Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003 and Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
Early Intervention data for pre-school children were from Pennsylvania Department of Education "Special Education in PA – Early Intervention" January 18, 2006.
Early Intervention data for infants and toddlers (under age 3) were from the Pennsylvania Department of Public Welfare.
The community mental health estimate was from Pennsylvania Department of Public Welfare "Pennsylvania Child and Adolescent Service System Program (CASSP)" March 6, 2006.

In addition to Medicaid-covered services, the community mental health grants described on page 44 provide services not covered under Medicaid and serve people who do not meet Medicaid eligibility criteria. The state estimates that roughly 60,000 children and adolescents per year receive grant-funded services.[104] Also, the state-funded Family Support Services provides a small amount of support (a maximum of $1,200 per year) to about 15,000 people with mental retardation – both adults and children – who are on waiting lists for waiver services.

[103] Information provided by Pennsylvania Department of Public Welfare.
[104] Pennsylvania Department of Public Welfare "Pennsylvania Child and Adolescent Service System Program (CASSP)" March 9, 2006.

Children under age three have a separate support system for Early Intervention services. DPW's Office of Child Development and local county MH/MR programs operate the Early Intervention system for infants and toddlers. These children transition to the education system's Early Intervention program when they reach age three.

Early Intervention is available to any child with a developmental delay in any of five areas of development: physical, language and speech, social and emotional, self-help, and cognitive development. The program provides a variety of therapies to help the child gain skills and to train families and caregivers, including child care staff, to work with the child independently. Services are always provided in the presence of a parent or caregiver. Pennsylvania is unique in using a Medicaid HCBS waiver – the Infant, Toddlers, and Families (ITF) Waiver – to fund some of these services for children under age three who meet the ICF/MR level of care criteria.[105] The state funds most early intervention services, with help from U.S. Department of Education grants.[106]

Non-HCBS Programs

In addition to medical services and long-term supports, children with disabling conditions are often eligible for services from a variety of other sources. Other important public sources of support are:

Common Non-HCBS Supports and Programs for Children with Disabilities

- The Title V (Maternal and Child Health) Program, called the Special Kids Network, primarily provides information and referral. Title V also covers educational, health, social, and recreational services if not covered by other programs;[107]
- Income support from Supplement Security Income (SSI);
- Vocational rehabilitation services for youth; and
- Public health programs targeting children with specific conditions such as Cooley's anemia, orthopedic conditions, spina bifida, and children who require ventilators. These programs provide screening, information and referral, community education, and at times directly pay for health and rehabilitative services for low and moderate-income individuals who do not have private or public insurance.[108]

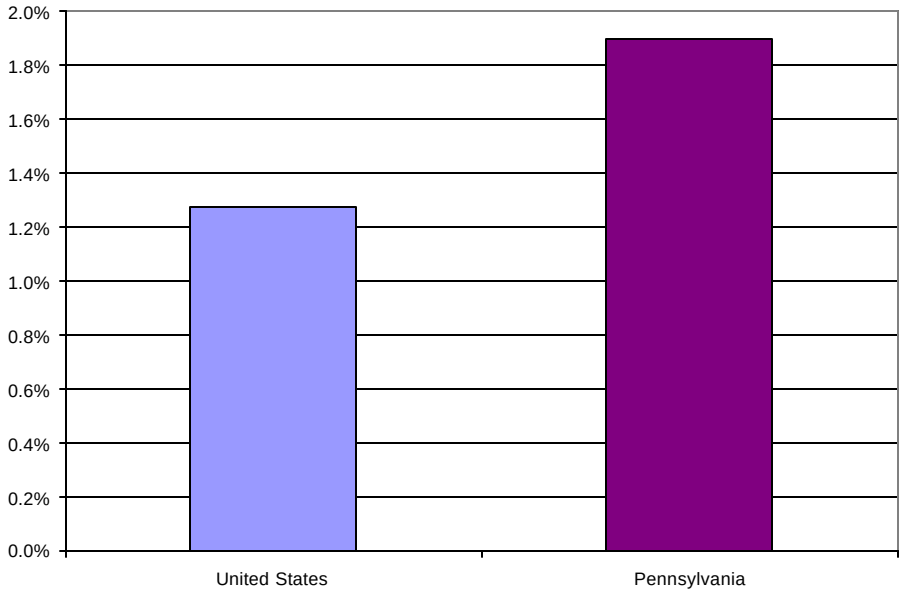
Appendix A describes these programs and non-HCBS programs that support adults with long-term support needs.

Demographic and Utilization Trends

As described on page 2, Pennsylvania has a relatively high incidence of childhood disability. Children in Pennsylvania are more likely to have disabilities than children in other states and to also receive SSI payments due to their disability.

[105] Mullen, Dorothy; Eiken, Steve; Steigman, Daria. "Promising Practices in Long Term Care Systems Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation" Medstat: March 3, 2003.
[106] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[107] Pennsylvania Department of Public Welfare "Children with Special Needs" September 14, 2004.
[108] Pennsylvania Department of Health "Bureau of Family Health" March 16, 2006.

Chart 10. Percentage of People under Age 18 Receiving SSI, 2004



Sources:
U.S. Social Security Administration *Annual Statistical Supplement, 2005* February 2006.
U.S. Census Bureau, Population Division "State Single Year of Age and Sex Population Estimates: April 1, 2000 to July 1, 2004 – Resident" March 10, 2005.

Despite the higher prevalence of disability among children and youth, they are significantly less likely to be institutionalized in the most restrictive settings: state institutions and nursing facilities (See Table 12).

Table 12. Institutional Residents per 100,000 Children Age 0-21 in State Population

Institution Type	Date	United States	Pennsylvania
State Mental Retardation Institution	June 30, 2004 census	2.1	0.0
State Mental Health Hospital*	June 30, 2004 census	4.4	1.6
Nursing Facilities	Federal Fiscal Year 2003	6.2	1.2

* United States state mental health hospital data includes reports from 38 states.

Sources:
Mental retardation institution data were from Prouty, Robert; Smith, Gary; Lakin, K. Charlie; Bruininks, Robert; Byun, Soo-Yong; Coucouvanis, Kathryn; Larson, Sheryl. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004* University of Minnesota: July 2005.
Mental health hospital data were from NASMHPD Research Institute "State Profile Data and Reports: 2004" National Association of State Mental Health Program Directors: Undated.
Nursing facility data were from a Medstat analysis of data from the Centers for Medicare & Medicaid Services, Medicaid Statistical Information System (MSIS) State Summary Datamart.
Population data were from U.S. Census Bureau "State Single Year of Age and Sex Population Estimates: April 1, 2000 to July 1, 2004 – Resident" March 10, 2005.

Data comparing Pennsylvania to most states regarding children in other institutions – such as private intermediate care facilities for people with mental retardation and residential treatment facilities for

children with severe emotional disturbances – were not available. Data sources for community supports that include a majority of states also were not available.

Components Associated with Rebalancing

Streamlined HCBS Administration

For children under age three, a single administrative agency exists – the DPW Office of Child Development. This office was established in 2005 to coordinate services for pre-school age children, as described on pages 9 and 10. Its Deputy Secretary also holds a position among Department of Education leadership to further communication across departments regard infants, toddlers, and pre-schoolers.

Schools are such an important part of any child's life that the state Department of Education has a special role for supporting children with disabilities. The service agencies that work with the education system vary by type of disability. The Office of Mental Health and Substance Abuse Services (OMHSAS) manages supports for children with behavioral health challenges. The Office of Mental Retardation (OMR) administers waiver services for children with mental retardation. Finally, the primary Medicaid agency, the Office of Medical Assistance Programs, manages services for children with physical disabilities.

Single Access Point

The education system provides one of the most convenient access points, a child's school. However, the responsiveness and quality of services from Pennsylvania's 501 school districts vary considerably. Most districts contract for more specialized services, often with one of 29 Intermediate Units established by the Department of Education that cover the entire state. Outside the education system, Pennsylvania has several different entry points for community supports, depending on the child's disabling condition.

County MH/MR programs are a single entry point for early intervention services for children under age three. After the third birthday, the process for children with mental retardation or mental health is the same as it is for adults. Any services targeting people with MR are authorized by the County MR programs. For children with severe emotional disturbances, county mental health programs authorize grant-funded services and provide information and referral for all supports. Medicaid participants in the major metropolitan areas also receive mental health benefits through the Behavioral HealthChoices program, described on page 43. Families access services as specified by the behavioral health plans in these counties. In fee-for-service counties, consumers approach Medicaid providers directly, but the Commonwealth performs prior authorization for intensive supports that many children use.

Similarly, the Medicaid process for access to physical health services varies by county. HealthChoices, a mandatory managed care program, operates in the same 25 counties where Behavioral HealthChoices is available. Unlike Behavioral HealthChoices, families can select one of three managed care organizations that provide Medicaid services in their county. Families can voluntarily choose managed care in 27 of the remaining 42 counties.[109] Other consumers use fee-for-service Medicaid and are part of a primary care case management program called Access Plus.[110]

[109] Pennsylvania Department of Public Welfare "Statewide Managed Care Map" October 19, 2005.
[110] Pennsylvania Department of Public Welfare "Access Plus" May 4, 2006.

In both fee-for-service Medicaid and managed care options, most services are received through a primary care physician. Some services – including intensive long-term home health services – are subject to prior authorization by the health plan or the Commonwealth (under Access Plus). Also, each health plan and the Medicaid fee-for-service program has a Special Needs Unit that focuses on meeting the needs of children with special health care needs, including children with disabilities. Disease management programs may be available for particular conditions that can cause disability among children, such as asthma and diabetes.

Institutional Supply Controls and Transition from Institutions

The state institution closures and resident transition efforts for people with mental illness (pages 47-49) and mental retardation (pages 38 and 39) have assisted children and youth as well as adults. The Commonwealth rarely allows new admissions of people under age 21 to these facilities.[111]

Pennsylvania's supply of Medicaid-certified psychiatric residential treatment facilities (PRTF) actually increased in 2005 and 2006 as part of the Integrated Children's Services Initiatives. This initiative requires local systems that serve children with serious emotional disturbances to improve access to high-quality services. As is true for all Medicaid services, PRTF providers can only bill Medicaid for Medicaid services provided to Medicaid participants that meet medical necessity criteria. As part of this initiative, the Commonwealth worked with residential facilities that served children with serious emotional disturbances to help improve available services to PRTF standards. PRTFs must be accredited by one of three independent accrediting organizations.[112] The initiative has increased access to PRTFs in Pennsylvania. Over two years, 45 accredited PRTFs enrolled in Medicaid with a total capacity of 1,459 beds.[113] These beds are almost half the Commonwealth's 3,039 PRTF beds.[114]

Continuum of Residential Options

An important challenge for the service system is to establish quality residential services for children and youth who need services away from home. The availability of residential services varies among diagnosis groups. Pennsylvania does not offer a community residential service for children with physical disabilities. The intensive level of available home health services and the low usage of nursing facility services suggest there is little demand for a community residential option.

The Consolidated Waiver, the mental retardation system's only payment source for residential services, served only 798 children in State Fiscal Year 2004-05. This figure includes people who did not receive residential services. Children and youth with mental retardation can receive services from Family Living Homes that serve only one or two people, or from facilities that serve three to nine children. Since 1996, Pennsylvania has limited new group facilities to three or four beds.[115]

In the mental health system, Community Residential Rehabilitation Host Homes are intended to provide a family-like environment for three or fewer children with severe emotional disturbances. They provide housing, supervision, and independent living skills development. The host homes' supports are funded

[111] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[112] Department of Public Welfare *Bulletin 00-05-05: Integrated Children's Service Initiative* June 9, 2005. The accrediting organizations are the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the Commission on Accreditation of Rehabilitation Facilities (CARF), and the Council on Accreditation (COA).
[113] Pennsylvania Department of Public Welfare *ICSI Enrollments Effective Fiscal Year 05-06* Undated.
[114] Data provided by the Department of Public Welfare.
[115] Pennsylvania Department of Public Welfare *Mental Retardation Bulletin 00-06-04* January 31, 2006.

by the community mental health grants. OMHSAS has licensed homes with the capacity to serve over 1,200 children.[116]

Pennsylvania also funds residential services for a few hundred children with serious emotional disturbances (SED) who are placed out of state. In 2003, 339 children were placed out-of-state because no host home or PRTF could provide appropriate treatment. Anecdotal evidence suggests some of these children have a history of dangerous behaviors. A prohibition against serving children in locked facilities reportedly improves care in PRTFs and host homes in general, but discourages providers from serving these children.[117] Other children have dual diagnoses of SED and a developmental disability that affects cognition or communication, such as mental retardation or autism. The lack of in-state capacity is particularly surprising for the nation's sixth most populous state,[118] where economies of scale potentially exist for providers to specialize in supporting these individuals.

Building HCBS Infrastructure

Infrastructure development for long-term supports for children varies among the service systems. Services for children with physical disabilities reflect a medical model. Non-clinical supports often associated with HCBS, such as personal care and home modifications, are not available until the person reaches age 18 and qualifies for the OBRA Waiver described on page 25.

The same infrastructure development processes for all ages have been used for the mental retardation (page 40) and mental health system (page 50). The Integrated Children's Services Initiative may further improve the infrastructure for children. Starting in 2004, DPW required counties to develop local plans for behavioral health that involve several county agencies that serve children with mental health needs, including:

County Agencies Involved in Integrated Children's Services Initiative

- County mental health programs;
- County mental retardation programs (for children with dual diagnoses);
- Children, Youth, and Family programs that operate child protection services; and
- Single County Authorities that administer drug and alcohol treatment grants.

The county plans identify necessary new services or system improvements, and DPW awards competitive grants to counties to develop provider capacity. Funding for this initiative comes from state funds and a 2003 SAMHSA System of Care grant.[119]

[116] Pennsylvania Department of Public Welfare "Human Services Provider On-Line Directory" November 12, 2005.
[117] Stohl, Lana; Logsdon, Gloria; LeFlore, Bob; Brandt, Gordon; Cheek, Mattie Pennsylvania Mental Health Block Grant Core Monitoring Report U.S. Substance Abuse and Mental Health Services Administration, Center for Mental Health Services: 2004.
[118] U.S. Census Bureau, Population Division "State Single Year of Age and Sex Population Estimates: April 1, 2000 to July 1, 2004 – Resident" March 10, 2005.
[119] Pennsylvania Department of Public Welfare "Integrated Children's Service Initiative presentation to ICSI Advisory Committee" November 10, 2005.

The education system is also encouraging local service development. The Commonwealth offers several competitive grants to improve special education. Grants awarded in SFY 2006-07 will help local school districts adopt inclusive education practices and improve competitive employment supports for youth with disabilities.[120]

Participant Direction

Options to direct services are limited among children's services. No consumer-directed supports are available under the state's Medicaid state plan services. However, the Infant, Toddlers, and Families Waiver for children under age three provides opportunities for families to direct services.

Quality Management

Pennsylvania does not operate separate quality management efforts for children. For example, the quality management efforts for the mental retardation system (page 41) and the mental health system (pages 50 and 51) also apply to children with mental retardation and with mental health needs.

Similarly, services for children with physical disabilities are part of the quality management activities for Medicaid medical and rehabilitative services in general. These activities are more intensive for the mandatory managed care program, HealthChoices, because of concerns about the effect of managed care on access to necessary services. For each HealthChoices plan, a sample of consumers is surveyed each year using three consumer survey tools. Two are used by health plans across the country: the Health Plan Employer Data and Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS). The third is the state-developed Pennsylvania Performance Measures.

The Office of Medical Assistance Programs (OMAP) uses data from these surveys to evaluate the plans for contract compliance. OMAP publicly reports selected quality indicators. Children with physical disabilities are a small portion of the overall HealthChoices population, and no indicators relate to long-term supports for children.[121]

The Pennsylvania Department of Education monitors several school districts each year to ensure they help children with disabilities receive their education in the least restrictive environment. The Commonwealth first reviews policies and procedures and written information about available services. It then conducts an on-site monitoring visit to review a sample of student files and interview parents, students, and teachers regarding the service planning process and the supports received. If the district is not meeting IDEA requirements, reviewers work with the district to identify the cause, require corrective action, and follow-up with the district to ensure corrective action occurred.[122]

Pennsylvania is changing its quality management system based on a September 2005 settlement of a class-action lawsuit (*Gaskin et al. v. Pennsylvania*). Pennsylvania will develop an index to measure districts' progress across several outcomes, and prioritize the above monitoring process to poor-performing districts. Districts must report several priority outcomes regarding children with disabilities who have Individual Education Plans. Outcomes include graduation rates; suspensions and expulsion rates; adequate plans for transitioning to adult employment or education; and placements outside of a regular school.[123] An advisory panel appointed primarily by the lawsuit's plaintiffs – 12 children, their

[120] Pennsylvania Department of Education *Pennsylvania Part B State Performance Plan for 2005-2010* December 2, 2005.
[121] Pennsylvania Department of Public Welfare *HealthChoices Performance Trending Report 2005* December 6, 2005.
[122] Pennsylvania Department of Education *Part B State Performance Plan (SPP) for 2005-2010* December 2, 2005.
[123] Rhen, Linda "Penn*Link on Settlement Agreement in Gaskin v. PA" Pennsylvania Department of Education: October 14, 2005.

parents, and 11 advocacy organizations – will provide input regarding Pennsylvania's monitoring and technical assistance efforts in serving children with disabilities in regular classrooms.[124]

Summary

Schools and Medicaid have important mandates that ensure services for many children with disabilities. Within Medicaid, three main systems provide services for children, each with their own access points, services, infrastructure, and – for some systems – community residential options.

Pennsylvania has made significant progress to reduce reliance on state institutions and nursing facilities. The Commonwealth's use of these settings is well below the national average. However, some gaps in the system remain. Most notably, a few hundred Pennsylvanians are served in other states because the available service infrastructure does not accommodate them.

[124] Pennsylvania Department of Education "Gaskin v. Pennsylvania Department of Education (United States District Court, Philadelphia) Summary of Principal Provisions in the Proposed Settlement Agreement" December 23, 2004.

Appendix A

Common Programs Serving Older Adults and People with Disabilities

While this profile focused on long-term supports, many other supports are vital to older adults and people with disabilities living in the community. Programs that provide income support, health care, transportation, housing, nutrition, and vocational training can be essential for participants' qualify of life. As a result, changes in these programs can affect individuals' ability to live in the community and therefore affect Pennsylvania's rebalancing efforts.

The appendix describes common support programs, with recent trend data where available. The programs are grouped according to the supports they provide. Medical programs are listed first, because of the close coordination that is often necessary between the health and long-term care systems. Substance abuse treatment programs are then described, followed by programs that provide basic necessities everyone needs in daily life: housing, food, income, and heat in the winter. The appendix concludes with vocational rehabilitation and transportation, which help people with disabilities and older adults involve themselves in the community.

Medical Programs

People with disabilities and older adults can have significant health needs that affect community living. Medicare and Medicaid are important sources for medical care for Pennsylvanians with disabilities and older adults. In addition, two state-funded programs help people with prescription drug payments, and the Department of Health operates several additional programs that assist targeted populations.

Medicare

Medicare is a federal health insurance program available for almost all people age 65 or older and for many people with severe disabilities. Since its beginning, Medicare services have been divided into two components that are financed differently. Part A is funded by payroll taxes and covers hospital care and related services (e.g., post-acute nursing facility admissions). Part B is funded by participant premiums and covers physician and other outpatient services. Medicare is available as fee-for-service health insurance or through managed care organizations that cover both Part A and B (Medicare Part C or Medicare Advantage). Approximately 2.1 million Pennsylvanians received Medicare in July 2005,[1] and this figure has remained constant since 2002.[2]

Effective January 1, 2006, Medicare added a prescription drug benefit, called Medicare Part D. This benefit is available either through stand-alone Prescription Drug Plans or through Medicare Advantage plans that cover drugs along with other Medicare services. People who enroll for the program must pay a monthly premium that varies according to the plan they choose. A subsidy is available for people with low income and resources, including Medicaid participants.[3] As of June 11, 1,028,782 individuals were

[1] U.S. Centers for Medicare & Medicaid Services "Medicare Enrollment – All Beneficiaries: as of July 2005" Undated.
[2] U.S. Centers for Medicare & Medicaid Services "Medicare Enrollment by State, Age Group, and Entitlement for Year 2002 as of July 1" Undated.
[3] U.S. Social Security Administration "Help Available To Pay Costs Of Medicare's New Prescription Drug Program" April 2005.

enrolled in the stand-alone plans or Medicare Advantage plans, including 162,816 Medicaid participants.[4]

Medicaid (Medical Assistance)

Medicaid provides health and long-term care services for older adults, people with disabilities, and low-income families with children. As described on page 43, most Medicaid participants receive medical care through managed care organizations. However, many people with disabilities and older adults receiving Medicaid also are eligible for Medicare. These dual eligible individuals use Medicare for medical needs such as hospital and physician services. Medicaid covers co-payments, deductibles, and services that Medicare does not cover.

Until January 1, 2006, Pennsylvania included dual eligibles in Health Choices. The Medicaid managed care organization was responsible for copayments, deductibles, prescription drugs, and certain mental health services. The Commonwealth removed dual eligibles from the physical health component of Health Choices on January 1, 2006, when these individuals began receiving prescription drug coverage from Medicare Part D. The Behavioral HealthChoices plans are still responsible for mental health services, which include some services not covered by Medicare.

Pharmaceutical Assistance Contract for the Elderly (PACE) and PACE Needs Enhancement Tier (PACENET)

The Department of Aging manages two prescription drug programs for low-income people age 65 and older who do not have Medicaid, which are funded by the Pennsylvania Lottery and the state's share of a lawsuit settlement with tobacco companies. The programs are similar except PACENET serves people with higher incomes (up to $23,500 for a single person) and has higher deductibles.[5] In SFY 2004-05, these programs together served 290,482 Pennsylvanians. The overall number of people served has increased eight percent a year since SFY 2001-02. The number of PACE participants decreased in the past three years, but the number of PACENET participants more than tripled.[6] This number is expected to increase further with the implementation of Medicare Part D. PACE and PACENET coordinate benefits with Medicare Part D and therefore can serve more people at a lower cost.

Special Pharmaceutical Benefits Program

The Special Pharmaceutical Benefits Program purchases vital prescription drugs for individuals with HIV/AIDS or schizophrenia who do not have Medicaid. The program pays only for treatment regimen specific to these two conditions, and does not cover other drugs the person may need.[7] Expenditures have increased an average of ten percent a year from $32.6 million in SFY 2001-02 to $43.9 million in SFY 2004-05.[8] Most of these expenditures, $38.4 million in SFY 2004-05, were for HIV/AIDS medications. This includes a $25 million federal grant for an AIDS prescription drug program. The remaining $5.5 million funded schizophrenia medication treatment.[9]

[4] U.S. Centers for Medicare & Medicaid Services "State Enrollment in Prescription Drug Plans Nov. 15, 2005- June 11, 2006" June 11, 2006.
[5] Pennsylvania Department on Aging "PACE ((Pharmaceutical Assistance Contract for the Elderly) and PACENET (PACE Needs Enhancement Tier)" December 12, 2005 and Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[6] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[7] Pennsylvania Department of Public Welfare, November 15, 2005.
[8] Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[9] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.

Diagnosis-Specific Programs

The Pennsylvania Department of Health operates several programs that target services to people with specific diagnoses that may cause disability (shown below). Some programs directly pay for individuals' services when private and public insurance is not available and the family meets income guidelines. Other programs fund providers dedicated to treating these conditions. A few programs serve both purposes.[10]

Health Conditions Targeted by Specific Pennsylvania Department of Health Programs

- Cancer
- Chronic renal disease
- Cleft palate
- Cooley's anemia
- Cystic fibrosis
- Epilepsy and related disorders
- Hemophilia
- Heart disorders for children under age 21
- HIV/AIDS
- Orthopedic conditions for children under age 21
- Spina bifida
- Sickle cell anemia
- Speech and hearing disorders for children under age 21
- Tourette's Syndrome
- Traumatic brain injuries
- Children who use ventilator assistance

Substance Abuse Treatment Grants

The Department of Health administers state and federally-funded grants to 49 county-based Single County Authorities (SCAs) for drug and alcohol abuse related services. These county agencies are responsible for prevention, intervention (e.g., hotlines and drop-in centers), and treatment. In SFY 2004-05, over 92,000 Pennsylvanians received treatment for drug or alcohol abuse, including people with privately-funded treatment.[11] This figure has increased by an average of 11 percent each year since SFY 2001-02, when 67,000 were admitted for inpatient or outpatient treatment.[12]

[10] Pennsylvania Department of Health "Bureau of Family Health" October 18, 2005.
[11] Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[12] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.

Housing Assistance

This section provides an overview of major housing programs targeted to people with disabilities or older adults. These programs are funded by the federal department of Housing and Urban Development (HUD) and operated locally by city and county Public Housing Authorities (PHA). In addition to the programs mentioned here, several community development programs support the development of affordable housing, and can be used to improve or increase housing for people with disabilities and older adults. Examples include: the Low-Income Housing Tax Credit; the Community Development Block Grant; the HOME Investment Partnerships Program; and the Mortgage Insurance for Nursing Homes, Intermediate Care, Board & Care and Assisted-living Facilities Program.

Section 8 Housing Choice Voucher Program

The Section 8 Program pays part of a low-income household's rent. Eligible households are put on a waiting list until new vouchers are available or a family leaves the program. When vouchers become available, people select their housing among landlords that accept the public housing authorities' payment standard. The PHA pays this standard, minus a minimum monthly rent. The household pays the minimum rent, typically 30 percent of income.[13]

A portion of Section 8 vouchers are reserved specifically for people with disabilities. Mainstream Vouchers can be paid to any landlord that accepts Section 8 vouchers. Designated Housing Vouchers and Certain Development Vouchers can help people with disabilities access housing developments that target older adults.[14]

In federal fiscal year 2004, HUD allocated a total of $885 million dollars to Public Housing Authorities in Pennsylvania for all Section 8 programs. Between October 2004 and January 2006, more than 57,000 people received assistance through housing vouchers. This figure includes 17,431 people in households that include someone with a disability and 10,549 people in households with someone age 62 or older.[15]

Section 202 Supportive Housing for the Elderly Program

Section 202 is one of several HUD programs that encourage development of affordable housing, rather than directly fund rent. This program provides interest-free capital to develop and rehabilitate housing structures, and offers rental assistance for five years to cover the difference between operating costs and the residents' rental payments. Residents are expected to pay 30% of their income for rent. Funds do not have to be repaid if the project serves low-income people age 62 or older for at least 40 years.[16]

Section 811 Supportive Housing for Persons with Disabilities

The Section 811 program is similar to Section 202, but serves people with disabilities. The requirements are the same as for Section 202, except eligible residents must have at least one household member age 18 or older with a physical, mental, or developmental disability.[17]

[13] U.S. Department of Housing and Urban Development "Housing Choice Vouchers" January 27, 2006.
[14] U.S. Department of Housing and Urban Development "Vouchers for People with Disabilities" October 15, 2002.
[15] U.S. Department of Housing and Urban Development "Resident Characteristics Report" January 31, 2006.
[16] U.S. Department of Housing and Urban Development "Section 202 Supportive Housing for the Elderly Program" March 16, 2005.
[17] U.S. Department of Housing and Urban Development "Section 811 Supportive Housing for Persons with Disabilities" March 16, 2005.

Emergency Shelter Grants

The Emergency Shelter Grants fund projects that operate, increase, and improve the quality of emergency shelters. Grants can also be used to provide transitional housing and social services for homeless people or to provide funds to prevent homelessness. Federal funding for Pennsylvania's Emergency Shelter Grants have remained relatively unchanged between Federal Fiscal Years 2000-04.[18] In FFY 2004, Pennsylvania and PHA in the Commonwealth received a total of $9.6 million.[19]

Supportive Housing Program

The Supportive Housing Program funds the development, rehabilitation, and operation of supportive housing services to help homeless persons live more independently. Housing and support options available under these grants are listed below.

Housing and Supports Available Under the Supportive Housing Program

- Transitional housing, which is temporary housing available for up to 24 months
- Permanent housing for people with disabilities
- Supportive services only, for programs that do not provide housing but offer a range of assistance such as outreach, substance abuse treatment, rent deposits, and employment assistance
- Safe havens for hard-to-reach adults with severe mental illness living on the streets
- Innovative supportive housing options outside the scope of the other programs.[20]

Federal funds for Pennsylvania's Supportive Housing program have grown slightly from $57.9 million in 2001 to $60.2 million in federal fiscal year 2004.[21]

Shelter Plus Care Program

The Shelter Plus Care Program provides rental assistance for long-term housing and support for homeless people with disabilities and their families. Grantees – states, local governments, or Public Housing Authorities – may target particular conditions such as serious mental illness, addiction disorders, or AIDS.[22] Between Federal Fiscal Years 2001 and 2004, HUD has increased federal funds to Pennsylvania for this program from $1.8 million to $9 million.[23]

[18] U.S. Department of Housing and Urban Development "FY 2001 Continuum of Care Competition Homeless Assistance Awards Report" December 21, 2000.
[19] U.S. Department of Housing and Urban Development "FY 2004 Continuum of Care Competition Homeless Assistance Grants Report with ESG" 2004.
[20] U.S. Department of Housing and Urban Development "Understanding SHP" April 26, 2001.
[21] U.S. Department of Housing and Urban Development "FY 2001 Continuum of Care Competition Homeless Assistance Awards Report" December 21, 2000 and U.S. Department of Housing and Urban Development "FY 2004 Continuum of Care Competition Homeless Assistance Grants Report with ESG" 2004.
[22] U.S. Department of Housing and Urban Development "Understanding S+C" May 23, 2002.
[23] U.S. Department of Housing and Urban Development "FY 2001 Continuum of Care Competition Homeless Assistance Awards Report" December 21, 2000 and U.S. Department of Housing and Urban Development "FY 2004 Continuum of Care Competition Homeless Assistance Grants Report with ESG" 2004.

Nutrition Services

The federal Food Stamp Program pays for groceries for households that meet income and asset requirements, including many older adults and people with disabilities. Eligible groceries include most foods, but exclude meals made for immediate consumption, alcohol, and pet food.[24] The number of Pennsylvanian's receiving food stamps has grown an average of nine percent each year, from 748,074 in Federal Fiscal Year (FFY) 2001 to almost 961,000 in FFY 2004.[25]

Older adults receive additional assistance from federal grants for nutrition services through the Pennsylvania Department of Aging. The congregate meals and home delivered meal programs provide prepared foods with a focus on reducing social isolation as well as meeting dietary needs. Congregate meals are available at 650 senior centers operated by Pennsylvania's 52 Area Agencies on Aging. Meals are usually served near the noon hour. People age 60 or older and their spouses can come to the senior center for the meal and for other activities. Home delivered meals are available for older adults unable to participate in congregate meals. Meals may be delivered between one and five days per week, depending on the person's need. For either meal program, people are encouraged to make a suggested donation that pays the meal's cost if they are able.[26] The number of people receiving congregate meals has decreased by an average of four percent each year since SFY 2001-02. Over 147,000 people received meals that year and only 136,396 people received them in SFY 2003-04.[27] Meanwhile, the number of people eating home delivered meals rose from 43,890 in SFY 2001-02 to 49,400 people in SFY 2004-05, an average annual increase of four percent.[28]

Income Support

Most older adults and people with severe disabilities receive monthly income support from the federal Social Security Administration. Most adults age 65 and older receive the traditional Social Security benefit for retired workers and their surviving spouses and children, Old Age and Survivors Insurance. Two additional benefits serve people with disabilities whose impairments affect their ability to work. The Pennsylvania Department of Labor and Industry operates the disability determination program, which reviews applications for disability benefits and makes recommendations to the Social Security Administration regarding eligibility.[29] The state-funded General Assistance Program serves people who do not qualify for the federal programs, including people whose application for Supplemental Security Income is pending.

Social Security Disability Insurance

People who have worked a minimum number of quarters in the United States and paid into the Social Security system are eligible for Social Security Disability Insurance (SSDI). The required minimum varies depending on the person's age at the onset of disability. The payment also varies according to the

[24] Pennsylvania Department of Public Welfare, June 30, 2005.
[25] U.S. Food and Nutrition Service "Average Monthly Participation (Persons)" January 25, 2006.
[26] Pennsylvania Department of Aging "Nutrition Services" October 31, 2005.
[27] Commonwealth of Pennsylvania *2005-06 Governor's Executive Budget* February 8, 2005 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003. Congregate meals data for SFY 2004-05 indicate a one-year 30% decrease. Such a sudden, large decrease may reflect a reporting error rather than a reduction in available meals.
[28] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[29] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.

person's income before the disability. SSDI benefits are also available for the disabled person's spouse and dependent children. The number of disabled workers receiving SSDI benefits in Pennsylvania increased 229,190 in December 2001 to 275,590 December 2004, an average increase of six percent per year.[30]

Supplemental Security Income

People who have not worked enough to qualify for SSDI can qualify for Supplemental Security Income (SSI), which has a lower benefit than SSDI. Pennsylvania, like many states, increases the monthly SSI payment with a state-funded supplement.[31] A person can qualify for the state supplement, but not for SSI, if his or her income is greater than the SSI benefit but lower than total of SSI and the state supplement. In SFY 2004-05, a monthly average of 321,700 people received SSI and/or the state supplement.[32] This number has increased an average of two percent each year since SFY 2001-02, when there were 301,780 participants.[33]

General Assistance

The state-funded General Assistance program supports people who are unable to work but who do not meet requirements for SSI or Temporary Assistance to Needy Families (TANF), a federal and state program for families with children. General Assistance also provides interim assistance for people applying for SSI.[34] The Department of Public Welfare, Office of Income Maintenance, administers the program and local County Assistance Offices determine financial eligibility.[35] In SFY 2004-05, General Assistance served a monthly average of 54,771 people. The number of people has increased seven percent per year since SFY 2001-02, when the average was 44,832 participants.[36] Between October 1999 and September 2004, 85 percent of General Assistance participants were people with disabilities. Most individuals had temporary disabilities expected to last less than 12 months (59% of total participants).[37]

Energy Assistance

Many low-income individuals, including older adults and people with disabilities, are unable to pay heating bills in winter months. For qualified individuals, DPW sends grant payments directly to the utility/fuel dealer, which credits the residents' bill.[38] In addition, the Department of Community and Economic Development contracts with local human service agencies to provide weatherization, which includes repairing and improving heating systems, installing insulation, and other services.[39] In crisis situations,

[30] U.S. Social Security Administration *Annual Statistical Supplement, 2005* February 2006 and U.S. Social Security Administration *Annual Statistical Supplement, 2002* December 2002.
[31] For most people, this supplement is $27.40 per month for an individual and $43.70 for a married couple. Higher state supplements are provided in certain facilities as discussed on pages 13 and 14. In SFY 2005-06, the state supplement was $394.30 for individuals and $867.40 for couples in personal care homes. For domiciliary care homes, the state supplement was $389.30 for individuals and $857.40 for couples.
[32] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[33] Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[34] Pennsylvania Department of Public Welfare *Cash Assistance Handbook* April 1, 2005.
[35] Pennsylvania Department of Public Welfare "Cash Assistance Benefits" January 6, 2006.
[36] Pennsylvania Department of Public Welfare "Medical Assistance, Food Stamps, and Cash Assistance Statistics Reports" January 10, 2006.
[37] Pennsylvania Department of Public Welfare "Characteristics Report" December 5, 2005.
[38] Pennsylvania Department of Public Welfare "LIHEAP State Plan – Introductory Information" October 27, 2005.
[39] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.

the bill payments and repairs can occur within 48 hours, or within 18 hours in life-threatening situations.[40] The grant payments are supported primarily by the Low-Income Home Energy Assistance Program (LIHEAP). Pennsylvania uses some of its LIHEAP funds to support weatherization, and also receives a grant from the federal Weatherization Assistance Program.[41]

DPW provided grants to 340,447 households in SFY 2004-05. The number of people decreased by an average of three percent from 368,357 households in SFY 2001-02.[42] Pennsylvania added $20 million in state funds for SFY 2005-06 to help an additional 61,000 households in response to rising heating costs.[43] Home weatherization increased an average of 11 per year from 9,017 homes in SFY 2001-02 to 12,397 homes in SFY 2004-05.[44]

Vocational Rehabilitation

The vocational rehabilitation program offers a variety of supports to help individual with disabilities obtain employment. Vocational rehabilitation counselors conduct in-person assessments, work with people to develop career goals, and provide ongoing counseling and guidance. Additional services include educational services, vocational and on-the job training, transportation, assistive technology, and personal assistance to help people perform daily living activities.[45]

A grant from the U.S. Department of Education provides most funds for this program. Pennsylvania provides the required state match, 21 percent of the total budget.[46] [47] In SFY 2004-05, 86,814 people received vocational rehabilitation services. This figure has increased about two percent per year since SFY 2001-02. More than one-third of vocational rehabilitation consumers are youth with disabilities.[48]

Transportation Services

The Commonwealth offers separate transportation options specifically for people with disabilities and for older adults. Senior transportation programs are supported by the Pennsylvania Lottery and provide options at lower cost.

Paratransit

Door-to-door, accessible transportation service is available in each of Pennsylvania's 67 counties for older adults and people with disabilities. People must schedule trips a day in advance and be willing to share their vehicle with other passengers. Paratransit agencies provided 8.4 million trips in SFY 2004-

[40] Pennsylvania Department of Public Welfare "LIHEAP State Plan – Introductory Information" October 27, 2005.
[41] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[42] Ibid.
[43] U.S. Administration for Children and Families "PA Governor Approves $20 Million in Aid" December 19, 2005.
[44] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[45] Pennsylvania Department of Labor and Industry *Office of Vocational Rehabilitation: 2004 Annual Report* Undated.
[46] U.S. Department of Education "Guide to U.S. Department of Education Programs" February 9, 2006 and Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[47] Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[48] Pennsylvania Department of Labor and Industry *Office of Vocational Rehabilitation: 2004 Annual Report* Undated.

05,[49] a small decline from 8.5 million in SFY 2001-02.[50] Most riders are people age 65 or older, who pay only 15 percent of the cost under the Shared Ride Program. The number of rides from older adults has decreased about four percent each year, from 6.0 million in SFY 2001-02 to 5.4 million trips in SFY 2004-05.[51] A similar program, started in 2001, provides this discount to people age 18 to 64 with disabilities. The Rural Transportation Program for People with Disabilities started as an eight county pilot and is scheduled to serve 35 counties in 2006.[52] It provided almost 140,000 one-way trips in SFY 2004-05, when it served 28 counties.[53]

Free Transit Program

In addition, the Commonwealth offers free rides on fixed bus, trolley and rail routes for people age 65 and older. The Free Transit Program is available in 51 of Pennsylvania's 67 counties.[54] In SFY 2004-05, this state-funded program provided more than 38.7 million rides.[55] The number of rides has decreased an average of four percent per year since SFY 2001-02, when there were 43.4 million rides.[56]

Medical Assistance Transportation Program

Medicaid provides transportation for almost all its services to people who need transportation assistance. Since Medicaid is a payer of last resort, all other transportation options including those described above must be exhausted before authorizing Medicaid transportation funding.[57] This program has grown an average of eight percent from SFY 2001-02 to SFY 2004-05, from 5.3 to 6.7 million one-way trips.[58]

[49] Pennsylvania Department of Transportation *Pennsylvania Public Transportation Statistical Report Fiscal Year 2004-05* April 2006.
[50] Pennsylvania Department of Transportation *Shared Ride Service Statistical Report 2001-02* September 2003.
[51] Pennsylvania Department of Transportation *Pennsylvania Public Transportation Statistical Report Fiscal Year 2004-05* April 2006.
[52] Pennsylvania Auditor General *The Pennsylvania Department of Transportation's Rural Transportation for Persons with Disabilities Program* June 13, 2006.
[53] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[54] Pennsylvania Department of Transportation "Summary of Transit Assistance Programs" Undated.
[55] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006.
[56] Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.
[57] Pennsylvania Department of Public Welfare "MATP Fiscal Requirements" October 28, 2004.
[58] Commonwealth of Pennsylvania *2006-07 Governor's Executive Budget* February 8, 2006 and Commonwealth of Pennsylvania *2003-04 Governor's Executive Budget* March 4, 2003.