Congressional Research Service

Report RL31850

A CRS Review of 10 States: Home and Community-Based ServicesStates Seek to Change the Face of Long-Term Care: Pennsylvania

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April 2, 2003

Abstract. This report presents background and analysis about long-term care in Pennsylvania. Reports on the other nine states and an overview report will e available during 2003.

Order Code RL31850

Report for Congress

Received through the CRS Web

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Home and Community-Based Services – States Seek to Change the Face of Long-Term Care: Pennsylvania

Summary

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care for persons with disabilities have drawn the attention of federal and state policymakers. Spending on long-term care by both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (almost $152 billion of $1.24 trillion). Federal and state governments accounted for almost two-thirds of all spending. By far, the primary payer for long-term care is the federal-state Medicaid program, which paid for almost half of all long-term care spending in 2001.

Many states have devoted significant efforts to respond to the desire for home and community-based care for persons with disabilities and their families. Nevertheless, financing of nursing home care, chiefly by Medicaid, still dominates most states' spending for long-term care today. To assist Congress understand issues that states face in providing long-term care services, the Congressional Research Service (CRS) undertook a study of 10 states in 2002. This report, the first in the series of ten state reports, presents background and analysis about long-term care in Pennsylvania.

Long-term care issues have high prominence among state officials in Pennsylvania as a result of its large elderly population and concern about the impact of long-term care costs on the state's budget. Its population aged 65 and older is 15.6% of its total population, ranking second only to Florida. By 2025, 21% of its population will be 65 and older. Pennsylvania federal and state Medicaid spending for long-term care in FY2001 was $5.1 billion – almost half of all Medicaid spending. Spending for nursing homes was more than one-third of Medicaid spending. While spending for home and community-based services has increased dramatically in recent years, these services represented less than one of every five dollars spent on long-term care in FY2001.

Over the last 2 decades, Pennsylvania has documented issues it has confronted in providing long-term care services. Among these issues are: an imbalance in financing favoring institutional care, rather than home and community-based care (which most people prefer); fragmentation in the management and delivery of services; difficult access to services, especially for low and moderate income persons who do not qualify for Medicaid; and disparities in service availability across the state and populations in need of care. According to state officials, Pennsylvania's guiding principles in long-term care are to: control surplus growth of nursing home beds; support consumer choice; encourage expansion of home and community-based services; fund services rather than capital construction; and assure quality of care.

The 10-state study was funded in part by grants from the Jewish Healthcare Foundation and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Office of Rural Health Policy.

Contents

List of Figures

List of Tables

Acknowledgments

CRS wishes to acknowledge the significant time and contributions of the many state officials and stakeholders who provided information on long-term care services in the Commonwealth of Pennsylvania. Without their invaluable experience and insight, this report would not be possible. We would particularly like to acknowledge officials from the Pennsylvania Intra-Governmental Council on Long-Term Care; the Department of Aging; the Department of Public Welfare; and the Department of Health. We also would like to thank the numerous advocates and providers who provided valuable perspectives on the long-term care services delivery system in Pennsylvania.

The authors also gratefully acknowledge the excellent assistance of Charlotte B. Foote in the production of this report.

Preface

Demographic challenges posed by the growing elderly population and demands for greater public commitment to home and community-based care for persons with disabilities have drawn the attention of federal and state policymakers for some time. Spending on long-term care by both the public and private sectors is significant. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (almost $152 billion of $1.24 trillion). Federal and state governments accounted for almost two-thirds of all spending. By far, the primary payor for long-term care is the federal-state Medicaid program, which paid for almost half of all U.S. long-term care spending in 2001.

Federal and state Medicaid spending for long-term care in FY2001 was about $75 billion, representing over one-third of all Medicaid spending. Over 70% of Medicaid long-term care spending was for institutions – nursing homes and intermediate care facilities for the mentally retarded (ICFs/MR). Many believe that the current federal financing system paid through Medicaid is structurally biased in favor of institutional care. State governments face significant challenges in refocusing care systems, given the structure of current federal financing. Many states have devoted significant efforts to change their long-term care systems to expand home and community-based services for persons with disabilities and their families. Nevertheless, financing of nursing home care – primarily through the Medicaid program – still dominates most states' spending on long-term care today.

While some advocates maintain that the federal government should play a larger role in providing support for home and community-based care, Congress has not yet decided whether or how to change current federal policy. One possibility is that Congress may continue an incremental approach to long-term care, without major federal policy involvement, leaving to state governments the responsibility for developing strategies that support home and community-based care within existing federal funding constraints and program rules.

To help Congress review various policy alternatives and to assist policymakers understand issues that states face in development of long-term care services, the Congressional Research Service (CRS) undertook a study of ten states in 2002. The research was undertaken to look at state policies on long-term care as well as trends in both institutional and home and community-based care for persons with disabilities (the elderly, persons with mental retardation, and other adults with disabilities). The research included a review of state documents and data on long-term care, as well as national data sources on spending. CRS interviewed state officials responsible for long-term care, a wide range of stakeholders and, in some cases, members or staff of state legislatures.

The 10 states included in the study are: Arizona, Florida, Illinois, Indiana, Louisiana, Maine, Oklahoma, Oregon, Pennsylvania, and Texas. States were chosen according to a number of variables, including geographic distribution, demographic trends, and approaches to financing, administration and delivery of long-term care services.

This report presents background and analysis about long-term care in Pennsylvania. Reports on the other nine states and an overview report will be available during 2003.

Home and Community-Based Services – States Seek to Change the Face of Long-Term Care: Pennsylvania

Introduction: Federal Legislative Perspective

> *The Social Security Amendments of 1965, which created the Medicaid program, required states to provide skilled nursing facility services under their state Medicaid plans, and gave nursing home care the same level of priority as hospital and physician services.*
>
> *"Section 1902 (a) A State plan for medical assistance must provide for inclusion of some institutional and some noninstitutional care and services, and, effective July 1, 1967, provide (A) for inclusion of at least ... (1) inpatient hospital services ...; (2) outpatient hospital services; (3) other laboratory and X-ray services; (4) skilled nursing home services (other than services in an institution for tuberculosis or mental diseases) for individuals 21 years of age or older; (5) physicians' services . . . .;"* P.L. 89-97, July 30, 1965.

States choosing to modify their programs for long-term care face significant challenges. Financing of nursing home care has dominated long-term care spending for decades. The federal financing structure that created incentives to support institutional care reaches back to 1965. A number of converging factors have supported reliance on nursing home spending. Prior to enactment of Medicaid, homes for the aged and other public institutions were financed by a combination of direct payments made by individuals with their Social Security Old Age Assistance (OAA) benefits, and vendor payments made by states with federal matching payments on behalf of individuals. The Kerr-Mills Medical Assistance to the Aged (MAA) program, enacted in 1960, a predecessor to Medicaid, allowed states to provide medical services, including skilled nursing home services, to persons who were not eligible for OAA cash payments, thereby expanding the eligible population.[1]

In 1965, when Kerr-Mills was transformed into the federal-state Medicaid program, Congress created an *entitlement* to skilled nursing facility care under the expanded program. The Social Security Amendments of 1965 required that states provide skilled nursing facility services and gave nursing home care the same level of priority as hospital and physician services. Amendments in 1967 allowed states to provide care in "intermediate care facilities" (ICFs) for persons who did not need skilled nursing home care, but needed more than room and board. In 1987, Congress eliminated the distinction between skilled nursing facilities and intermediate care

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[1] CRS Report 83-181, *Nursing Home Legislation: Issues and Policies*, by Maureen Baltay.

facilities (effective in 1990). As a result of these various amendments, people eligible under the state's Medicaid plan are *entitled* to nursing home facility care; that is, if a person meets the state's income and asset requirements, as well as the state's functional eligibility requirements for entry into a nursing home, he or she is entitled to the benefit.

These early legislative developments were the basis for the beginnings of the modern day nursing home industry. Significant growth in the number of nursing homes occurred during the 1960s – from 1960 to 1970, the number of homes more than doubled, from 9,582 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than one million.[2] (Today there are about 17,000 nursing homes with 1.8 million beds.[3])

Since its inception, Medicaid has been the predominant payor for nursing home care. In 1970, over $1 billion was spent on nursing home care through Medicaid and Medicare. Federal and state Medicaid payments accounted for almost all of this spending – 87%. Medicaid spending for nursing home care grew by 50% in the three-year period beginning in 1967.

In FY2001, Medicaid spent $53.1 billion on institutional care (for nursing homes and care in intermediate care facilities for the mentally retarded).

During the latter part of the 1960s and the 1970s, nursing home care attracted a great deal of congressional oversight as a result of concern about increasing federal expenditures, and a pattern of instances of fraud and abuse that was becoming evident. Between 1969 and 1976, the Subcommittee on Long-Term Care of the Senate Special Committee on Aging, held 30 hearings on problems in the nursing home industry.[4]

Home care services received some congressional attention in the authorizing statute – home health care services were one of the optional services that states could provide under the 1965 law. Three years later in 1968, Congress amended the law to require states to provide home health care services to persons entitled to skilled nursing facility care as part of their state Medicaid plans (effective in 1970). During the 1970s, the Department of Health, Education and Welfare (now Health and Human Services, DHHS) devoted attention to "alternatives to nursing home care" through a variety of federal research and demonstration efforts. These efforts were undertaken not only to find ways to offset the high costs of nursing facility care, but also to respond to the desires of persons with disabilities to remain in their homes and

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[2] U.S. Congress, Senate Special Committee on Aging, Developments in Aging, 1970, Report 92-46, Feb. 16, 1970, Washington, cited from the *American Nursing Home Association Fact Book, 1969-1970.*

[3] American Health Care Association, *Facts and Trends 2001, The Nursing Facility Sourcebook*, 2001, Washington. The number of nursing homes is for 1999-2000 and number of beds is for 1998. (Hereafter referred to as American Health Care Association. *The Nursing Facility Sourcebook*.)

[4] U.S. Congress, Senate Special Committee on Aging, Nursing Home Care in the United States: Failure of Public Policy, Washington, 1974, and supporting papers published in succeeding years.

in community settings, rather than in institutions. However, it was not until 1981 that Congress took significant legislative action to expand home and community-based services through Medicaid when it authorized the Medicaid Section 1915(c) home and community-based waiver program.

Under that authority (known then as the Section 2176 waiver program), the Secretary of DHHS may waive certain Medicaid state plan requirements to allow states to cover a wide range of home and community-based services to persons who otherwise meet the state's eligibility requirements for institutional care. The waiver provision was designed to alter the fact that the Medicaid program had emphasized institutional care rather than care in home and community-based settings. Services under the Section 1915(c) waiver include: case management, personal care, homemaker, home health aide, adult day care, habilitation, environmental modifications, among many others.[5] These services are covered as an *option* of states, and under the law, persons are not entitled to these services as they are to nursing facility care. Moreover, states are allowed to set cost caps and limits on the numbers and types of persons to be served under their wavier programs.

Notwithstanding wide use of the Section 1915(c) waiver authority by states over the last two decades, total spending for Medicaid home and community-based services waivers is significantly less than institutional care – about $14.4 billion in 2001, compared to $53.1 billion for nursing facility care services and care for persons with mental retardation in intermediate care facilities (ICFs/MR). Despite this disparity in spending, in many states the Section 1915(c) waiver program is the primary source of financial support for a wide range of home and community-based services, and funding has been increasing steadily. Federal and state Medicaid support for the waiver programs increased by over 807% from FY1990 to FY2001 (in constant 2001 dollars).

The home and community-based waiver program has been a significant source of support to care for persons with mental retardation and developmental disabilities as states have closed large state institutions for these persons over the last two decades. Nationally, in FY2001, almost 75% of Section 1915(c) waiver funding was devoted to providing services to these individuals.

States administer their long-term care programs against this backdrop of federal legislative initiatives – first, the *entitlement* to nursing home care, and requirement to provide home health services to persons entitled to nursing home care, and, second, the *option* to provide a wide range of home and community-based services

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[5] States may waive the following Medicaid requirements: (1) statewideness – states may cover services in only a portion of the state, rather than in all geographic jurisdictions; (2) comparability of services – states may cover state-selected groups of persons, rather than all persons otherwise eligible; and (3) financial eligibility requirements – states may use more liberal income requirements for persons needing home and community-based waiver services than would otherwise apply to persons living in the community. For further information, see CRS Report RL31163, *Long-Term Care: A Profile of Medicaid 1915(c) Home and Community-based Services Waivers*, by Carol O'Shaughnessy and Rachel Kelly.

through waiver of federal law, within state-defined eligibility requirements, service availability, and limits on numbers of persons served.

A CRS Review of Ten States: Report on Pennsylvania

Pennsylvania's policy stance on long-term care is oriented toward improving options for home and community-based care for all populations in need of care and stemming the growth of surplus institutional care support. Its guiding principles are to: control surplus growth of nursing home beds; support consumer choice; encourage expansion of home and community-based services; fund services rather than capital construction; and assure quality of care.[6]

Over the last two decades, Pennsylvania has documented the issues it has confronted in attempting to provide services to persons with disabilities. Pennsylvania officials have produced a variety of documents on long-term care, primarily through its Intra-Governmental Council on Long-Term Care. State reviews have produced the following findings and recommendations:[7]

- the need for long-term care services is growing and is driven by an increasing older population and the desire by virtually all persons with disabilities to live in home and community-based settings, rather than institutions;
- institutional care financing should be constrained and more effort should be placed on supporting home and community-based care;
- fragmentation and duplication exists in the planning, management and delivery of services among state agencies;
- access to long-term care services is difficult for many, especially low and moderate income persons who do not qualify for Medicaid. Persons in need of care must generally become impoverished before they qualify for Medicaid assistance;
- cost-sharing mechanisms should be encouraged and strengthened to spread the burden of payment of long-term care services by public and private sources; and
- a system-wide shortage of frontline long-term care workers represents a serious and growing problem and threatens access to

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[6] Pennsylvania Department of Public Welfare, Office of Medical Assistance Programs, Commonwealth of Pennsylvania, *Long Term Care In Pennsylvania*. Briefing Book prepared by the Department of Public Welfare. Apr. 22, 2002. (Hereafter cited as *Long-Term Care in Pennsylvania*, Briefing Book.)

[7] Pennsylvania Intra-Governmental Council on Long-Term Care, *Long-Term Care for the 21st Century: A Time for Change*, Sept. 9, 1996, p. 20. Reviews by various agencies in state government include *State Long-Term Care Plan*, 1982; *Human Services CHOICES Report*, 1986; *Report of the Pennsylvania House Select Committee on Long-Term Care*, 1988; *OPTIONS in Long-Term Care: An Interim Report of the Pennsylvania Intra-Governmental Council on Long-Term Care*; and *Intra-Governmental Council Report*, 1996; *Pennsylvania's Frontline Workers in Long-Term Care*, prepared by the Polisher Research Institute at the Philadelphia Geriatric Center for the Pennsylvania Intra-Governmental Council on Long Term Care, Feb. 2001; *Home and Community-Based Services Barriers Elimination Work Group Report*, Mar. 2002; Pennsylvania Intra-Governmental Council on Long-Term Care *Transition Report* (to the Governor), Nov. 2002.

services by persons with disabilities and quality of care across settings.

Summary Overview[8]

Overview

- Pennsylvania's guiding principles in long-term care are to: control surplus growth of nursing home beds; support consumer choice; encourage expansion of home and community-based services; fund services, rather than capital construction; and assure quality of care.[9]
- Long-term care has high prominence among state officials. This is exemplified by significant state funding of services as well as by the creation of the Pennsylvania Intra-Governmental Council on Long-Term Care, first by Executive Order of the Governor, and then later by the General Assembly. The Council has produced a number of high-profile reports.

Demographic Trends

- An aging population poses challenges for the state. Pennsylvania's population age 65 and older – 1.9 million persons in 2000 – represents 15.6% of its total population, ranking it second highest in the nation, following only Florida.
- Its population age 85 and older – the group in greatest need of long-term care services – grew by 38.3% from 1990-2000, ranking seventh highest in the nation. Persons aged 85 and over with two or more limitations in activities in daily living (ADLs) are estimated to grow by 22% by 2010.

Administration of Long-Term Care Programs

- The Department of Public Welfare (DPW) is one of the largest state human service agencies in the nation with over 23,000 employees. DPW administers the Medicaid program and 10 of Pennsylvania's 11 Medicaid Section 1915(c) home and community-based services waivers for persons with disabilities. The Department of Aging administers the home and community-based services waiver program for the elderly.
- There is general recognition among state officials and stakeholders that issues of coordination of management and delivery of services among the various state and local levels is difficult to achieve. The

[8] Information based on Pennsylvania data and documents, national data, and interviews with state officials. This report does not discuss programs for persons with mental illness. It also generally excludes discussion of programs for infants and children with disabilities, other than those serving persons with mental retardation and developmental disabilities.

[9] *Long-Term Care in Pennsylvania*, Briefing Book.

Intra-governmental Council on Long-Term Care, housed in the Department of Aging, was established to address issues around policy coordination among the various departments.

Trends in Institutional Care

- The number of nursing homes in Pennsylvania has remained fairly stable over the last 20 years. The number of beds per 1,000 elderly persons is somewhat lower than the national average. The occupancy rate is 89.7%, higher than the national average of 80.8%. Pennsylvania policy entails a number of strategies that are designed to control growth in surplus nursing home capacity financed by Medicaid.
- The type of care provided to persons with mental retardation and developmental disabilities has changed dramatically over the last several decades, moving from care in large institutions to care in small group homes and home settings. Partly in response to litigation, Pennsylvania has closed 17 large state-supported institutions for persons with mental retardation and significantly downsized others since 1976.

Trends in Home and Community-Based Care

- There has been slow but steady expansion of Medicaid Section 1915(c) home and community-based services funding, but institutional care still is predominant. In FY2001, less than 1 of every 5 Medicaid dollars spent on long-term care was for home and community-based care. Pennsylvania administers 11[10] waiver programs for persons with disabilities, each covering discrete populations.
- Pennsylvania has developed two unique state-funded home and community-based service programs that are financed by the state lottery and from the state's tobacco settlement funds. These programs provide services to persons who do not meet state Medicaid financial eligibility requirements, but who cannot afford the full cost of home and community-based care. Cost sharing is an important component of both programs.
- Area agencies on aging play a key role in performing case management for adults with disabilities. They conduct assessment of need for services using a standardized assessment tool.
- Pennsylvania devotes significant state resources toward providing services to persons with mental retardation. Of the almost $1.6 billion spent from both federal and state sources in 2000, about 52% came from state funding. About 72% of the total was for community services.

[10] One of the 11 Medicaid Section 1915(c) home and community-based waiver programs covers infants, toddlers and families; this waiver is outside the scope of this report.

Long-Term Care Spending

- Long-term care comprises a significant portion of Medicaid spending in Pennsylvania – 47% of all Medicaid spending was devoted to long-term care in FY2001 ($5.1 billion out of $10.9 billion). Nursing home spending represented more than one-third of all Medicaid spending.
- As a share of Medicaid long-term care spending, nursing home spending increased from 63% to 72% from FY1990-FY2001. At the same time, Medicaid spending for institutions for persons with mental retardation decreased from 29% to 9.5%.
- In FY2001, Pennsylvania spent almost $880 million on Medicaid Section 1915(c) home and community-based services waiver programs, a 627.3% increase from FY1990. About three-quarters of waiver services spending is for persons with mental retardation and developmental disabilities.

Issues in Financing and Delivery of Long-Term Care

- A recurring theme discussed by state officials is the view that the federal financing system under Medicaid guarantees heavy use of institutional care. This is largely due to the fact that nursing facility care is an entitlement under Medicaid for persons needing such care who meet its eligibility criteria. In the view of state officials, the impetus for heavy reliance on institutional care is built into the incentive structure for providers, resulting in funding disparities between institutional and home and community-based care.
- Pennsylvania officials indicated that they want to move to a system that relies more on home and community-based services, and that consumers should be given clear choices regarding their options, with adequate supports to stay at home and in the community.
- State officials indicated that the Medicaid Section 1915(c) home and community-based services waiver programs have significantly expanded opportunities for many people with disabilities to receive services they would not have absent the waiver. However, the waivers have created another set of categorical requirements. Each program is identified as a discrete, distinct program resulting, state officials say, in a silo approach to service provision. The procedures locating the appropriate waiver or other service program and the administering agency, and trying to fit a person's needs into the prescribed waiver requirements, can be burdensome on clients as well as providers.
- State officials and stakeholders indicated that a systemwide problem facing the long-term care system is a significant shortage of frontline workers to care for persons with disabilities residing in both institutions and in the community.

Demographic Trends

Pennsylvania is one of most populous states in the United States. With 12.3 million people in 2000, it ranks as the sixth largest state. It also is one of the states with the oldest population. Its population aged 65 and older – 1.9 million persons in 2000 – represents 15.6% of its total population ranking it second highest in the nation, following only Florida (**Table 1**).

Pennsylvania's total elderly population grew by less than 5% in1990-2000 but its population age 85 and older, those in greatest need for long-term care services, grew by 38.3%. The proportion of Pennsylvania's population aged 85 and older is seventh largest in the nation. From 1990 to 2000, the state experienced a 21% increase in the population aged 75 to 84, those at near risk of needing assistance with daily tasks (**Table 1**).

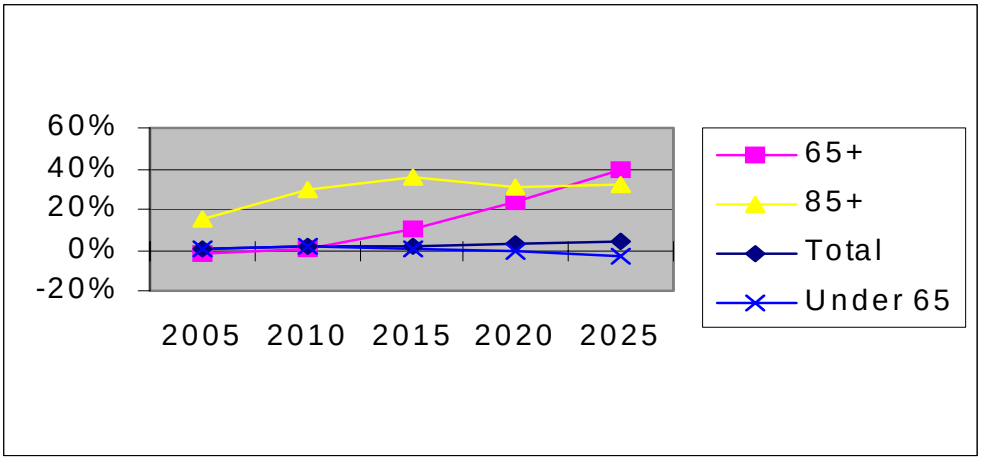
Table 1. Pennsylvania Population Age 65 and Older, 1990 and 2000

	1990		2000		1990-2000 percent change	2000 population rank in U.S. (based on percent)
Age	Number	Percent of total population	Number	Percent of total population		
65+	1,829,106	15.4	1,919,165	15.6	4.9	2
65-74	1,070,021	9.0	969,272	7.9	-9.4	3
75-84	587,249	4.9	712,326	5.8	21.3	2
85+	171,836	1.4	237,567	1.9	38.3	7
Under 65	10,052,537	84.6	10,361,889	84.4	3.1	50
Total	11,881,643	100	12,281,054	100	3.4	6

Source: U.S. Census Bureau. Profile of General Demographics for Pennsylvania: 1990. 2000: [http:// www.census.gov/census2000/states/pa.html]. Percentages may not sum to 100 due to rounding.

Pennsylvania, as all states, will experience large increases in its older population over the next 25 years. By 2025, its 65 and older population will increase by 40% (see **Figure 1**). In 2025, 21% of Pennsylvania's population will be 65 years or older, compared to 18.5% for the nation (**Table 2).** While its older population will not experience a percentage growth as large as that of the total U.S. elderly population, its proportion of older people will exceed that of the nation and it will continue to outrank many other states.

Figure 1. Percentage Population Increase in Pennsylvania, 2000-2025



Source: CRS calculations based on data from the U.S. Census Bureau. Projections: [http://www.census.gov/population/www/projections/st_yrby5.html]; analyzed data from State Populations Projections: Every Fifth Year.

Table 2. Elderly Population as a Percent of Total Population, Pennsylvania and the United States, 2025

Age	Percent of total population, Pennsylvania	Percent of total population, United States
65+	21%	18.5%
65-74	11.8%	10.5%
75-84	6.7%	5.8%
85+	2.4%	2.2%
Under 65 population	79%	81.5%

Source: CRS calculations based on data from the U.S. Census Bureau. Projections: [http://www.census.gov/population/www/projections/st_yrby5.html]; analyzed data from State Populations Projections: Every Fifth Year.

Need for Long-Term Care

Table 3 presents estimates of the number of persons aged 18 and over who have limitations in two or more activities of daily living (ADLs) in Pennsylvania. These estimates were derived from data generated by The Lewin Group, Inc., and combine national level data on persons with disabilities with state-level data from the U.S. Census Bureau on age, income, and broad measures of disability. Persons aged 85 and over with two or more limitations in ADLs are estimated to increase by 22% by 2010. This growth will place pressure on public and private long-term care resources.

Table 3. Estimated Number of Persons with Two or More Limitations in Activities of Daily Living (ADLs), by Poverty Status, in Pennsylvania

	2002			2005			2010		
Percent of poverty	**Persons with 2+ ADLs by age and income**								
	18-64	**65+**	**85+**	**18-64**	**65+**	**85+**	**18-64**	**65+**	**85+**
Up to 100%	7,614	7,474	1,955	7,717	7,536	2,125	7,810	7,730	2,392
Up to 150%	11,350	20,178	5,552	11,504	20,412	6,036	11,641	20,791	6,796
Up to 200%	14,860	29,414	7,983	15,062	29,752	8,678	15,242	30,242	9,770
All incomes	31,924	66,274	19,065	32,361	67,155	20,724	32,741	68,395	23,334

Source: CRS analysis based on projections generated by The Lewin Group, Inc. through the HCBS State-by-State Population Tool available on-line from: [http://www.lewin.com/cltc]. *The Lewin Group Center on Long Term Care HCBS Population Tool*, by Lisa M.B. Alecxih, and Ryan Foreman (2002).

Administration of Long-Term Care Programs

State and Local Administration

Responsibility for administration and management of long-term care services for the elderly and persons with disabilities is spread among several state agencies. In addition, various sub-state agencies have responsibility for various aspects of long-term care administration and services. **Figure 2** displays an organization chart of state and local agencies with responsibilities for administration of long-term care.

The Department of Aging administers home and community-based services for the elderly, including the Medicaid 1915(c)waiver program for the elderly known as the Pennsylvania Department of Aging waiver (PDA) and Older Americans Act programs.

The Department of Aging is host to the *Intra-Governmental Council on Long-Term Care,* which serves in an advisory role and is chaired by the Secretary of the Department of Aging. The Council's mission is to study Pennsylvania's long term care system and to provide options and recommendations to the Governor, the General Assembly, and state government administration on consumer access to the long-term care system, financing of long-term care services, and ways to streamline the system so that it will be responsive to the needs of consumers and their families. The Council was established by the Select Committee on Long-Term Care in the Pennsylvania House of Representatives in 1986. Then, in March 1988 the Council was created by Executive Order of the Governor, and in December 1988, Act 185 codified the Council in Pennsylvania state law. In 1996, Governor Tom Ridge appointed members representing diverse areas related to long-term care. The Council is comprised of 37 members, including 5 members of the Cabinet, 4 members of the General Assembly, representatives from consumer groups, and service providers appointed by the Governor. The Council has developed numerous high-profile state reports.[11]

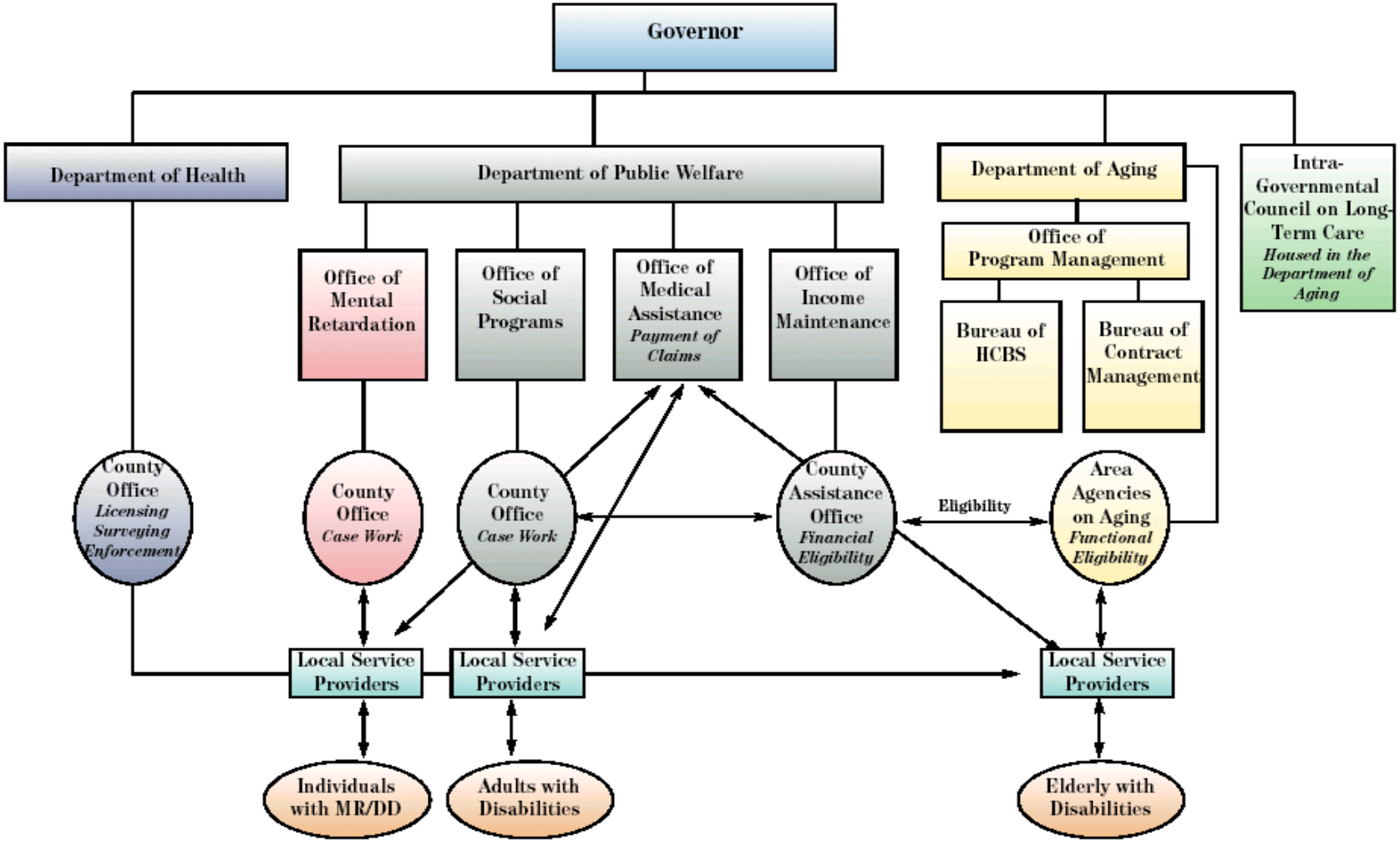
The *Department of Public Welfare* (DPW) is one of the largest state human service agencies in the nation with over 23,000 employees. DPW administers the Medicaid program, including Pennsylvania's Section 1915(c) waiver programs. DPW and the Department of Aging jointly administer the Section 1915(c) waiver program for the elderly. DPW also houses the *Office of Mental Retardation,* which administers state-operated institutions for the mentally retarded; and the *Office of Social Policy* which is responsible for the licensing of the state's personal care homes.

The *Department of Health* is responsible for licensing and certification of nursing homes and home health agencies. The Department conducts over 5,000 nursing home inspections each year, including licensure and certification surveys,

[11] For example, *Options in Long-Term Care,* February 1990; *Long-Term Care for the 21st Century: A Time for Change,* Sept. 1996; *Pennsylvania's Frontline Workers in Long-Term Care,* Feb. 2001; *Home and Community-Based Services Barriers Elimination Work Group,* Mar. 2002.

follow-up surveys and complaint investigations. It also operates a nurse aide registry containing information on over 154,000 nurse aides in Pennsylvania.

Figure 2. Pennsylvania Long-Term Care System



Source: Prepared by CRS based on Pennsylvania documents.

Responsibility for Financial and Functional Eligibility Determinations

Pennsylvania has 67 counties and 67 county offices in about 80 locations in the state. Responsibility for various aspects of administration and management of long-term care services is divided among the county agencies and 52 area agencies on aging that operate on a individual-county or multi-county basis.

County assistance offices (under supervision of the Office of Income Maintenance, DPW) are uniformly responsible for determination of Medicaid financial eligibility for persons applying for nursing home and home and community-based care for persons with disabilities of all ages – persons aged 60 and older, younger persons with disabilities aged 18-59, and persons with mental retardation of all ages.

The state is phasing in use of an on-line financial eligibility determination system, Commonwealth of Pennsylvania Application for Social Services (COMPASS).[12] The system is intended to serve as single access point for a wide variety of programs, including health care coverage, food stamps, and cash assistance benefits. Use of COMPASS for eligibility determinations for long-term care services is to be phased in by 2003.

Area agencies on aging (authorized under Title III of the Older Americans Act) carry out a number of long-term care responsibilities for both persons aged 60 and older as well as for younger persons with disabilities aged 18 through 59 under contract with DPW. Area agencies perform pre-admission screening for persons of all ages applying for nursing home care. They also are responsible for determining level of care and services assessment for persons aged 18 and over applying for home and community-based care under Medicaid waiver and state-funded programs.

Area agencies conduct client assessments and determine need for services using a uniform statewide tool, the OPTIONS Assessment Forms.[13] There are two forms used, one for community services assessments, and one for nursing facility assessments. The assessment tool is a comprehensive instrument that assesses a person's physical and cognitive functioning, limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), availability of formal and informal supports, physical environment and social participation, among other variables. This tool has been the standard instrument used since the 1980s.

County offices of mental retardation are responsible for case management and service delivery for persons with mental retardation across the state. The Mental Health/Mental Retardation Act of 1966 established the framework for Pennsylvania's

[12] [www.compass.state.pa.us].

[13] Pennsylvania Department of Aging. *Options Assessment Forms* (Comprehensive OPTIONS Assessment Form) and the Nursing Facility OPTIONS Assessment Form.

service system for people with mental retardation.[14] The statute set out state responsibilities for funding and licencing of state institutions for mental retardation. In the 67 counties, there are 46 county offices that are responsible for assessment and case management of services for persons with mental retardation.

Pennsylvania's Long-Term Care Services for the Elderly and Persons with Disabilities

Trends in Institutional Care

There are almost 780 nursing homes with about 95,000 beds in Pennsylvania. According to state officials, the total number of facilities has remained fairly stable over the last 20 years. The number of beds per 1,000 elderly persons is somewhat lower than the national average. There are about 51 beds per 1,000 persons aged 65 and older, and 401 beds per 1,000 elderly persons aged 85 and older, as compared to 53 and 435, respectively, for the United States as a whole (**Table 4**). The occupancy rate is 89.7%, higher than the national average of 80.8%.

Table 4. Nursing Home Characteristics in Pennsylvania and the United States

(data are for 1999-2000 unless otherwise noted)

Characteristic	Pennsylvania	United States
Number of facilities	778	17,023
Number of residents	84,588	1,490,155
Number of beds	95,083 (2000)	1,843,522
Number of Medicaid beds	88,950 (2001)	841,458
Number of total beds per 1,000 pop. aged 65 and older	51.1 (2000)	52.7
Number of total beds per 1,000 pop. aged 75 and older	100.1 (2000)	111.1
Number of total beds per 1,000 pop. aged 85 and older	401.2 (2000)	434.8
Occupancy rate	89.7% (2000)	80.8%

Source: Data come from the following sources: *For Pennsylvania*: For total beds and occupancy, and facilities, Pennsylvania Department of Health, Bureau of Health Statistics, Data from the long-Term Care Facilities Questionnaire; for Medicaid beds, Long-Term Care in Pennsylvania Briefing Book, Department of Public Welfare, Apr. 22, 2002; for residents, American Health Care Association, Facts and Trends: The Nursing Facility Source book. *For the U.S.*, American Health Care Association.

[14] County offices of mental health and mental retardation are authorized under Pennsylvania state statute, the Mental Health and Mental Retardation Act of 1966. Pa. State. Ann. 50.

As in most states, long-term care in Pennsylvania is dominated by spending for nursing home care. In FY2001, of total long-term care spending under Medicaid, 72% was spent on care in nursing homes. Pennsylvania state officials as well as long-term care stakeholders indicate that the financing incentives inherent in Medicaid cause a bias toward institutional care spending.

Changes in financial incentives and provider culture regarding use of institutions are difficult to achieve. Nonetheless, Pennsylvania policy entails a number of strategies that affect institutional care utilization.

Development of Medicaid Nursing Home Participation Review Program (PRP). In 1996, the State Assembly allowed the state's certificate of need (CON) program for health care providers to sunset. After that time, the number of nursing home facilities and beds increased. In recognition of this and the state's goal to control surplus growth, in 1998, the Department of Public Welfare instituted the PRP – a process of reviewing the need for nursing home facilities and beds that participate in Medicaid. Nursing homes seeking to participate, either as new facilities, or as an expansion of existing facilities, must be approved by DPW through the PRP. The main objective of the PRP is to "respond to consumers' desire to age in place by redirecting limited state resources from higher-cost, less preferable institutional settings to more cost-effective home and community-based services, through encouraging the development of other components of the array of long-term care services."[15]

The state reviews an application from a provider on a case-by-case basis using a number of criteria including Medicaid program need; availability of home and community-based services in the area; and economic and financial feasibility. This procedure is intended to implement the Department's goals of promoting home and community-based services and control the number of nursing home beds that enter the market.

Implementation of Medicaid Section 1915(c) Waiver Program. In January 1999, the state implemented its Section 1915(c) waiver program (Pennsylvania Department of Aging waiver) for persons aged 60 and older on a statewide basis. The waiver provides a wide range of home and community-based services to persons who meet the nursing home level of care requirements and is intended to divert persons from use of nursing homes. Area agencies on aging are under contract with DPW to carry out level of care determinations for both home and community-based services under the waiver program for the elderly and most younger persons with disabilities. Area agencies also perform level of care determinations for nursing home care. According to state officials interviewed, because area agencies are community-based organizations, they have the capacity to access community-based services for those persons who could be cared for in the community and to divert persons from nursing homes when possible.

According to state officials, implementation of the PRP in January 1998, as well as statewide implementation of the PDA waiver, have reduced utilization of

[15] *Long-Term Care In Pennsylvania*, Briefing Book, p. 15.

Medicaid patient days.[16] The average occupancy of Medicaid facilities declined from 92.1% in February 1998 to 88.8% in October 2001. Since January 1998, the number of Medicaid-certified beds has dropped from 90,750 to 88,950 in 2001. The number of facilities has dropped from 665 to 653 in 2001.[17]

In addition to these strategies to control Medicaid nursing home utilization, state officials indicate that the characteristics of nursing home users have changed. Acuity levels of patients entering nursing homes have increased in recent years. This is attributed to a greater use of home and community-based services that delays entry into nursing home care until older ages.

Trends in Home and Community-Based Care

Pennsylvania supports a wide range of home and community-based services for the elderly and persons with disabilities, comprised chiefly of a series of Medicaid Section 1915(c) waiver programs, and two state-funded programs for persons who do not qualify for waiver services. The waiver programs, while intended to provide a base of support to persons with disabilities, are targeted, carefully designed with caps on the cost of services, and have very specific eligibility groups with stringent income and asset tests. In addition, using state funds, the state has developed a unique way to address some of the financial barriers that inhibit access to home and community-based care through Medicaid. Two sources of funding, specifically the Pennsylvania State Lottery and the state's share of the tobacco settlement funds (see section below on financing) open access to persons who otherwise would not qualify financially for waiver programs.

Other actions the state has taken to improve information and access to home and community-based care include: establishing a long-term care web-based helpline and website [www.longtermcare.state.pa.us]; developing consumer-friendly publications and a media campaign explaining the range of home and community-based services available; establishing a program to allow persons residing in nursing homes to transition to the community; and phasing-in a web-based financial eligibility application process for long-term care.[18]

Although progress has been made in increasing options for home and community-based care for the elderly and persons with disabilities, according to a report authored by state officials and long-term care stakeholders, the state "has not completely purged its long history of institutional bias from its long-term care system."[19] The report indicated that in 2000, the state's public funding supported over 54,208 elderly and younger persons with disabilities in nursing homes – 92% of the total – compared to 4,563 persons in home and community-based settings –

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[16] Ibid., p. 21.

[17] Ibid., p. 18.

[18] Pennsylvania Intra-Governmental Council on Long Term Care. *Home and Community-Based Services Barriers Elimination Work Group*. Mar. 2002, p. 4. (Hereafter referred to as *Home and Community-Based Services Barriers Elimination Work Group*.)

[19] Ibid.

8% of the total. An additional 11,000 persons resided in personal care homes only partially funded with public funds.[20]

Medicaid 1915(c) Waivers. Pennsylvania administers eight waiver programs for the elderly and persons with disabilities (two waivers for persons with mental retardation and developmental disabilities are discussed below and another waiver for infants and children is outside the scope of this report). Certain general principles apply to each of the waivers. First, in order to qualify for services, persons must have income that does not exceed 300% of the Supplemental Security Income (SSI) eligibility level ($1,656/month in 2003 for an individual) and must meet SSI's assets limit of $2,000 (for an individual).[21] Second, except for one waiver program (Elywn), all are operated on a statewide basis.

The following describes target groups, services, number of persons served, and cost caps for each of the waivers (for more detailed information, see **Appendix Table A-1**.)

- *Pennsylvania Department of Aging (PDA) Waiver*. The PDA waiver provides a wide range of services for persons aged 60 and older. Persons must meet the state's requirements for nursing facility level of care. Services available include attendant care; companion services; environmental modifications; home-delivered meals; home health services; home support services; adult day care services; personal care services; personal emergency response system (PERS); respite care; specialized medical equipment and supplies; and transportation. The PDA waiver served 9,309 persons in State Fiscal Year (SFY) 2001-2002 and 10,049 slots are approved for SFY2002-2003. The cost cap for the PDA waiver is $35,000 (the equivalent of 80% of the nursing facility rate, excluding the costs of case management and administration) and is applied on an individual basis. The average cost of the PDA waiver in SFY2001-2002 was $8,136 per person.
- *Attendant Care Waiver*. The Attendant Care Waiver was initiated to serve a group of persons who had been on a waiting list for a previously state-funded program for persons with physical disabilities (ACT 150 program). Persons eligible are those aged 18-59 who meet the state's requirements for nursing home eligibility as well as meet the state's definition of disability. They must also be capable of selecting and supervising attendants, and of managing their own financial and legal affairs. Services included in the Attendant Care Waiver are: *basic care services*, such as helping the consumer in and out of bed, wheelchair, and/or motor vehicle; and assistance with *routine bodily functions* such as bathing, grooming

[20] Ibid., p.5. *Note:* persons in personal care homes partially fund their own room and board through their own SSI payments.

[21] Certain items are excluded, such as an individual's home; up to $2,000 of household goods and personal effects; life insurance policies with a face value of $1,500 or less; an automobile with value up to $4,500; and burial funds up to $1,500, among other things.

and eating. When a client in the attendant care waiver program turns age 60, the PDA waiver can continue services and the client may keep the same provider. The program has 2,396 DHHS approved slots and served 1,804 persons in SFY2001-2002. The cost cap for the Attendant Care Waiver is $38,059, which is assessed on a statewide aggregate basis.

- *Independence Waiver*. The Independence Waiver provides a wide range of services to persons age 18 years and over who have substantial functional limitations in at least three of the following areas: self-care; understanding and use of language; learning; self-direction; capacity for independent living; and mobility. Persons must meet the nursing home level of care. Those with a primary diagnosis of a mental illness or with mental retardation, or who are ventilator dependent are not eligible for services under this waiver. Services include service coordination; assistance with daily living; respite care; environmental accessibility adaptions; and specialized medical equipment and supplies. A relatively small number of slots are DHHS-approved – 403 as of December 2002. As of December 2002, 452 individuals were receiving services (As of December 2002, the state was in the process of amending its waiver to increase the number of approved slots.) The aggregate cost cap is $42,116 (average per case).
- *Michael Dallas Waiver*. The target group for this waiver is persons of all ages who are technology dependent (that is, those who require technology to sustain life or replace a vital bodily function) and whose private insurance has been exhausted. The waiver was originally initiated for children in 1987, then was expanded in 2001 to include adults. Services provided include: case management; private duty nursing; attendant care; respite; durable medical equipment and nutritional supplements. The cost cap for this waiver is $236,000 per year which is applied on an aggregate basis. Costs range from $180,000 to $200,000 per year per individual. In SFY2001-2002, 136 slots were DHHS-approved with 57 persons enrolled.
- *Elwyn Waiver*. The only waiver program that is not statewide, this waiver provides services to a specially targeted group of persons age 40 and over who are deaf, blind or deaf/blind who live in Delaware County in an assisted living facility. The waiver was initiated to provide assisted living services to persons who resided in a nursing home that was being closed. A relatively small waiver, it has 45 DHHS-approved slots with 39 people enrolled in 2002. The annual cost cap for this waiver is $23,000 and is applied on an individual basis.
- *AIDS Waiver*. This waiver provides services to persons aged 21 through 64 who have symptomatic HIV and AIDS, who do not have Medicare coverage, and who are not eligible for hospice care. The waiver is administered by managed care plans in managed care areas and under fee-for-service agreements in areas that are not covered by managed care plans. Services include skilled nursing and home health aid; homemaker services; supplies and nutritional

supplements not covered by Medicaid; and nutritional consultations by registered dieticians. The waiver is approved to serve up to 250 people, and 78 people were enrolled in SFY2001-2002. The annual cost cap is $14,000 per year and is applied on an individual basis.

- *Commcare Waiver*. The most recent waiver, initiated in April 2002, the Commcare waiver provides services to prevent institutionalization of persons with traumatic brain injury (TBI). Persons must have substantial functional limitation in three or more major life activities. Services include care coordination; personal care; respite prevocational and habilitation and support services; and supported employment, among others. Services may be provided to persons living in group living arrangements with up to six beds. As of December 2002, three individuals were being served under this waiver which has received DHHS approval for 98 slots. The aggregate cost cap for the wavier is $146,740.

State Programs. There are a number of pathways that establish Medicaid eligibility for home and community-based long-term care services. These include coverage of persons whose income does not exceed 300% of the federal SSI payment level, as allowed under the Section 1915(c) waiver program and used for the Section 1915(c) waiver programs in Pennsylvania. However, despite use of this more liberal standard, there are still many people who need home and community-based services, but who cannot meet the income limits or resource tests under Medicaid, and who cannot afford home and community-based services. Many of these persons could not establish eligibility until they spend-down almost all their resources and income, and by that time, are in danger of having to go into an institution. One of the issues many states have confronted is how to provide services for such persons. Pennsylvania has addressed this issue through two state-funded programs that provide services using more liberal income or resource tests than required under the waiver programs.

These state-funded programs for the elderly provide services that are similar to the PDA waiver, but expand eligibility requirements to include persons financially ineligible for the waiver. The *Bridge Program* provides services to persons who cannot meet the Medicaid resource test limitation, and the *Options Program* provides services to persons who have income above the Medicaid limit for persons in the waiver (300% of the federal SSI level). Both programs require different forms of cost-sharing by participants.

The Bridge Program. Implemented for the first time in January 2002, this program provides home and community-based services similar to those under the PDA waiver, but to persons aged 60 and over who have assets greater than the $2,000 limit required under the waiver. Persons may have assets up to $40,000 and qualify for services, but must still meet the waiver income test. The program is unique in its cost-sharing system. Each beneficiary is required to pay 50% of the cost of direct services, such as homemaker, chore, home-delivered meals, and home health care; the remaining 50% is covered by the program. The cost-sharing system allows persons with higher resources to receive services; and when they "spend down" their resources, they may qualify under the Medicaid PDA waiver.

The Bridge Program is financed through the state's tobacco settlement funds. As of April 2002, 200 persons had enrolled in the program. The cost cap for the Bridge program is the same as the PDA waiver.

Options Program. Financed through the Pennsylvania State Lottery, the Options Program provides assessment, case management, and pre-admission screening for persons aged 18 and over applying for nursing home care, and for SSI eligible persons applying for residence in a domiciliary or personal care home. For the elderly, the program supports a wide range of home care services similar to those provided by the PDA waiver.

The unique aspect of the Options Program is its financial eligibility criteria. Eligibility is based on a sliding scale of income with beneficiary cost-sharing. Beneficiaries whose income is below 125% of the federal poverty level (FPL) are not required to pay for services. (About two-thirds of participants fall into this category.) Persons with income from 125% up to 300% of the FPL pay for services on a sliding fee scale basis; persons with income above 300% are required to pay the full cost. Unlike either the waiver or Bridge program, resources are not considered in determining eligibility. The SSI limit on resources used to determine Medicaid eligibility ($2,000 for an individual) disqualifies many persons who would otherwise be eligible on the basis of income.

For SFY2001-2002 about 91,000 persons were served. The cost cap for the Options program is $625 per month applied on an individual basis.

Family Caregiver Program. Inspired by former Pennsylvania Governor Casey, the state initiated a family caregiver program in 1987, and it became statewide in 1991. This program served as a model for the Older Americans Act family caregiver program that Congress enacted in 2000 (P.L. 106-501). The program, now funded by both the Older Americans Act and state funds, as well as by the state lottery funding, provides services to persons age 60 and older or persons with chronic dementia or Alzheimer's disease and their families.

Area agencies on aging assist family caregivers assess their needs in caring for family members. Caregivers choose the services most needed to help them care for their relatives. Services include assessment of need, counseling on coping skills and caregiver training, respite, financial assistance to purchase supplies or services, one-time grants for home adaptations, and benefits counseling.

Families receive assistance on a cost-sharing basis and may receive from $200 to $500 a month in services or caregiving supplies to assist with out-of-pocket expenses. (The average monthly expenditure for recipients is about $350.)

In order to be eligible for assistance, family caregivers must provide the majority of care and must be doing it without charge. Except for assessment, case management, benefits counseling, and caregiver education and training, families receive services and/or supplies on a cost-sharing basis, as follows:

- persons with income below 200% of the federal poverty level (FPL) receive assistance without charge;

- persons with income between 200% up to 380% of the FPL receive assistance on a sliding fee scale basis;
- persons with income of 380% of the FPL or more may receive services but are not eligible for cash reimbursements.

About 10,000 persons receive services under the family caregiver program at any given time. In FY2002-2003, the state will spend $17.8 million on the program ($11.5 from state funds and $6.3 from federal sources).

Pennsylvania's Long-Term Care Services for Persons with Mental Retardation and Developmental Disabilities

Overview

Services to persons with mental retardation and other development disabilities in the United States have changed dramatically over the last half of the 20th country as a result of a number of converging factors. These include the advocacy efforts of families and organized constituency groups, various changes to the Social Security law that provided payments to individuals through SSI and SSDI and to service providers through the Medicaid program, and significant litigation brought on behalf of persons with mental retardation.[22]

Pennsylvania's system of services for persons with mental retardation has been influenced by a number of significant factors. These include:

- the passage of Pennsylvania's Mental Health/Mental Retardation Act of 1966, which established state responsibility for funding and licensing of services, and made county government responsible for program administration, service delivery and case management;[23]
- the 1977 settlement of *Pennhurst State School and Hospital v. Haldeman*, which ordered the closure of a large state institution and became one of the most important cases influencing care of the persons with mental retardation in the United States;
- the initiation of the Medicaid Section 1915(c) home and community-based waiver services option in 1983;
- a 1991 Pennsylvania initiative entitled *Everyday Lives* which set forth values governing services for persons with mental retardation, and a vision of self-advocacy, community services and supports for families;
- a 1997 Multi-Year Plan which set forth actions to be accomplished to improve self-determination for persons with mental retardation and quality of care, including increased community services options;[24]

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[22] For a detailed history of the development of services for persons with developmental disabilities, see *The State of the States in Developmental Disabilities* by David Braddock, Richard Hemp, Susan Parish, James Westrich. University of Illinois at Chicago. American Association on Mental Retardation, Washington, 1998. (Hereafter cited as Braddock, et. al., *The State of the States in Developmental Disabilities*, 1998.)

[23] Pa. State. Ann. 50, Section 4101, et. al.

[24] Pennsylvania Department of Public Welfare, Planning Advisory Committee to the Office Of Mental Retardation, *A Multi-Year Plan for Pennsylvania's Mental Retardation Service System*, July 1997. (Hereafter cited as Office of Mental Retardation, *A Multi-Year Plan*.)

- a 1999 plan to reduce the size of waiting lists for services;[25] and
- a 5-year plan initiated in 2002, *Everyday Lives: Making It Happen*, which seeks to implement the vision for services developed by stakeholders.[26]

There are an estimated 115,000 persons of all ages with mental retardation in Pennsylvania. The State Fiscal Year 2002-2003 budget for services for persons with mental retardation is $1.9 billion. More than 70% of the total budget supports 82,000 persons in a variety of home and community-based care settings.[27]

Trends in Institutional Care

The early history of services to persons with mental retardation nationwide is characterized by the development of large state institutions or training schools begun during the latter part of the 19th century and continuing through the first part of the 20th century. Between 1920 and 1967, institutions quadrupled in size and peaked to serving almost 200,000 individuals nationwide in 165 free-standing state-operated mental retardation institutional facilities.[28] Today, some states are still faced with the legacy of large state-operated institutions.

In the nation as a whole and in Pennsylvania, over the last several decades, many large state-operated institutions have been closed or downsized, a development that has been prompted by litigation. One of the earliest and most publicized cases on behalf of persons with mental retardation residing in these institutions was filed in Pennsylvania in1976, *Pennhurst State School and Hospital v. Haldeman*. The case was ultimately heard by the U.S. Supreme Court. The Pennhurst State School and Hospital, opened in 1908, once housed over 4,000 individuals with mental retardation in Chester County, Pennsylvania. In 1977, U.S. Judge Raymond Broderick ordered the state-run institution to be closed after hearing evidence of the facility's abuse and neglect of patients in the case. Even decades later, this landmark case continues to profoundly affect the care of mentally retarded children and adults, as well as other individuals receiving long-term care in institutions.

Although parents of the Pennhurst residents initially filed the lawsuit to improve conditions in the facility, their legal representative, the Public Interest Law Center, encouraged them to focus on the broader issue of whether adequate care could ever be achieved in large institutional settings, such as Pennhurst. The case ultimately recognized the rights of citizens with mental retardation to have access to community-based care. After more than a decade of legal battles, the Commonwealth of Pennsylvania reached a settlement with the Association of

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[25] Pennsylvania Department of Public Welfare, Office of Mental Retardation, *A Long Term Plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*, Oct. 1999. (Hereafter cited as Office of Mental Retardation, *A Long-Term Plan to Address the Waiting List*.)

[26] Pennsylvania Office of Mental Retardation, *Program Overview*, 2002.

[27] See website: [http://www.dpw.state.pa.us/omr]

[28] Braddock, et. al., *The State of the States in Developmental Disabilities*, 1998.

Retarded Citizens (now known as the ARC), the families of the Pennhurst residents, and the U.S. District Court in 1986. Pennhurst was closed in 1988. The state eventually closed most of its state-run institutions for the mentally retarded and placed residents in small community-based facilities with improved access to care. In addition to profoundly altering the quality of care for the mentally retarded in Pennsylvania, the case has provided a legal basis for other groups currently living in institutional settings to argue for access to community-based services. Because a settlement was reached with the plaintiffs, the impact of the lawsuit only directly impacted the Commonwealth of Pennsylvania, but the implications of the lawsuit were felt across the country as policies toward persons with mental retardation in institutions began to shift. Another related Pennsylvania case, *Youngberg v. Romeo*, originally filed in 1976 and later heard by the U.S. Supreme Court, established the rights of residents to receive basic services and to be free of undue restraint.[29]

As in most states, the number of persons residing in large state institutions in Pennsylvania has declined dramatically over the years partly as a result of litigation. Since 1960, Pennsylvania has closed 17 large state facilities and significantly downsized others. Some of these facilities date back to the very end of the 19th century or early part of the 20th century. (See **Appendix Table 2** for a list of the institutions that have been closed and those in operation and their 2001 census.)

Persons living in large institutions with 16 or more persons declined from 43.7% of all persons living in group residences in Pennsylvania to just under 30% in 2000. This decline is primarily due to the downsizing and closure of the large *state* institutions since 1990. In 1990, almost two-thirds of persons in large facilities were residing in state institutions compared to 30% in 2000. The decline in the census in large state institutions is not reflected in the use of large *private* institutions, however. This is primarily due to the use of private facilities funded as intermediate care facilities for the mentally retarded (ICFs/MR) under Medicaid. The proportion of persons residing in these private facilities with 16 or more beds was 31% in 1990 and was about the same proportion (29%) in 2000 (**Table 5**).

The Medicaid home and community-based services waiver option (discussed below) has allowed Pennsylvania to focus on development of small congregate care options. In 2000, almost 22,000 persons with mental retardation were living in group residential settings, with the majority (68%) living in residences of six or fewer persons. This is an increase since 1990 when 47% of the total in group residences were in small facilities (see **Table 5**).

[29] Braddock, et. al., *The State of the States in Developmental Disabilities*, 1998, p. 9. See also, U.S. Supreme Court, *Youngberg v. Romeo* 457 U.S. 307 (1982) Decided June 18, 1982.

Table 5. Persons with Mental Retardation and Developmental Disabilities Served in Residential Settings, by Size of Setting, 1990, 1995, and 2000

Persons served by residential setting			
	1990	**1995**	**2000**
Setting by size	**15,007 (100%)**	**19,051 (100%)**	**21,948 (100%)**
16+ PERSONS	**6,567 (43.8%)**	**8,000 (42%)**	**6,376 (29.1%)**
Nursing facilities	not available	2,235	2,350
State institutions	4,043	3,460	1,969
Private ICFs/MR	2,041	1,989	1,869
Other residential	483	316	188
7 - 15 PERSONS	**1,429 (9.5%)**	**1,078 (5.7%)**	**689 (3.1%)**
Public ICFs/MR	0	0	0
Private ICFs/MR	1,135	724	463
Other residential	294	354	226
<6 PERSONS	**7,011 (46.7%)**	**9,973 (52.3%)**	**14,883 (67.8%)**
Public ICFs/MR	0	0	0
Private ICFs/MR	0	695	643
Other residential	7,011	9,278	14,240

Source: *Disability at the Dawn of the 21st Century and the State of the States*, David Braddock, editor, with Richard Hemp, Mary C. Rizzolo, Susan Parish, and Amy Pomeranz, American Association on Mental Retardation, Washington, 2002.

Pennsylvania has used the Medicaid waiver options to increase community service options and small group residences and reduce the number by large facilities. However, according to data compiled by Braddock et. al., Pennsylvania ranked only 25th in the Nation in its use of small facilities (based on the percent of individuals in residences of six or fewer persons).[30] There is a belief on the part of state officials and stakeholders that the use of larger facilities should be further reduced in keeping with the state's commitment to community-based care. The state's 1997 *Multi-year*

[30] *Disability at the Dawn of the 21st Century and the State of the States*, David Braddock, ed, American Association on Mental Retardation, Washington, 2002, p. 86. (Hereafter cited as Braddock, *Disability at the Dawn of the 21st Century*, 2002.)

Plan recommended that the Office of Mental Retardation move, over a 5-year period beginning in 1997-98, 1,500 persons who resided in large public facilities to community living services.[31] Data compiled by the Office of Mental Retardation show that in 2001, about 1,700 persons resided in state facilities. Another goal of the *Multi-Year Plan* was to transfer 2000 people from private ICFs/MR facilities to services under the waiver program.[32]

Trends in Home and Community-Based Care

As the number and size of facilities has decreased over the years, the state has made significant use of Medicaid financing for community-based care. In Pennsylvania, as in many states, the Medicaid Section 1915(c) waiver program is the chief source of revenue for home and community based services for this group. Unlike the service system for the elderly and disabled where the state has access to state lottery and tobacco settlement funds to complement federal sources, the waiver program is considered the chief financing source for community-based care.

Medicaid 1915(c) Waivers. *Consolidated Waiver for Individuals with Mental Retardation*. The largest waiver program, both in terms of persons served and expenditures for any one population group with disabilities in Pennsylvania, is the *Consolidated Waiver for Individuals with Mental Retardation.* This waiver has 16,491 slots approved by Center for Medicare and Medicaid Services (CMS) for SFY2002-2003[33] and provides a wide range of services to persons age 3 and older who have mental retardation.[34] Persons with developmental disabilities who do not have mental retardation are not generally covered under this waiver, but can receive services under the Omnibus Budget Reconciliation Act (OBRA) waiver, described below.

A wide range of services are provided: including habilitation (residential and day habilitation); prevocational services; supported employment; transportation; respite care; private duty nursing; specialized therapies; and permanency planning for children and youth. The cost cap is applied on an aggregate basis to individuals receiving services across the state; the average per capita costs of waiver services for 2002-2003 is $52,143.[35] About 13,614 persons were served in SFY2001-2002.

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[31] Office of Mental Retardation, *A Multi-Year Plan*, p. 10.

[32] Ibid.

[33] CMS has approved the following slots for this waiver: for July 1, 2001-June 30, 2002, 15,493; for July 1, 2002-June 30, 2003, 16,491; for July 1, 2003-June 30, 2004, 17, 387; and for July 1, 2004-June 30, 2005, 18,279 slots. Letter from CMS Acting Regional Administrator to Secretary of the Department of Public Welfare, Jan. 29, 2001. (Hereafter cited as Letter from CMS, Jan. 29, 2001.)

[34] In addition to the waivers described, the Department of Public Welfare, Office of Mental Retardation administers a Medicaid Section 1915(c) waiver program for infants and children which is outside the scope of this report.

[35] Letter from CMS, Jan. 29, 2001.

The *Person/Family Directed Waiver*. This waiver provides services to the same population and with similar services as the Consolidated Waiver. The chief differences between the two waivers is a lower cost cap and the fact that this waiver is applied on an individual, rather than aggregate basis. The cost cap for this waiver is $21,225 for SFY2002-2003. About 6,218 persons were served under this waiver in SFY2001-2002. For SFY2002-2003, 7,361 slots are approved.

OBRA Waiver. A third wavier, which focuses on a broader category for persons with developmental disabilities, is the *OBRA Waiver*.[36] The purpose of the OBRA waiver[37] is to move persons with development disabilities from nursing homes to community settings and to prevent persons with physical disabilities from being institutionalized. Persons eligible are those with severe chronic disabilities attributed to cerebral palsy, epilepsy, and other developmental disabilities whose onset occurred prior to age 22; and whose conditions are likely to continue indefinitely and result in substantial functional limitations in three or more major life activities.

A wide range of services is available under the OBRA waiver, including service coordination; assistance with daily living; respite care; environmental adaptions; assistive technology/specialized medical equipment and supplies; physical, speech and occupational therapies; prevocational and supported employment services. A relatively small waiver, it has 356 CMS approved slots. As of December 2002, about 377 consumers were being served. (As of December 2002, the state was in the process of amending its waiver to increase the number of slots.) The aggregate cost cap for the OBRA waiver is $129,949 for SFY2001-2002.

Financing Long-Term Care in Pennsylvania

In most states, the federal-state Medicaid program is the chief source of financing for long-term care. In Pennsylvania, the Medicaid program accounted for $5.1 billion in long-term care spending in FY2001. In addition, state resources, through the Pennsylvania State Lottery and the state's share of the tobacco settlement, provided about $232 million for home and community-based long-term care services for the elderly in SFY2001-2002. State revenue supported over $819 million for services for persons with mental retardation in 2000.

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[36] This waiver is administered by the Department of Public Welfare, Office of Social Programs. It is listed here because the target group is persons who have developmental disabilities. Waivers for persons with mental retardation are administered by the Department of Public Welfare, Office of Mental Retardation.

[37] The waiver is named after the federal law (the Omnibus Budget Reconciliation Act) that required persons with mental retardation/developmental disabilities to be screened to determine appropriate placement to meet their unique needs (PASSAR).

Medicaid Spending in Pennsylvania

Medicaid is a significant part of state budgets. After elementary, secondary and higher education spending, Medicaid spending was the largest share of state budgets in 2001. According to data compiled by the National Association of State Budget Officers (NASBO), *federal and state* Medicaid spending represented 19.6% of state budgets for the United States as a whole in 2001.

In Pennsylvania, Medicaid spending is the largest single category of *federal and state* spending. Of the state's $40.7 billion budget in 2001, federal and state Medicaid spending represented 28% – more than 1 of every 4 dollars. Federal and state spending for Medicaid more than doubled as a proportion of the state's budget from 1990 to 2001, now outranking spending for elementary, secondary and higher education, and public assistance combined (**Table 6**).

State spending for Medicaid services in Pennsylvania contributed from state funds *only* (excluding federal funds)[38] also increased during the 1990s. As a percent of spending for all categories of state spending, state Medicaid spending increased from 8.1% in 1990 to 19% in 2001 – almost 1 of every 5 dollars (**Table 7**).

[38] Federal and state governments share the costs of Medicaid spending according to a statutory formula based on a state's relative per capita income (federal medical assistance percentage, or FMAP). In FY2001, the federal share for Medicaid in Pennsylvania was 53.62%.

Table 6. Share of State Spending by Category, Pennsylvania and the United States,1990-2001

Expenditure category	Pennsylvania				All states
	1990	1995	2000	2001	2001
Total expenditures (in millions)	**$21,824**	**$30,753**	**$38,426**	**$40,694**	**$1,024,439**
Medicaid	**12.2%**	**25.5%**	**27.9%**	**28.3%**	**19.6%**
Elementary and secondary education	22.6%	20.2%	18.9%	18.8%	22.2%
Higher education	6.8%	6.1%	5.2%	5.4%	11.3%
Public assistance	5.3%	4.7%	2.8%	2.4%	2.2%
Corrections	1.7%	3.3%	3.9%	3.9%	3.7%
Transportation	12.0%	10.1%	10.0%	10.9%	8.9%
All other expenses	39.3%	30.1%	31.4%	30.3%	32.1%

Source: CRS calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1992, 1997 and 2001. Data reported are for state fiscal years. Percentages may not sum to 100% due to rounding.

Table 7. State Spending for Medicaid as a Percent of Total State Spending, Pennsylvania and the United States, 1990-2001

State spending	Pennsylvania				All states
	1990	**1995**	**2000**	**2001**	**2001**
Total state spending (in millions)[a]	**$16,706**	**$22,026**	**$27,402**	**$28,694**	**$760,419**
State Medicaid spending (millions)[b]	$1,350	$3,586	$5,055	$5,441	$85,141
State Medicaid spending as a percent of total state spending	8.1%	16.3%	18.4%	19.0%	11.2%

Source: CRS calculations based on data from the National Association of State Budget Officers (NASBO), State Expenditure Reports for 1991, 1997 and 2001. Data reported are for state fiscal years. Percentages may not sum to 100% due to rounding.

[a.] Total state spending for all spending categories, excluding federal funds.
[b.] State spending for Medicaid, exclusive of federal funds. Includes intergovernmental transfers of $287 million in 1995; $997 million in 2001; and $1,044 million in 2001. Intergovernmental transfers were 8% of total state funding for Medicaid in 1995; 19.7% in 2000; and 19.2% in 2001. Intergovernmental transfers are transfers of funds from local government entities (counties or cities) to state government. Pennsylvania requires a 10% local match for Medicaid nursing home residents.

Medicaid Long-Term Care Spending in Pennsylvania[39]

Long-term care spending represented 47% of all federal and state Medicaid spending in Pennsylvania in FY2001,[40] declining slightly from 51% in FY1990. (**Table 8**). Institutional care dominates long-term care spending and is a significant share of all Medicaid spending. However, over the period FY1990-FY2001, institutional care spending (including care in nursing homes and ICFs/MR) decreased slightly as a share of total long-term care spending, while spending for home and community-based services increased slightly over the period. According to state officials, these trends are due to a number of factors implemented at varying times during the 1990s. These include implementation of the Provider Participation Review process for nursing homes which participate as Medicaid providers; statewide implementation of the PDA waiver for persons aged 60 and older; implementation of the state-funded Bridge Program for persons who do not meet Medicaid financial eligibility requirements; significant use of Medicaid's Section 1915(c) home and community-based waiver services for persons with mental retardation; and closure of large state institutions for persons with mental retardation and developmental disabilities.

***Medicaid long-term care financing in Pennsylvania at a glance*:**

Medicaid long-term care spending in Pennsylvania was $5.1 billion in FY2001 and represented 47% of all Medicaid spending in FY2001.

Spending for nursing homes represented more than one-third of total Medicaid spending in FY2001.

Spending rate for nursing home care outpaced the state's total Medicaid spending rate from FY1990-FY2001 (196.7% compared to 182.3%).

Spending for nursing home care increased as a share of long-term care spending from 63% to 72% from FY1990-FY2001. At the same time, spending for institutions for persons with mental retardation decreased from 29% to 9.5%.

Less than 1 of every 5 Medicaid dollars spent on long-term care is for home and community-based services. However, there has a been a slow but steady increase in spending for these services, primarily due to use of Section 1915(c) waiver services.

The prominence of long-term care spending as a share of Medicaid is chiefly attributed to spending for institutional care – nursing homes and ICFs/MR. In FY2001, 38%, or $4.2 billion, of all Medicaid spending ($10.9 billion) was for care in institutions. However, by far, *most* institutional care spending was for nursing homes – $3.7 billion, almost 34% of all Medicaid spending (**Table 9**), and 72% of all Medicaid long-term care spending (**Table 8**).

Although care in institutions still dominates Medicaid long-term care spending, it has declined as a percent of long-term care spending from FY1990 to FY2001. Institutional care represented 92.2% of total long-term care spending in FY1990,

[39] This section discusses total Medicaid spending, both federal and state.

[40] Total Medicaid spending using NASBO data differ from data shown in this table due to differences in data collection methods.

declining to 81.6% in FY2001 (**Figure 3** and **Table 8**). The decrease is attributed solely to the spending decline for ICFs/MR care. Spending for care in ICFs/MR *decreased* by almost 15% from FY1990 to FY2001 (in constant 2001 dollars), while spending for nursing homes *increased* by almost 200% (**Table 9** and **Figure 3**). Moreover, spending for nursing home care outpaced total Medicaid spending which increased by 182% (**Table 9**).

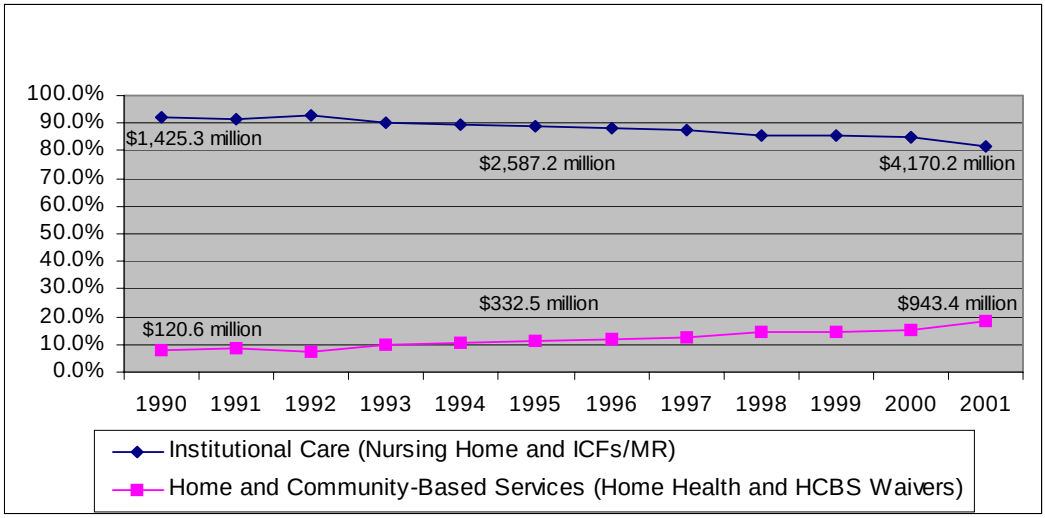
Table 8. Medicaid Long-Term Care Spending In Pennsylvania, FY1990-FY2001

	FY1990	FY1995	FY2000	FY2001
Long-term care spending as a % of Medicaid spending	51.0%	42.1%	49.1%	47.0%
Institutional care spending as % of long-term care spending	92.2%	88.6%	84.7%	81.6%
Nursing home spending as a % of long-term care spending	63.2%	71.5%	74.9%	72.0%
ICFs/MR* spending as a % of long-term care spending	29.0%	17.1%	9.8%	9.5%
Total home and community-based services spending as a % of long-term care spending	7.8%	11.4%	15.3%	18.4%
HCBS waivers spending as a % of long-term care spending	6.1%	9.0%	14.2%	17.2%

Source: CRS calculations based on CMS/HCFA 64 data provided by The Medstat Group, Inc. For 2000 and 2001, Burwell, Brian et al. *Medicaid Long-Term Care Expenditures in FY2001*, May 10, 2002. For 1995, Burwell, Brian. *Medicaid Long-Term Care Expenditures in FY2000*, May 7, 2001. For 1990, Burwell, Brian. *Medicaid Expenditures for FY1991.* Systemetrics/McGraw-Hill Healthcare Management Group, Jan. 10, 1992. (Hereafter cited as Burwell, *Medicaid Expenditures FY1991-FY2001.) 1990* total Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington, (Hereafter cited as Burwell, *Medicaid Expenditures FY1991-FY2001.* Percentages may not sum to 100% due to rounding.)

*Intermediate care facilities for the mentally retarded.

Figure 3. Institutional and Home and Community-Based Services as a Percent of Medicaid Long-Term Care Spending in Pennsylvania, 1990-2001



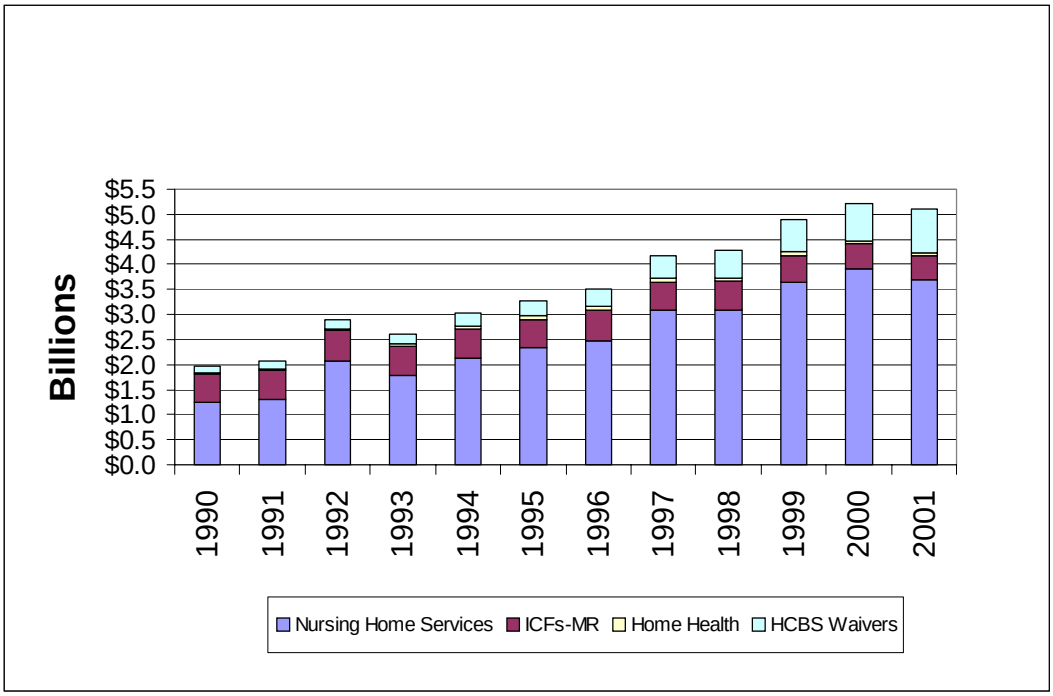
Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*, 1990 total Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington, D.C.

Table 9. Medicaid Spending in Pennsylvania, Total Spending and Long-Term Care Spending, by Category, and Percent Change, FY1990-FY2001 in Constant 2001 Dollars
(dollars in millions)

Spending category	FY1990	FY1995	FY2000	FY2001	Percent change FY1990-FY2001 (in constant 2001 dollars)
Total medicaid	$3,033.5	$6,936.9	$10,322.2	$10,886.9	182.3%
Total long term care	$1,545.9	$2,919.6	$5,073.3	$5,113.6	160.2%
Total institutional care	**$1,425.3**	**$2,587.2**	**$4,296.5**	**$4,170.2**	**130.1%**
Nursing homes	$976.6	$2,087.6	$3,799.6	$3,684.0	196.7%
ICFs/MR	$448.7	$499.6	$496.9	$486.1	-14.8%
Total home and community-based services	**$120.6**	**$332.5**	**$776.8**	**$943.4**	**515.5%**
Home health	$25.5	$69.3	$57.6	$64.7	99.4%
Personal care	$0.0	$0.0	$0.0	$0.0	0.0%
HCBS waivers	$95.0	$263.2	$719.2	$878.7	627.3%

Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*. 1990 total Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington, D.C.

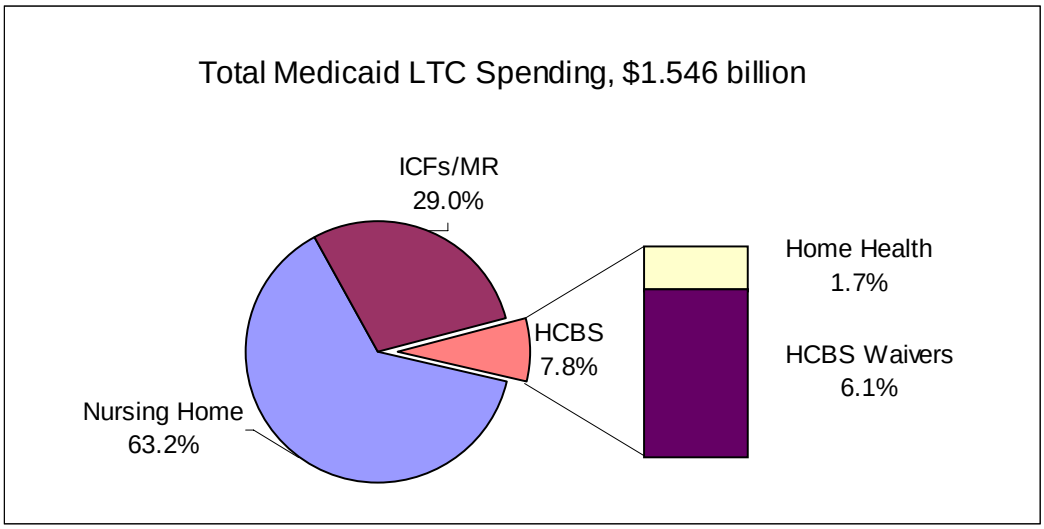
Figure 4. Medicaid Long-Term Care Spending by Category in Pennsylvania, FY1990-FY2001
(in constant 2001 dollars)



Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*, 1990 total Medicaid spending, based on HCFA 64 data provided by Urban Institute, Washington, D.C.

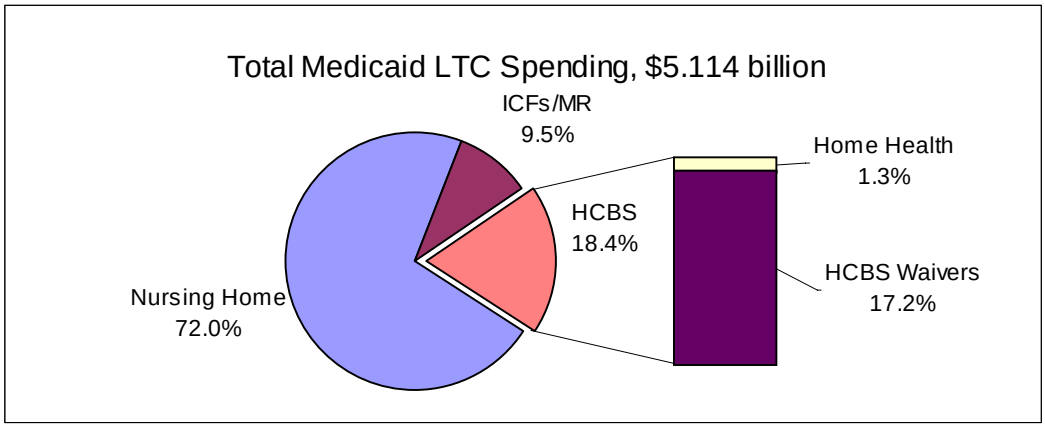
Figures 5a and **5b** depict changes in long-term care spending patterns from FY1990 to FY2001. In FY1990, 29% of Medicaid long-term care spending was devoted to care for persons with mental retardation in ICFs/MR, decreasing dramatically to 9.5% in FY2001. At the same time, nursing home spending increased from 63.2% in FY1990 to 72% in FY2001.

Figure 5a. Medicaid Long-Term Care Spending in Pennsylvania by Category, FY1990



Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*.

Figure 5b. Medicaid Long-Term Care Spending in Pennsylvania by Category, FY2001



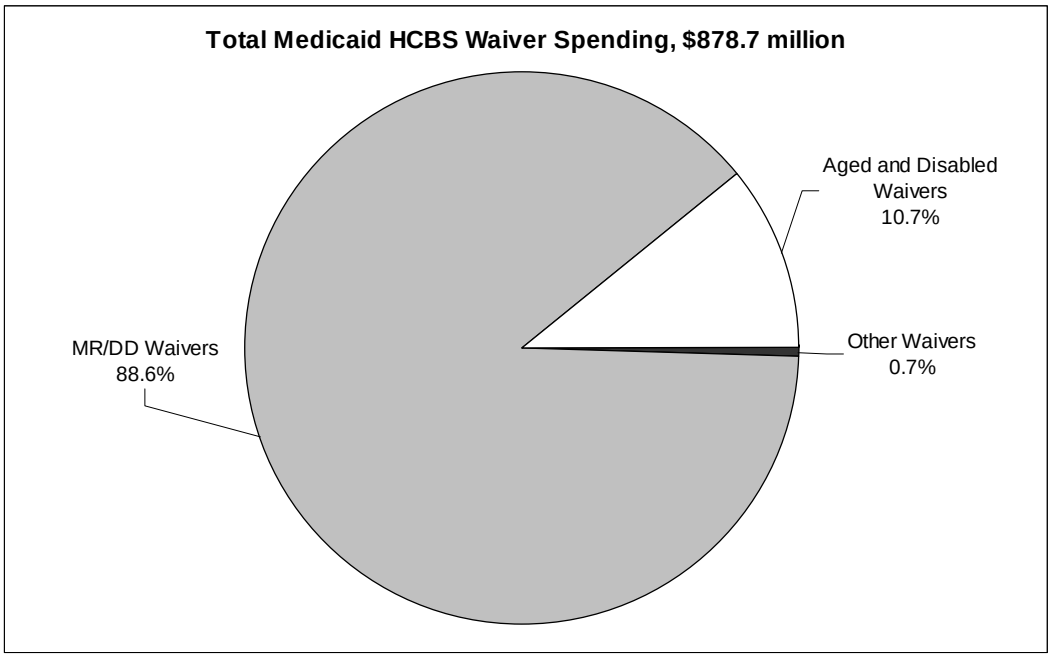
Source: CRS calculations based on Burwell, *Medicaid Expenditures FY1991-FY2001*.

Although home and community-based services represent a small portion of long-term care spending – less than 1 of every 5 dollars – the share of spending on these services has increased in a slow but steady pattern over the period. Spending on home and community-based services more than doubled as a share of long-term care spending, increasing from 7.8% in FY1990 to 18.4% in FY2001 (**Figures 5a and 5b**). This is primarily due to expansion of the various Section 1915(c) waivers for persons with disabilities in Pennsylvania. Waiver spending increased from 6.1% of long-term care spending to 17.2% in FY2001.

Increased funding for waiver services, however, does not affect all populations equally. By far the majority of Medicaid waiver spending is for persons with mental

retardation and developmental disabilities. In FY2001, 88.6% of waiver spending was for these persons, with less than 12% devoted to spending on the elderly and other disability groups (**Figure 6**).

Figure 6. Medicaid Home and Community-Based Services Waiver Spending by Target Population in Pennsylvania, FY2001



Source: CRS calculations based on *Medicaid HCBS Waiver Expenditures, FY1995 throughFY2001* by Steve Eiken and Brian Burwell, The Medstat Group, Inc., May 13, 2002.

State Spending on Home and Community-Based Services for the Elderly

Medicaid funding represents only part of total funding for home and community-based services – Pennsylvania devotes significant funding from state sources. A long-standing source of support for services to persons aged 60 and older is the Pennsylvania Lottery. The Lottery was established by the General Assembly in 1971 with the primary purpose of generating funds to benefit older residents. It is the only state lottery in the nation that dedicates all of its proceeds to programs for older persons. Since 1972, it has contributed more than $12 billion to a number of programs, including pharmaceutical benefits, home and community-based services, tax rebate programs, transportation, and a variety of services supported by the 52 area agencies on aging.[41] Another significant source of support for home and community-base services used by Pennsylvania is the state's share of the tobacco settlement

[41] Pennsylvania Department of Aging, *Benefits and Rights for Older Pennsylvanians,*Dec. 2001.

funds.[42] While a large portion of both lottery and tobacco settlement funds is devoted to the state's pharmaceutical benefit program for the elderly, these sources also play a significant role in funding home and community-based services.

The following table shows the Pennsylvania Department of Aging's budget for FY2001-2002 by source. State lottery and tobacco settlement funds are almost 80% of the total budget, with almost 30% of the total budgeted for home and community-based services. Federal funds (primarily Older Americans Act funds) represent only about 14% of the total budget. The total shown does not include funding for the Medicaid Section 1915(c) waiver services for the elderly, which in FY2001 amounted to over $260 million (these funds do not appear as part of the budget for the Department of Aging, but rather are in the Department of Public Welfare).

Table 10. Pennsylvania Department of Aging (PDA) Budget, FY2001-FY2002, by Source of Funds

Source and use of funds	Amount (in millions)	Percent
Total PDA budget, FY2001-FY2002	**$775.8**	**100.0**
Lottery, total	**$562.1**	**72.5**
Home and community-based services administered by PDA*	203.1	26.2
Pharmaceutical program	359.0	46.3
Tobacco settlement, total	**56.9**	**7.3**
Home and community-base services administered by PDA	29.2	3.8
Pharmaceutical program	27.6	3.6
Federal funds**	**109.0**	**14.1**
Other	**47.8**	**6.2**

Source: *Pennsylvania Department of Aging, Budgeted Fiscal Years, 2001/2002 and 2002/2003,* unpublished document.

*Does not include funding for Medicaid Section 1915(c) waiver funds for the elderly which is included in the budget for the Department of Public Welfare.
**Includes Older Americans Act, and Medicaid funds for case management services.

[42] For information on the tobacco settlement agreement, see CRS Report RL30058, *Tobacco Master Settlement Agreement (1998): Overview, Implementation by States, and Congressional Issues*, by Stephen Redhead.

Medicaid and State Spending on Services for Persons with Mental Retardation and Developmental Disabilities

Federal and state spending for persons with mental retardation and developmental disabilities was almost $1.6 billion in 2000 (**Table 11**). This represented more than a 50% increase (in constant 2000 dollars) since 1990. Of total 2000 spending, a significant share – 52% – was contributed by state sources.

As discussed earlier, Pennsylvania has devoted considerable efforts to increasing services in home and community-based settings to persons with mental retardation. In 2000, almost three quarters of total spending was for home and community-based services – $1.1 billion. Federal funding under the Medicaid Section 1915(c) waiver program is an important component of spending for these services, representing 34.3%.

Of total institutional and home and community-based services spending in 2000, 22.4% was from federal waiver funds in 2000. This spending increased by almost 418% (in constant 2000 dollars) since 1990. The state has used the waiver to dramatically increase federal Medicaid reimbursement for home and community-based services, while at the same time it has decreased federal spending for institutional services in constant dollars. Federal spending for institutional services in Pennsylvania decreased by over 18% from 1990 to 2000 (in constant 2000 dollars).

Table 11. Federal and State Spending for Institutional and Community Services for Persons with Mental Retardation/Development Disabilities in Pennsylvania, 1990 and 2000

	1990	2000	Percent of FY2000 total	Percent change in constant 2000 dollars
Services	**$ 837.4**	**$ 1,586.3**	**100%**	**52.6%**
Congregate/institutional services	**398.0**	**442.7**	**27.9%**	**-10.4%**
Federal funds	220.0	223.2	14.1%	**-18.2%**
State funds	178.0	219.5	13.8%	-0.7%
Home and community-based services	**439.3**	**1,143.6**	**72.1%**	**109.7%**
Federal funds	107.6	544.0	34.3%	307.3%
ICFs/MR funds*	(21.8)	(47.8)	3.0%	76.8%
HCBS waiver**	(55.3)	(355.5)	22.4%	417.9%
Title XX/SSBG funds***	(18.0)	(16.2)	1.0%	-27.6%
Other	(12.5)	(124.5)	7.8%	699.9%
State funds	331.7	599.6	37.8%	45.7%

Source: CRS calculations based on data presented in *The State of the States in Developmental Disabilities*, by David Braddock et al., 1998. American Association on Mental Retardation, Washington, p. 404 (for 1990 data). Unpublished data furnished by Richard Hemp, University of Colorado (for 2000 data).

*Intermediate care facilities for the mentally retarded. These funds are used for community services.
**Home and community-based waiver (Section 1915(c)) of the Medicaid statute.
***Social Services Block Grant (Title XX of the Social Security Act).

Selected Issues in Financing and Delivery of Long-Term Care Services in Pennsylvania

Pennsylvania officials and stakeholders have identified issues that pervade the state's long-term care system in a series of reports over the years. Prominent among these is a report issued by a working group of the Pennsylvania Intra-Governmental Council on Long Term Care in March 2002.[43] The following discussion highlights selected issues identified in that report and other state reports, as well as issues that surfaced in CRS interviews with state officials, providers, and consumers.

Institutional Bias. A recurring theme in discussions of long-term care with state officials is their view that the federal financing system guarantees heavy use of institutional care. This is largely due to the fact that nursing facility care is an entitlement under Medicaid for persons needing such care and who meet its eligibility criteria. Financing of institutional care is a federal mandate; home and community-based care is not. Although states may choose to provide home and community-based services under various Medicaid options, state officials indicate that state funding constraints and the provider system that was created as a result of the institutional entitlement make it difficult to reorient the system. Pennsylvania officials indicated that they want to move to a policy of expanding home and community-based services, and that consumers should be given clear choices regarding their options, with adequate supports to stay at home and in the community.

Officials noted that while the rhetoric regarding changing the institutional bias has intensified over the years, actually accomplishing this objective is difficult and moving slowly. The impetus for heavy reliance on institutional care is built into the incentive structure for providers resulting in funding disparities between institutional care and home and community-based care. State officials and stakeholders indicated that the institutional bias has created a provider culture that is counter to the desires of the population needing long-term care services. This is exemplified in a number of ways. Incentives in the service system are built around referral to nursing homes. For example, hospital personnel are more likely to discharge persons needing long-term care services to nursing facilities, rather than to home and community-based settings which are seen by discharge planners as riskier choices for some people. State officials noted that the risks of referring clients to nursing homes are somewhat easier to manage given the 24-hour care provided. Home and community-based providers have to take on greater risk because of complexities of planning for 24 – hour care. Because home care options often do not involve a single service, they are seen by many as more complicated than simply a referral to a nursing home unless there are sufficient informal care providers to assist.

Once a person is referred and served in a nursing home, the likelihood of staying in the institutional setting increases as more time is spent there. State officials indicated that most persons become eligible for Medicaid within 6 months to a year

[43] Pennsylvania Intra-Governmental Council on Long Term Care, Home and Community-Based Services Barriers Elimination Work Group, Mar. 2002.

after entering a nursing home. And, once a person has resided in a nursing home for 2 or 3 months, it is difficult to discharge the person to community care. Clearly, some people need care that can only be provided in an institution, for example, those persons who have multiple, complex needs, weak or non-existent informal supports, and who lack appropriate housing arrangements. The challenge to the long-term care system is to respond with services that are appropriate to needs, and that would use institutional care appropriately until a person can safely be cared for at home, and to arrange a package of home and community-based services that will prevent the person from entering or reentering an institution.

State officials state that the institutional bias is built into the federal requirements for eligibility for the Section 1915(c) home and community-based wavier program – that is, persons are only eligible for the waiver services if they meet institutional functional eligibility criteria. State officials representing non-elderly persons with disabilities indicated that using the "nursing home eligible" criteria perpetuates a medical/institutional model of care, not appropriate for younger persons who will need support throughout their lifetimes.

According to state officials, one method to ameliorate the institutional bias is to control or downsize institutional capacity. The primary method used by Pennsylvania to control institutional capacity is through approval of Medicaid beds through the PRP process (described earlier) and through limitation on reimbursements. This has had some impact on the supply of beds. Controlling the supply of state institutions for the mentally retarded differs somewhat from that for nursing homes. As pointed out earlier, the state has closed a number of care facilities for persons with mental retardation in the past several decades, and could do so because these facilities were operated by state government. Virtually all nursing homes in the state are either privately owned (75% are for-profit and 25% are non-profit)[44] and therefore controlling or downsizing institutional capacity is not as direct as in the case of state-operated facilities.

State officials indicated that the system should be changed so that nursing homes are an exception rather than the rule. Home and community-based care should be considered first, and then, if services are judged to be inappropriate or unavailable, the alternative would be an institutional placement. In addition, state officials note the need to have in place methods to divert people from nursing homes who would be in danger of spending down their income and assets to establish Medicaid eligibility.

Categorical Approach to Home and Community-Based Services. State officials indicated that while the waiver programs have expanded opportunities for many people with disabilities to receive services they would not have absent the waiver, the waivers have created another set of categorical requirements. Pennsylvania has eleven waivers in all, each targeting certain groups with certain types of disabilities. In addition, there are six other state-funded programs for which consumers might qualify. Each program is identified as a discrete, distinct program resulting in a silo approach to service provision. The procedures of locating the

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[44] American Health Care Association, *Nursing Facility Sourcebook*, p. 134.

appropriate waiver or other service program and the administering agency, and trying to fit needs into the prescribed waiver requirements, can be burdensome on clients as well as providers.

Service packages, eligibility requirements, and financial caps on amounts of services vary among the programs. In addition, for the federal waiver programs, a person does not become eligible until his or her condition has deteriorated to the "level of care" provided by an institution. Some people may not meet the narrow categories of eligibility on the basis of disability that define eligibility for waivers.

State officials and stakeholders recommended that services should be promoted without identifying different waiver programs that cover different services for different populations. In addition, they recommended that there be more comparability across waivers in order to prevent a silo approach and that the scope and eligibility for waivers should be expanded.

Medicaid Eligibility Requirements and Access to Services. A number of issues identified by state officials relate to Medicaid eligibility for home and community-based services.

Medicaid Eligibility Income and Resource Limits. Persons needing long-term care services paid for by Medicaid must have countable income and resource limits established by the state within federal requirements. States may allow persons with income up to 300% of the federal SSI level to become eligible for Section 1915(c) home and community-based waiver services (in 2003, $1,656/month for an individual); this is the level used by Pennsylvania for the waiver programs. In addition, people may qualify if their assets do not exceed $2,000 for an individual and $3,000 for a couple.[45] While these requirements limit the number of people who may become eligible for Medicaid, they also act as a barrier to many persons in need of long-term care who live at home. For example, state officials indicated that people in need of home and community-based care who live in their own homes do not feel comfortable depleting almost all of their liquid assets that may be needed for household expenses and emergencies. (Medicaid law allows states to use more liberal standards under Section 1902(r)(2) of the Social Security Act; however, few states have employed this option. States may permit persons with higher income and resources to qualify for Medicaid, but this would expand eligibility groups and therefore Medicaid costs.)

Pennsylvania, through its state-funded *Bridge* and *Options Programs*, has addressed some of these Medicaid financial eligibility issues. These programs may serve as models for other states that have the financial capacity to expand the pool of eligibles. They may also serve as examples for any federal initiatives that may be proposed to expand eligibility. (More liberal income and resources levels are used under another federal Medicaid option for the "working disabled," established by the Ticket to Work and Work Incentives Act of 1999, P.L. 106-170. Under that option,

[45] Certain items are excluded, such as an individual's home; up to $2,000 of household goods and personal effects; life insurance policies with a face value of $1,500 or less; an automobile with value up to $4,500; and burial funds up to $1,500, among other things.

states may choose to apply more liberal income and resources standards for persons with disabilities who are working. Medicaid coverage is used as an incentive to retain these persons in the workforce. Under the law, these persons may "buy-into" Medicaid through various forms of cost-sharing and premiums based on income.)[46]

The *Options Program* allows people with income up to 300% of the *federal poverty level* (up to $2,245/month for an individual in 2003) to become eligible for state-funded home and community-based services, with cost-sharing applied on a sliding fee-scale basis. There is no resource test to qualify. On the other hand, the *Bridge Program* allows people with resources up to $40,000 to access state-funded home and community-based services. Cost sharing of 50% toward the cost of services is applied for a period of up to 12 months until a person spends down resources to the Medicaid eligibility level of $2,000. This allows people needing long-term care to receive services, and gradually become eligible for Medicaid, rather than having to wait to receive services until all countable resources are depleted to the $2,000 level.

Length of time to process Medicaid financial and functional eligibility for home and community-based services. Under federal law and regulation, the state Medicaid agency must establish time standards for determining eligibility and inform applicants what they are. States must make an eligibility determination for persons who apply for benefits on the basis of disability within 90 days of the date of application. State officials estimate that it can take from 3 to 4 months or more from the point of identification of the need for home and community-based services to the point of actually receiving Medicaid services. Home and community-based providers must rely on county assistance offices to determine financial eligibility on behalf of clients they wish to serve, and providers cannot take the risk of serving persons without eligibility verification. In contrast, officials pointed out that when a referral for nursing homes is made, nursing homes can often assume the risk that the person will become eligible for Medicaid, and spend down within a predictable period of time, usually 6 months to a year. In addition, nursing homes usually have the administrative staff to assist applicants with the process of completing financial eligibility forms for Medicaid expeditiously.

One of the ways to address the risk faced by home and community-based providers would be to allow providers to make prospective clients *provisionally* eligible for waiver services. However, the Medicaid statute does not provide for presumptive eligibility for home and community-based services. In recognition of these issues, the Center for Medicare and Medicaid Services (CMS) has been cooperating with several states to establish a programmatic equivalent of presumptive eligibility for Section 1915(c) waiver services. A few states have implemented a system whereby providers may establish a preliminary plan of care for persons who meet the functional eligibility criteria, provide some services under the plan of care

[46] For further information, see CRS Report RL31157, *Ticket to Work and Work Incentives Improvement Act of 1999*, by Jennifer Hess, et. al.,

using funds other than Medicaid, and then certify the person for Medicaid wavier services once financial eligibility is established.[47]

Equity of Home and Community-Based Service Access Across Populations in Need of Care. Issues of equity of access to Section 1915(c) waiver services cross a number of dimensions. In Pennsylvania, the number of approved slots for persons with mental retardation and developmental disabilities exceed those for persons with other disabilities. Of the total number of approved slots in the state for FY1998-FY1999 – 17,208, about 63% were for persons with mental retardation, with the balance for other persons with disabilities.[48] Moreover, there are waiting lists for the waiver services for both persons with mental retardation and the elderly. State officials and stakeholders have indicated that needs assessments should be conducted to achieve more proportional and geographic equity across populations.[49]

Another dimension of equity relates to comparability of service packages within waivers and application of different cost caps for different waivers. Some waivers are capped at 80% of the cost of nursing home care[50] while others are capped at 100%. While states have the discretion to decide where to place the cap for each service, this does lead to differences in service levels across populations. In addition, some cost caps are applied to each individual, and some are applied on an aggregate basis across the state which allows persons with high cost needs to be served. Of the 10 waivers discussed in this report, seven are applied on an aggregate basis and three are applied on an individual basis. In this regard, advocates in Pennsylvania are requesting that the state shift from individual cost caps to aggregate cost caps for all waivers.[51] The state is investigating this option.

State officials and stakeholders have recommended that the waiver programs should be evaluated to determine if service packages should be made more uniform throughout the state, to eliminate gaps in services for different eligibility groups.[52]

Waiting Lists for Home and Community-based Care for Persons with Mental Retardation and Developmental Disabilities. Waiting lists for services for persons with mental retardation and developmental disabilities have drawn attention across many states, including Pennsylvania. Despite the sizable amount of funding devoted to services for persons with mental retardation in Pennsylvania, waiting lists for services have been a persistent problem. A 1997 survey by Temple University revealed that over 14,000 persons were on waiting lists for services. Of those, 74% needed services in more than 1 year, 23% needed

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[47] Personal communication with CMS staff, Oct. 24, 2002.

[48] *Home and Community-based Services Barriers Elimination Work Group,* p. 25 (see footnote 46 of that document).

[49] *Home and Community-based Services Barriers Elimination Work Group*, p. 25.

[50] This applies to the PDA waiver and excludes case management and administration.

[51] *Home and Community-Based Services Barriers Elimination Work Group*, p. 27.

[52] *Home and Community-Based Services Barriers Elimination Work Group*, p.p. 25-27.

services within 1 year, and less than 3% needed services on an emergency basis. The vast majority (78%) of persons on the waiting lists live in their own home or a relative's home. One of the chief factors involved in planning for persons on waiting lists is the capacity of caregivers. Many of those in critical need of services had either an aging or ill caregiver. Of all persons on the waiting list, 38% had a caregiver aged 60 and over.

Former Governor Tom Ridge requested that a plan be developed to address the waiting list issue. A Planning Advisory Group to the Office of Mental Retardation recommended a series of steps to be taken by the state to reduce waiting lists and expand community-based services. (*A Long-Term plan to Address the Waiting List for Mental Retardation Services in Pennsylvania*, October 1999.)

Long-Term Care Staffing. Across the country, states are faced with the challenge of finding sufficient numbers of qualified staff for long-term care. This is a system-wide problem. The Pennsylvania Intra-Governmental Council on Long-Term Care commissioned a study to examine the issues affecting the long-term care workforce and to make recommendations to improve the current staffing shortages. In Pennsylvania, nearly 70% of the state's long-term care providers reported significant problems with the recruitment or retention of frontline workers, and 35% of providers reported that the worker shortage was extreme.

Finding direct care workers (defined as home health aides, nurse aides, personal attendants and personal care aides) has become increasingly difficult in Pennsylvania. A survey of the state's 3,400 providers revealed that in the fall of 2000 an estimated 94,150 persons were employed in frontline positions; for this same time period an additional 11,300 positions went unfilled. The report indicated that nursing homes accounted for 46% of the positions and 53% of the openings; larger personal care homes accounted for 23% of the positions and 16% of the openings. Home health and home care agencies represented 20% of the positions and 23% of the openings.[53]

From interviews with front-line workers across the state, the study was able to identify some of the industry's major problems in the recruitment and retention of qualified staff. Most often mentioned were inadequate compensation (the average hourly wage of a frontline worker was $7.29 in 2001), a lack of benefits, and a lack of respect for the contribution that frontline workers make to long-term care. In addition, the focus groups identified transportation issues for home health workers, high patient-to-staff ratios, and the demanding nature of the work (both physically and emotionally) as challenges to attracting new workers and retaining current workers.

The study made a variety of recommendations to the state and the long-term care industry to help address the workforce shortage, including most importantly improvements in pay scales and benefits. The study also made a number of

[53] Pennsylvania Intra-Governmental Council on Long-Term Care, Pennsylvania's Frontline Workers in Long-Term Care, Report to the Pennsylvania Intra-Governmental Council on Long-Term Care, Feb. 2001.

recommendations intended to professionalize the field and improve recruitment strategies.

Nursing home and home care agencies compete for the same staff, and these providers compete for any new funding that might be available for long-term care. State officials indicate that when new funding is available for long-term care, nursing home lobbyists make the case that they need the money to improve quality of care. State officials urged that if the federal government is serious about promoting home and community-based care, then more incentives should be given to states to support this care.

Fragmentation of Responsibility for Long- Term Care. Many states confront issues of fragmentation of responsibilities for administration of long-term care programs. There is general recognition among state officials and stakeholders across many states that coordination of long-term care services is difficult to achieve. This is due to many factors, including:

- The long-term care system spans many services and benefits – skilled nursing facilities, housing, a wide range of home care and community-based services, cash payments, adaptive technology and rehabilitation, among others. Generally, no single agency or department in state governments is responsible for this wide array of services and benefits.
- Eligibility for public long-term care is premised on both financial and functional requirements, which in many cases are handled by separate entities.
- Requirements for enforcement of quality of care and payment to providers is the responsibility of separate entities in many cases.

In Pennsylvania, three distinct state departments are responsible for various components of the long-term care system – the Department of Public Welfare, the Department of Aging, and the Department of Health (see **Figure 2**). Responsibility for management, reimbursement policy, coordination of services, administration of facility-based and home and community-based care, and quality of care are spread among these departments. In addition, fragmentation is present on the sub-state level. County-based agencies that are operated by the state are responsible for financial eligibility for nursing home and home and community-based services, while area agencies on aging that are locally administered are responsible for functional eligibility determinations for the elderly and disabled under contract with the state. Administrative fragmentation and difficulties in coordination of services have been documented in various reviews conducted by the state.[54]

The state has separated responsibility for payment of providers from responsibility for oversight on quality of care, recognizing that there might be conflicts of interest in having the payor agency also be an enforcer of quality standards. In addition, responsibility for oversight of quality of care for various

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[54] Pennsylvania Intra-Governmental Council on Long-Term Care, *Long-Term Care for the 21st Century: A Time for Change*, Sept. 9, 1996, p. 22.

services within the long-term care system resides in different agencies. For example, responsibility for licensure of personal care homes resides with the Department of Public Welfare while oversight of quality of care in nursing homes resides with the Department of Health.

While there is no right or wrong way to organize the various responsibilities, issues of coordination continue to be problematic for Pennsylvania according to state officials. The state has taken steps to resolve some of these issues. The Intra-governmental Council of Long-Term Care was established to address issues around policy coordination among the various departments and through the long-term care system. In addition, some service coordination problems around managing services for clients have been addressed by moving toward a single point of entry for functional eligibility determination through area agencies on aging. These agencies perform functional eligibility determination for both the elderly and younger persons with disabilities for nursing facilities as well as for home and community-based care.

Appendix 1. Major Home and Community-Based Long-Term Care Programs for the Elderly and Persons with Disabilities in Pennsylvania

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
PDA Waiver (1915(c)) **Statewide** **Initiated statewide in 1999**	Persons aged 60 and over	Nursing facility (NF) level of care	Area agencies on aging under contract with DPW	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Assessment; case management; attendant care; companion; counseling; environmental modifications; extended physical services; home-delivered meals; home health; home support; adult day care services; personal care; personal emergency response system; respite care; specialized medical equipment and supplies; and transportation	9,309 persons served in State Fiscal Year (SFY)2001-2002 10,049 slots approved in SFY 2002-2003	$35,000 individual cost cap (equivalent to 80% of the nursing facility rate; excludes cost of administration and case management). Average cost in SFY2001-2002, $8,136 per person	PDA/DPW	OMA/DPW

NF – nursing facility
OIM – Office of Income Maintenance
OMR – Office of Mental Retardation
PDA – Pennsylvania Department of Aging
OMA – Office of Medical Assistance
SSI – Supplemental Security Income
DPW – Department of Public Welfare
OSP – Office of Social Programs

[a] "Aggregate Cost Cap" refers to costs spread across all persons receiving services under the waiver. "Individual Cost Cap" refers to costs per each person receiving services under the waiver.

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Independence Waiver (1915(c) **Statewide** **Initiated in 1997**	Persons age 18 and over with physical disabilities	Persons with substantial functional limitations in at least three of the following areas: self-care; understanding and use of language; learning self-direction; capacity for independent living; and mobility	Area agencies on aging under contract with DPW	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Service coordination; assistance with daily living activities ($13.64 to $18.38 per hour); respite care ($13.64 to $18.38 per hour); up to $10,000 in environmental accessibility adaptions; up to $10,000 in specialized medical equipment per consumer per lifetime; PERS; physical, occupational and speech therapies; visiting nurse; community integration (up to $50/hour); educational services up to $120/day; transportation generally up to $215/month	452 persons served as of 12/02 402 slots as of 12/02 Waiver amendment to increase slots is in process as of December 2002.	$42,116 aggregate cost cap in SFY2001-2002	DPW/OSP	DPW/OIM

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OIM – Office of Income Maintenance
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PDA – Pennsylvania Department of Aging
OMA – Office of Medical Assistance
SSI – Supplemental Security Income
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OSP – Office of Social Programs

[a] "Aggregate Cost Cap" refers to costs spread across all persons receiving services under the waiver. "Individual Cost Cap" refers to costs per each person receiving services under the waiver.

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Michael Dallas Waiver (1915(c)) **Statewide** **Initiated in 1987 for children; expanded to all ages in 2001**	Technology dependent persons of all ages	Must be dependent on a technologic device to replace a vital body function or sustain life; must have exhausted private insurance coverage	Physician certification	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Private duty nursing; case management; attendant care; respite care; durable medical equipment; and nutritional supplements	57 served/136 slots in SFY2001-2002	$236,000 aggregate cost cap Annual cost ranges from $180,000 to $200,000 per person. Cost cap is based on state rate for Special Rehabilitation Facilities (SRFs).	DPW/OIM	DPW/OIM

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Elwyn Waiver (1915(c)) **Delaware County only**	Persons aged 40 and over who are deaf, blind, or deaf/blind who live in Delaware County	Must be NF eligible and reside in Valley View Assisted Living facility	Area agencies on aging under contract with Dept of Public Welfare	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	Dept of Public Welfare/ Office of Income Maintenance/ County assistance offices	Personal care; counseling; home health; therapeutic social and recreation services; special medical equipment and supplies; and transportation	39 persons/45 slots in SFY2001-2002	$23,000 individual cost cap	DPW/OIM	DPW/OIM

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DPW – Department of Public Welfare
OSP – Office of Social Programs

[a] "Aggregate Cost Cap" refers to costs spread across all persons receiving services under the waiver. "Individual Cost Cap" refers to costs per each person receiving services under the waiver.

Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
AIDS waiver (1915(c)) **Statewide** **Initiated in 1990**	Persons aged 21-64 with symptomatic HIV and AIDS	May not be enrolled in HMOs or HI Organizations or hospice care	Physician	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Skilled nursing; home health aide; homemaker; supplies and nutritional supplements not covered by Medicaid; nutritional consultations by registered dietitians	78 persons served/ 250 slots in SFY2001-2002	$14,000 individual cost cap. Cost of care may not exceed comparable group in hospital or nursing facility.	DPW/OIM	DPW/OIM

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource Limits	Determined by					
Commcare Waiver (1915(c)) **Statewide** **Initiated in 2002**	Persons aged 21 and older with traumatic brain injury (TBI)	Persons with TBI who require Special Rehabilitative Facility (SRF) level of care. Disability must result in substantial functional limitation in three or more of major life activities: mobility, behavior, communication, self-care self-direction, capacity for independent living and cognitive capacity	Area agencies on aging under contract with Dept of Public Welfare. Other contractors determine need for SRF care.	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Service coordination; personal care; respite care prevocational; supported employment; habilitation; education (including community college, university, tutoring); environmental adaptions ($20,00 lifetime limit); non-medical transportation; spec. medical equipment ($10,000 lifetime limit); chore; PERS; physical, occupation, speech therapies; part-time nursing; coaching; night supervision; day programs	Three persons served as of 12/02 98 slots SFY2002-2003	$146,740 aggregate cost cap	DPW/OIM	DPW/OIM

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OSP – Office of Social Programs

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Attendant Care Waiver (1915(c)) **Statewide** **Initiated as a waiver in 1994**	Persons aged 18-59 who meet NF level of care	Must be capable of selecting and supervising attendants and managing their financial and legal affairs	Area agencies on aging under contract with DPW	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Basic care services such as assisting the consumer in and out of bed, wheelchair, and/or motor vehicle; and assistance with routine bodily functions such as bathing, grooming, and eating.	1,804 served/2,396 slots in SFY2002-2003	$38,059 aggregate cost cap	DPW/OSP	DPW/OIM

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Consolidated Waiver for Persons with Mental Retardation (1915(c)) **Statewide** **Initiated in 1996**	Persons with mental retardation age 3 and over	Persons who have significant sub-average intellectual functioning; who have significant limitations in maturation, learning, personal independence; who have substantial functional limitations in three or more areas of major life activities, including self-care, mobility, and receptive and expressive activities; and who experienced onset of these conditions before the age of 22. Also can include persons with autism who meet the prescribed criteria.	County Mental Health/ Mental Retardation offices	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Respite care; habilitation (including residential; day; preocational; supported employment; education); environmental accessibility adaptions; transportation; chore; private duty nursing; specialized therapies; and permanency planning for children and youth	13,614 persons served in SFY2001-2002 16,491 slots for SFY2002-2003	$52,143 aggregate cost cap for SFY2002-2003	DPW/ OMR	DPW/OIM

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Person/ Family Directed Waiver (1915(c)) **Statewide** **Initiated in 1999**	Persons with mental retardation age 3 and over	Persons with significant sub-average intellectual functioning; who have significant limitations in maturation, learning, personal independence; who have substantial functional limitations in three of more areas of major life activities, including self-care, mobility, and receptive and expressive activities; and who has experienced onset of these conditions before the age of 22. Also can include persons with autism who meet the prescribed criteria.	County Mental Health/ Mental Retardation offices	300% of the federal SSI level ($1,635 in 2002)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Homemaker/chore; respite care; habilitation (residential, day, prevocational; supported employment); environmental accessibility adaptions; transportation; physical, occupational therapy; speech, hearing, and language services; visual/mobility, behavior therapy; visiting nurse; adaptive appliances and equipment; and personal support	6,218 persons served in SFY 2001-2002 7,361 slots for SFY2002-2003	$21,225 individual cost cap for SFY2002-2003	DPW/ OMR	DPW/ OMA

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OSP – Office of Social Programs

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
OBRA Waiver **1915(c)** **Statewide** **Initiated in 1991**	Persons who have severe chronic disabilities	Disabilities attributable to cerebral palsy, epilepsy or other conditions found to be closely related to MR, but excluding MR or major mental disorders. Condition was manifested prior to age 22 and is likely to continue indefinitely and results in substantial functional limitations in at least three major life activities (self-care; understanding/ use of language; learning; mobility; self-direction and capacity for independent living.)	Agencies under contract with DPW/OSP	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Service coordination; assistance with ADLs; respite care; environmental adaptations assistive technology/special-ized medical equipment; PERS; physical, occupational, speech, hearing and language and behavioral therapies; adult day care; prevocational education; supported employment; community integration; transportation	377 persons served as of 12/01 356 slots as of 12/02 Waiver amendment to increase slots is in process.	$129,949 aggregate cost cap	DPW/OSP	DPW/OIM

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PDA – Pennsylvania Department of Aging
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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Long Term Care Capitated Assistance program **Program of all Inclusive Care for the Elderly (PACE)** **Four sites covering portions of Philadelphia and Allegheny counties. One PACE program (receiving Medicare and Medicaid capitation payments) and three pre-PACE programs (receiving Medicaid capitation only)** **One site with permanent provider status Jan. 2002.**	Persons aged 60 and older	NF level of care	Multidisciplinary staff at four sites	300% of the federal SSI level ($1,656 in 2003)/ $2,000 for an individual	DPW/OIM/ County assistance offices	Comprehensive medical and long-term care services provided chiefly in adult day care setting. Includes primary medical and nursing, physical, speech, occupational therapies; in-home support; hospice; personal care; outpatient MH/MR services; drugs; meals at day health center and home.	2002: LIFE-Pittsburgh- 87 enrolled/250 slots approved LIFE-Philadelphia- 97 enrolled/250 slots approved LIFE-Univ. of PA. School of Nursing, Philadelphia– 143 enrolled/250 slots approved Community LIFE-McKeesport – 107 enrolled/250 slots approved	Medicare capitated rate based on monthly capitated amounts adjusted for a frailty factor (2002 $1,876.56). Medicaid rates negotiated with Dept of Public Welfare.	CMS and PA DPW	CMS and PA DPW

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Administrative oversight	Financial oversight
		Criteria	Determined by	Income/ Resource Limits	Determined by					
Bridge program (state financed) **Initiated in 2002** **Statewide**	Same as PDA waiver	Same as PDA waiver	Same as PDA waiver	*Income:* same as PDA waiver. *Resources:* up to $40,000. Cost-sharing fee of 50% applied to services for a period up to 12 months until person spends down assets to $2,000. No cost-sharing for assessment, counseling, case management, and protective services.	Same as PDA waiver	Same as PDA waiver	200 as of April 2002	Same as PDA waiver	Same as PDA waiver	Same as PDA waiver

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Options program (state financed) **Statewide** **Initiated in the 1970s; cost sharing initiated in 2002.**	Same as PDA waiver. Also includes certain services for persons aged 18-59.	Same as PDA waiver	Same as PDA waiver	Cost sharing based on income. Income up to 125% of FPL, no cost sharing. Income up to 300% of FPL, cost-sharing on a sliding fee scale basis. Cost-sharing does not apply to assessment, case management, home-delivered meals and Family Caregiver Support program. Resource test: none, though persons who spend down may retain income up to 125% of FPL and $10,000 in assets.	Same as PDA waiver	Same as PDA waiver. Also includes needs assessment and case management for persons aged 18-59 applying for nursing facility care; mandatory assessment for persons applying for Medicaid nursing facility care, and for SSI-eligible persons, assessment for placement in a domiciliary or personal care home	91,000 persons served in SFY2001-2002	$625 per month individual cost cap	Same as PDA waiver	Same as PDA waiver

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Program	Target group	Functional eligibility		Financial eligibility		Services	No. of persons enrolled/slots approved	Annual cost cap (aggregate/ individual)[a]	Admin. oversight	Financial oversight
		Criteria	Determined by	Income/ resource limits	Determined by					
Family Caregiver Support program (state and Older American Act funds) **Statewide** **Initiated in 1987; became statewide in 1991**	Frail and disabled persons aged 60 and older	Care receiver 60 years and older must have an informal primary caregiver who is providing majority of care.	Area agencies on aging	Cost-sharing based on sliding scale; reimbursement for expenses based on care receiver total household income. No cost-sharing for assessment, case management, benefits counseling, and education and training of caregivers. Persons with income below 200% of FPL, no cost-sharing. Persons between 200%-380% of poverty, receive services on a sliding fee scale basis. Persons with income above 380% of FPL, receive no cash reimbursement.	PDA	Assessment; counseling; respite education; one-time grants up to $2000 for home modification, assistive devises. Persons who meet income requirements may be eligible for subsidies from $200-$500/month in services or supplies.	10,000 persons receive services per year	Not applicable	PDA	PDA

Source: Prepared by CRS based on *Pennsylvania's Guide to Medicaid-Funded Home and Community-Based Services*, and data provided by Pennsylvania Department on Aging and the Pennsylvania Department of Public Welfare.

NF – nursing facility
OIM – Office of Income Maintenance
OMR – Office of Mental Retardation
PDA – Pennsylvania Department of Aging
OMA – Office of Medical Assistance
SSI – Supplemental Security Income
DPW – Department of Public Welfare
OSP – Office of Social Programs

[a] "Aggregate Cost Cap" refers to costs spread across all persons receiving services under the waiver. "Individual Cost Cap" refers to costs per each person receiving services under the waiver.

Appendix 2. Population in Large State Facilities

Table A-1. Population in Large State Facilities for Persons with Mental Retardation/Developmental Disabilities, Closure Date, and Per Diem Expenditures

Large state MR/DD facilities or units	Year facility opened	Year closed	Residents with MR/DD on 6/30/01	Average per diem expenditures FY01 ($)
Altoona center (Altoona)	1982	--	112	287.67
Cresson center (Cresson)	1964	1982	--	--
Embreeville center (Coatesville)	1972	1997	--	--
Ebensburg center (Ebensburg)	1957	--	320	395.00
Hamburg center (Hamburg)	1960	--	203	398.00
Laurelton center (Laurelton)	1920	1998	--	--
Marcy center (Pittsburgh)	1975	1982	--	--
Pennhurst center (Pennhurst)	1908	1988	--	--
Polk center (Polk)	1897		453	400.00
Allentown mental retardation unit (Allentown)	1974	1988	--	--
Retardation Unit (Clarks Summit)	1974	1992	--	--
Harrisburg mental retardation unit (Harrisburg)	1972	1982	--	--
Hollidaysburg mental retardation center (Hollidaysburg)	1974	1976	--	--
Mayview mental retardation unit (Mayview)	1974	2001	--	--
Philadelphia mental retardation unit (Philadelphia)	1983	1989	--	--

Large state MR/DD facilities or units	Year facility opened	Year closed	Residents with MR/DD on 6/30/01	Average per diem expenditures FY01 ($)
Somerset mental retardation unit (Somerset)	1974	1996	--	--
Selinsgrove center (Selinsgrove)	1929	--	477	363.00
Torrance mental retardation unit (Torrance)	1974	1998	--	--
Warren mental retardation unit (Warren)	1975	1976	--	--
Wernersville mental retardation unit (Wernersville)	1974	1987	--	--
Western center (Cannonsburg)	1962	2000	--	--
White Haven center (White Haven)	1956	--	245	380.00
Woodhaven center (Philadelphia)[55]	1974	1985	--	--

Source: *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001,* Research and Training Center on Community Living, Institute on Community Integration/UCEED, University of Minnesota (June 2002).

[55] Woodhaven (PA), although state-owned, became nonstate in 1985.

Appendix 3. About the Census Population Projections

"The projections use the cohort-component method. The cohort-component method requires separate assumptions for each component of population change: births, deaths, internal migration (Internal migration refers to State-to-State migration, domestic migration, or interstate migration), and international migration ... The projection's starting date is July 1, 1994. The national population total is consistent with the middle series of the Census Bureau's national population projections for the years 1996 to 2025." Source: Paul R.,Campbell, 1996, *Population Projections for States by Age, Sex, Race, and Hispanic Origin: 1995 to 2025*, U.S. Bureau of the Census, Population Division, PPL-47. For detailed explanation of the methodology, see same: available at [http://www.census.gov/population/www/projections/ppl47.html].

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