

Rebalancing Long-Term Care Systems in Pennsylvania

Long Version Report prepared by the Rebalancing Research Group

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The overall project was conducted through a Task Order under a CMS Master Contract between CMS and the CNA Corporation, Arlington, VA, and subcontracts and consultant agreements between CNAC and the various researchers. The 3-year study called for case studies of the experience of 8 states—other states in the study are: Arkansas, Florida, New Mexico, Pennsylvania, Texas, Vermont, and Washington. The baseline case study covers a period through July 31, 2005. An abbreviated version of this case study is also available at

http://www.hpm.umn.edu/lcresourcecenter/research/rebalancing/attachments/baseline_state_case_studies/Pennsylvania_abbreviated_baseline_case_study.pdf

The statements and opinions in the report are those of the writers and do not necessarily reflect the views of CMS or any of its staff, or the State liaisons to the project, or any other state staff or persons who spoke to us from participating states. We thank the Pennsylvania liaison to the study, Dale Laninga, Director, Long-Term Care Reform Project, Governor's Office of Health Care Reform.

Rebalancing Long-Term Care Systems in Pennsylvania

Preface.....	iii
Summary of Highlights.....	1
Section 1: Context for Rebalancing.....	4
Demographics and Economics.....	4
Geography.....	6
Rebalancing Status in Brief.....	8
Aging and Disability.....	8
Mental Retardation/Developmental Disability.....	9
Political Climate.....	9
Vision and Values for LTC.....	10
Leadership.....	13
State Government Organization for LTC.....	15
Organization of Long-Term Care at Local Levels.....	16
Advocacy Environment.....	20
Litigation Related to Rebalancing.....	22
Service Provider Environment.....	24
Institutional and Community-Based Residential Providers.....	24
Home-Based Service Providers.....	27
Issues in Service Environment.....	28
Historical Evolution of LTC.....	29
Programs and Services.....	32
Seniors and Adults with Physical Disabilities.....	32
PDA waiver.....	32
OPTIONS and Bridge Program.....	32
Attendant care waiver.....	33
The Attendant Care Services Act (Act 150).....	34
Independence waiver.....	34
COMMCARE waiver.....	34
Michael Dallas waiver.....	35
AIDS waiver.....	35
Elywn waiver.....	35
Developmental Disability.....	36
OBRA waiver.....	36
Infants, Toddlers and Families waiver.....	36
Consolidated waiver.....	36
Person/Family Directed Support waiver.....	36
Section II. System Assessment.....	39
Access to Services.....	39
Array of Services.....	39
Quality Initiatives.....	40
Consumer Direction.....	41
Institutional Downsizing.....	42
Data Capacity.....	43
Mental Health Linkages.....	43

Acute Care Linkages.....	44
Section III: Featured Management Approaches	46
Governor’s Office of Health Care Reform	46
Community Choices.....	48
Nursing Home Transition Program.....	51
Institutional Downsizing.....	54
Housing Initiatives	56
Workforce Initiative.....	57
Department of Aging Level of Care Integrity Project	58
Section IV. Quantitative Markers of Rebalancing.....	58
Markers of Change in Nursing Home Residents	58
Methods.....	59
Results.....	60
Conclusion	66

List of Tables

Table 1. Demographic Features Linked to LTC Needs in Pennsylvania.....	5
Table 2: Economic Characteristics in Pennsylvania and the United States.....	6
Table 3. Supply of Residential Services in Pennsylvania, 2000-2004	25
Table 4. Selected LTC Milestones in the State of Pennsylvania	31
Table 5. Summary of home and community based service programs	37
Table 6. Summary of services by waiver.....	38
Table 7: Characteristics of Admittees to Nursing Homes in Pennsylvania, 2002-2004.....	62
Table 8: Pennsylvania NH Residents 3 Months Post-Admission, 2002-2004.....	63

List of Figures

Figure 1. Pennsylvania County Map.....	7
Figure 2. Overview of Pennsylvania Cabinet Structure Related to Long-Term Care, as of July 2005.....	16
Figure 3. Organization of Pennsylvania Department on Aging.....	17
Figure 4. Organization of the Department of Public Welfare.....	18
Figure 5. Waiver, Options, and Bridge Programs of the Department of Aging	33
Figure 6. Clients Served in Selected Programs in Pennsylvania, 2000 to 2004.	64
Figure 7. Expenditures for Selected Programs in Pennsylvania, 2000-2004.....	65
Figure 8. Costs Per Consumer Served in Selected Programs, 2000-2004.	66

Preface

The baseline case studies performed for this project were prepared in two forms: an abbreviated case study of approximately 15 pages, and a much longer report, of which this is an example.

Each longer report is organized in 4 sections: context; system assessment; management features, and quantitative markers of rebalancing. The first 2 sections use uniform headings for all reports. The Context section includes: demographics and economics, geography, rebalancing status in brief, political climate, vision and values for LTC, leadership, state government organization for LTC, local organization for LTC, litigation related to re-balancing, advocacy environment, service environment, and a historical and descriptive review of programs and Services. Maps, organizational charts, and statistical background tables are provided beyond the material in the abbreviated reports. The System Assessment categories found in most long reports are: access to services, array of services, consumer direction, quality initiatives, institutional downsizing, data capacity, links to acute care, and links to housing. The illustrative management approaches in Section III are presented in considerable detail. Section IV presents data on supply of services and quantitative comparisons of utilization and expenditures in home-and-community based long-term supports versus institutional long-term support services from 2000 to 2004.

In these baseline reports, we endeavored to trace the evolution of long-term supportive services in the State back to their post-Medicaid and post-Medicare beginnings, with particular emphasis on developments

Rebalancing Long-Term Care Systems in Pennsylvania

Summary of Highlights

Government leaders in Pennsylvania have made “long term living” (the preferred term the State has recently begun using for the range of long-term care) a high priority since the inauguration of Governor Rendell in 2003. In his first Executive Order after taking office, Governor Rendell established the Office of Health Care Reform (OHCR), whose director is part of the Cabinet.¹ The OHCR Director, in turn, organized the new Office with parallel tracks for acute health care and long-term living, the latter co-chaired by two individuals with a long history of leadership in Pennsylvania long-term care. By choice, the OHCR Director declined a major budget line and direct staff, preferring to avoid creating a new bureaucracy and to draw upon staff of operational agencies as needed. By dint of its mandate and structure, the OHCR is empowered to direct health care reform including facilitating analysis of administrative, fiscal and regulatory policies and practices; over-seeing redesign of operations and structures; and directing the creation and maintenance of a system for accountability of agencies designated in the system. The OHCR Director chairs a high-level Governor’s Health Care Reform Cabinet, also created by the Executive Order.

The OHCR, thus, has the lead in reforming a diffuse long term support program spread across multiple provider agencies, multiple state departments, and 11 home and community based services (HCBS) waiver programs in the context of reforming overall health care. Prior to the formation of the OHCR, the main intradepartmental organization for long-term care was the Intra-Governmental Council on Long Term Care, established in 1986 and chaired by the

¹ Commonwealth of Pennsylvania, Governor’s Office Executive Order, Number 2003-1, Subject Commonwealth’s Health Care Reform Agenda, , January 21, 2003. Last visited 12/6/2005 on Website at: www.state.pa.us/papower/lib/papower/exeorder2003-1.org.pdf

Secretary of Aging. This Council conducted a number of seminal studies through the late 1980s and 1990s. It became inactive when its staff director moved from the Department of Aging to become the full-time co-director of the long-term living efforts at the OHCR, but has recently become re-activated under a new director. The creation of the OHCR and its prioritizing of long term living built on the earlier work of the Council, but raised the visibility of the topic and the prominence of the change agency.

With OHCR leadership, multiple initiatives for reform in long term living have been initiated. All told, Pennsylvania was the successful recipient of \$4, 539, 201 in 6 separate Real Choice Systems Change grants between 2002 and 2004, all of which have been designed to develop components of Pennsylvania's system of services. These include a Systems Change Grant, a Money Follows the Person grant, Housing with Services Grant, a Quality Improvement Grant, a Mental Health Systems Transformation Grant, and an Aging and Disability Resource Center Grant. In 2004, the OHCR also received a grant to establish Cash and Counseling benefit for selected waivers.

The Community Choice initiative, profiled in Section III, describes the OHCRs efforts to been put in place to establish building blocks for progress in developing building streamline Medicaid financial and functional eligibility requirements in one geographic region, a strategy that will be expanded elsewhere in the state. Other efforts, some also discussed in Section III, are being considered to reduce the supply of nursing homes, reduce fragmentation in the system, promote housing alternatives, develop capitated programs for dually eligible and low income individuals based on the national PACE program, improve labor force recruitment and retention, and develop a unified data system that could be used for monitoring what is currently widely agreed to be an overly complex system. At the time of our case study, the State of Pennsylvania

had contracted with the MedStat group to help state officials examine ways to rationalize the waiver process.²

Pennsylvania has a long history of providing HCBS, and pioneered in developing case management capacity for seniors, attendant programs for younger people with disabilities, and other program initiatives. These efforts preceded the availability of federal funding with the formation of a network of aging services, built around Area Agencies on Aging, funded through state funds and Older American's Act funds. Later, Pennsylvania used earmarked lottery revenues for aging services. The state came relatively late to its rapidly proliferating HCBS waiver programs, having already built a service structure. Yet, Pennsylvania's efforts to rebalance its efforts towards community care, which began consciously in the 1990s and accelerated in the 21st century, show rather modest results in terms of shifting the balance of utilization and expenditures. The percentage of Medicaid spending (HCBS) for older adults and adults with physical disabilities has increased from 2% of the total in 2000 to 6.8% in 2004 and from 57% to 66.5% for people with mental retardation. When state funding is added, the 2004 HCBS expenditures for seniors and physical disabilities rise to 11.5% of the total of public funds. These shifts in the right direction occurred in the face of difficult budget and revenue pressures. Because of current initiatives and focus, Pennsylvania may well be poised for major shifts in its care and service system, which we will track through this research project in the next two years.³

² The authors are indebted to Brian Burwell and Steve Eiken of The MedStat Group for their insights. It is noteworthy that apart from performing contractual work in Pennsylvania, MedStat is also using Pennsylvania to develop under CMS contract an illustrative approach to providing a comprehensive view of the system of long-term care and services in a given state. Pennsylvania was selected as an example in part because of its complexity.

³ Note: The team site-visiting Pennsylvania on July 25-27, 2005 included Robert Mollica from the National Academy for State Health Policy, Robert Kane from University of Minnesota, and Charley Reed from Seattle, Washington. This report is based on information gathered before, during, and after the site visit. In the baseline case study, we created a historical record and context for a period up to July 31, 2005, with the intent of up-dating

Section 1: Context for Rebalancing

Demographics and Economics

Pennsylvania was home to 12.3 million people in 2000, the 6th most populous state in the nation. It ranked third in population of people age 65 and older, exceeded only by Florida and West Virginia. The Census Bureau estimated that in 2004, Pennsylvania would have 1.76 million people over age 65, or 14.6% of the state population. Moreover, the proportion of the population over age 85 in Pennsylvania, at 1.8% is tied with Florida, Iowa, and West Virginia to lead the nation. People age 65 are expected to account for 22.6% in 2030. By then, the group over 85 will account 3.3% of the population. A little more than 15% of the population belongs to a racial minority group.

Demographic data suggest that demand for long term care services among elders is high. The state ranks 36th in the number of people age 65 and older who have incomes below the federal poverty level. Fifty six percent of the people over age 85 live alone. Eight percent of people age 65 and older have self-care limitations, 17.9% have mobility limitations and 9.1% have cognitive or mental limitations.⁴

An estimated 1,786,000 Pennsylvanians (15.9% of the population over age 5) have a disability and 302,000 of this group have difficulty performing self-care activities such as bathing, dressing or eating. (See Table 1).

the case study twice, as of July 31, 2006 and July 31, 2007. We thank our Pennsylvania study liaison, Dale Laninga, Co-Director, Long Term Care Reform Project, Governor's Office of Health Care Reform, and the many individuals in the public and private sector who provided us with insights for the report. The conclusions drawn are those of the authors and do not necessarily reflect any officials in Pennsylvania or at CMS.

⁴ Mary Jo Gibson, Steven R. Gregory, Ari N.Houser and Wendy Fox-Grage. Across the States: Profiles of Long Term Care. Sixth Edition. AARP. Washington, DC. 2004

Table 1. Demographic Features Linked to LTC Needs in Pennsylvania

Population Characteristic	Pennsylvania	United States
Total Population, 2004	12,406,292	293,655,404
Persons Age 65+, 2004	14.7%	12.1%
Persons Age 85+, 2004	1.8%	1.3%
Population Non-White,, 2003	15.2%	24.4%
Urbanicity, 2003 (population in MSA). ^a	84.8%	81.7%
Community Population age 5-20 with disability, 2004 ^a	7.2%	6.6%
Community Population, age 21-64 with a disability, 2004. ^a	12.4%	12.0%
Community Population 65+ with a disability, 2004 ^a	37.8%	39.9%
Percent non-elderly persons with a disability, 2003 ^a	11.1%	10.9%
Men per 100 woman over age 85, 2002 ^b	46.5	47.9
Percent persons over 65 with Self-Care Difficulty, 2002 ^b	8.1%	9.2%
Percent persons over age 85 living alone, 2002 ^b	56.2%	50.2%
Percent persons with disability living alone	33.9%	31.4%

Notes:

^a These statistics come from the US Census Bureau, American Community Survey, which excludes people living institutions—e.g. nursing homes. A broad definition of disability is used, i.e., persons who report a disability in employment, mobility, and/or personal care. <http://www.census.gov/acs/www/Products/Ramlomg/index.htm>.

^b More detailed analyses regarding older people are found in Gibson, et al, Reference 2. We also utilized statistics available on the Website of UC San Francisco’s Center for Personal Assistant Services, <http://www.pascenter.org/home/index.php>

Pennsylvania is slightly below average on some socioeconomic criteria, and slightly above on others. The median family household income in the state was \$42,941 in 2004 and the mean personal income \$23,511, both slightly below the national average,⁵ and per capita state income taxes are very slightly above average. The percentage of people living in poverty is less than the national average, as is the unemployment rate, and the percentage of people without health insurance.⁶

⁵ The Rockefeller Institute of Government in Albany, NY generates reports on state and local revenues and expenditures, most of which are on its website at: <http://rfs.rockinst.org/>. Also state summaries can be found on Websites maintained by the Bureau of Economic Analysis, US Department of Commerce, including: <http://www.bea.doc.gov/bea/regional/bearfacts/statebf.cfm>. Both last visited November 1, 2005.

⁶ Mills, R J & Bhandari, S (2003). Health Insurance Coverage in the United States, 2002. (Economics and Statistics Administration, U.S. Census Bureau, Current Population Reports, P60-22, pp. 1-23.. Washington, D.C. Department of Commerce. Website at: <http://www.census.gov/prod/2003pubs/p60-223.pdf> Last visited October 11, 2005.

Table 2: Economic Characteristics in Pennsylvania and the United States

Economic Characteristic	Pennsylvania	United States
State Taxes Per Capita in 2002 ¹	\$2,043	\$2,024.85
Median household income, 2004	\$42,941	\$44,684
Mean personal income per capita (2004)	\$23,511	\$24,020
Percent of Population in Poverty (average 2002-2004)	11.7%	13.1%
Percent Population Unemployed in Labor Force, 2003	4.6%	5.0 %
Persons without health insurance (3 year average, 2001-2003)	10.7%	15.1%
Households with cash public assistance, 2004.	2.6%	2.4%
Medicaid participation as % of population, 2003	14%	18%
Community dwelling persons age 65 in poverty, 2004.	8.1%	9.4%
Community dwelling persons age 5-17 with disability in poverty, 2004.	28.5%	27.0%
Community dwelling persons age 18-64 with disability in poverty, 2004	25.3%	24.5%
Community dwelling persons age 65 + with disability in poverty, 2005	12.6%	13.1%
Community dwelling persons age 5 to 17 with disability to 200% of poverty	57.4%	51.1%
Community dwelling persons age 18-64 with disability up to 200% of poverty	48.0%	46.9%
Community dwelling persons 65+ with disability up to 200% of poverty	45.2%	43%
Community dwelling persons 5-17 with disability up to 300% of poverty	74.3%	68.1%
Community dwelling persons age 18-64 with disability up to 300% of poverty	64.2%	63.5%
Community dwelling persons age 65 + with disability up to 300% of poverty	68.1%	63.4%

Sources: See Reference 3 and 4, respectively, for state and local tax data and health insurance coverage data respectively. The numerator for the Medicaid coverage rate per 1000 population includes all state population and came from a special study funded by the Kaiser Family Foundation in 2003,⁷ whereas the denominator from the American Population Survey includes only the community dwelling population. The cross-tabulations of disability status, age group, and poverty were performed in special analyses of the American Community Survey, US Census data by H. Stephen Kaye, PhD, Institute of Health and Aging, University of California at San Francisco. CMS

Geography

With an area of approximately 44, 817 square miles and 67 counties, Pennsylvania is the second largest state in the nation's Northeast (New York is the largest) and 33rd among all states. (Figure 1). Pennsylvania forms the geographic bridge between the Northeastern states and the Southern states and between the Atlantic seaboard and the Midwest. The Appalachian Mountains dominate much of central Pennsylvania. Major population centers include Philadelphia, the nation's 6th most populous metropolitan area and one of the largest seaports, in the state's southeast corner, and Pittsburgh in the west. Allegheny County, where Pittsburgh is located has one of the oldest populations in the country. Although containing major urban areas

⁷ Ellis, ER , Smith, VK & Rousseau, DM (2004). *Medicaid Enrollment in 50 States, June 2003 Update*. (Health Management Associates, Lansing, MI and Kaiser Commission on Medicaid and the Uninsured, prepared for Kaiser Family Foundation, October 2004). On website: <http://www.kff.org/medicaid/upload/Medicaid-Enrollment-in-50-States-June-2003-Data-Update-Report.pdf> Last visited, December 1, 2005.

and having population density of 274 per sq mile compared to 79.6 for the country as a whole, Pennsylvania also has a large rural population. Most of the 67 counties have their own Area Agency on Aging (AAA); 5 AAAs serve 2-county areas, 3 serve 3-county-areas, and serves a 4-county area. The Planning and Service Areas with 3 or more counties are in the southwest part of the state largely bordering West Virginia and the northeast and north central part of the state bordering New York. The county map that comprises Figure 1 is reconfigured slightly to depict how other public services (such as Offices of Mental retardation or Independent Living Centers) or voluntary organizations (e.g. the Arc of Pennsylvania) are organized with the county always serving as the dominant building block.

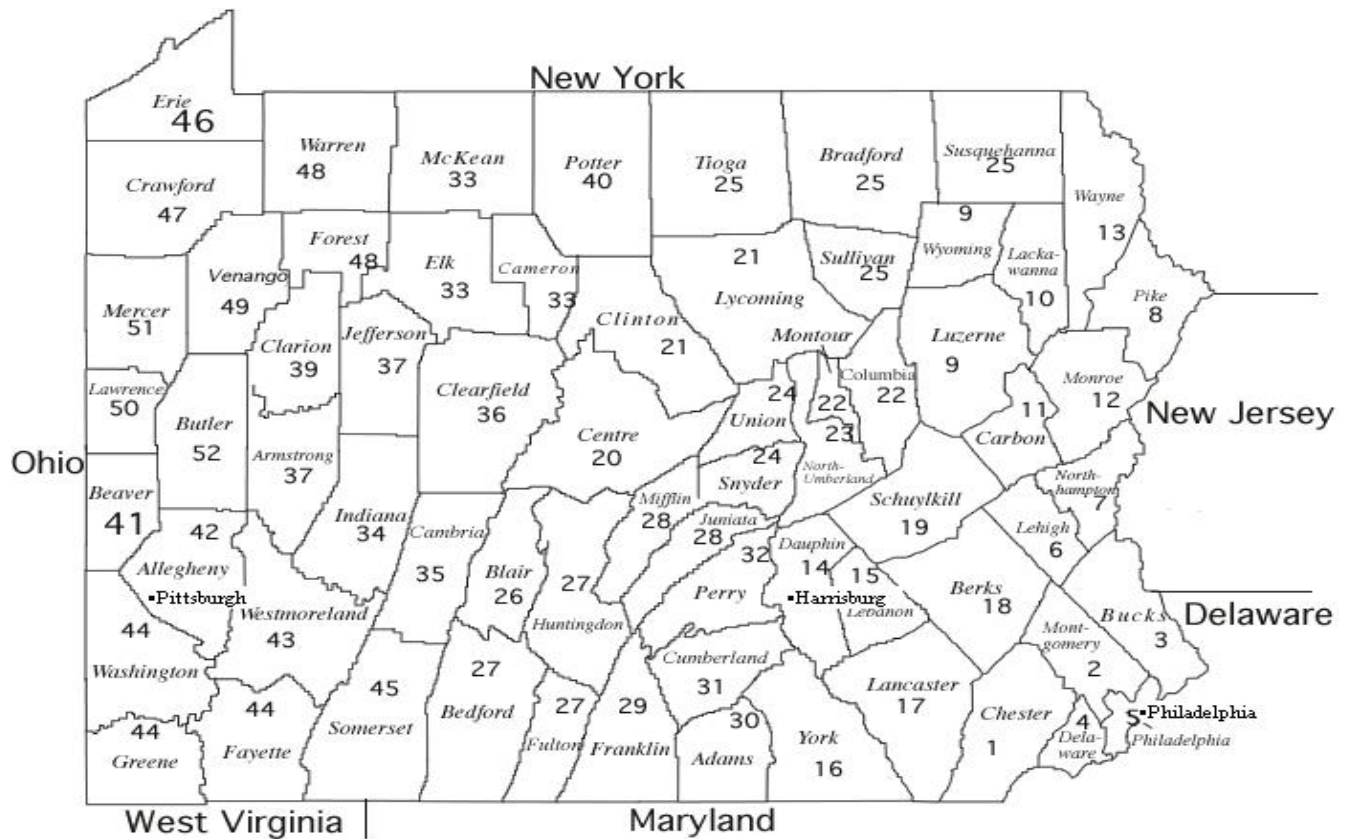


Figure 1. Pennsylvania County Map.

Note: The numbers in the counties indicate an Area Agency on Aging, most of which are comprised of a single county. For example, the 3 northern counties labeled 25 comprise a single AAA.

Rebalancing Status in Brief

Aging and Disability

According to data annually assembled by the MedStat Group, 22.3% of Medicaid long term care funds were spent on HCBS community based services in fiscal year 2004 compared to 15% in FY 2000.⁸ In Pennsylvania, the percentage of Medicaid funds spent on HCBS elders and adults with physical disabilities in FY 2004 was 6.8%, compared to 2% in FY 2000. However, the MedStat figures do not include services financed solely with state lottery funds and state general revenues. In FY 2004, the state spent \$207.8 million for community services under the OPTIONS program and \$11.5 million in state general revenues for family caregiver support and \$5.8 million in tobacco settlement funds from the Bridge program. Including these funds raises the percent spent on community based services to 11.4%. The percentage of Medicaid expenditures for people with development disabilities devoted to community services rose from 57% in FY 2000 to nearly 66.5% in FY 2004.

In a more detailed analyses that examined markers of rebalancing in all states just for persons over age 65 that used 1996 data and included state expenditures from lottery and Older Americans Act funds, Ladd and colleagues found that Pennsylvania ranked 50th or 51 on statistical markers of commitment to HCBS utilization and commitment to HCBS expenditures, whereas the state ranked above average in controlling nursing home expenditures, an improvement in controlling nursing home expenditures since 1992.⁹ At that time 99.4% of Medicaid LTC dollars and 93.4% of all public LTC dollars for seniors went to nursing homes. The earlier report based on 1992 data showed a similar picture, ranking Pennsylvania 49th in

⁸ Brian Burwell, Kate Sredl, and Steve Eiken. Medicaid Long Term Care Expenditures in FY 2004. Thomson Medstat. May 11, 2005.

⁹ Ladd, RC, Kane, RL & Kane, RA (1999). *State LTC Profiles Report, 1996*. (Report submitted to US Office for Assistant Secretary for Planning and Evaluation, HHS, April 1999). Minneapolis, MN: National Long-Term Care Mentoring Program, School of Public Health, University of Minnesota.

commitment to HCBS expenditures.¹⁰ In sum, these various measures from 1992 to 2004 show Pennsylvania making small shifts in rebalancing towards HCBS, yet lagging behind most states in terms of utilization and expenditures on HCBS.

Mental Retardation/Developmental Disability

The Office of Mental Retardation operates separately from other long term care programs. OMR has steadily reduced the number of individuals served in institutions, from 3,500 in 20 state centers in 1987 to 1,400 people in six centers in 2005. No one has been admitted to a Center in the past two years.

Political Climate

Governor Rendell, who assumed office in 2003, has been interested in and supportive of long term living. He made long-term care issues a priority when he established the Governor's Office on Health Care Reform and charged it to work with relevant state agencies to develop cost-effective programs for both the acute and long-term care sector. A member of the Executive Committee of the National Governor's Association (NGA), Governor Rendell met with ADAPT protestors who conducted an action at the NGA meeting in the Summer of 2004, and introduced ADAPT's resolution to the floor of NGA. The current political priorities of Governor Rendell and the Pennsylvania legislature related to health care, however, are influenced by Medicaid expenditures that have exceeded budget amounts; in that regard, the Governor enunciated overall policy of cutting costs without cutting services to citizens or changing eligibility. Rather, the goal is to achieving efficiencies in Medicaid, eliminating redundancy, finding new sources of

¹⁰ Ladd, RC, Kane, RL, Kane, RA, & Nielsen, WJ (1995). State LTC Profiles Report. (Report prepared under a grant from Administration on Aging, November 1995). Minneapolis, MN: National LTC Mentoring Program, School of Public Health, University of Minnesota. Richard Browdie, then Secretary of Aging for the Commonwealth, asked for 100 copies of this report to be sent to all Pennsylvania senators with the hope that Pennsylvania elected officials would be challenged to improve Pennsylvania's near-bottom ranking on most indicators.

funds, and controlling malpractice premiums. In the current political climate, the expansion of publicly-funded HCBS would be difficult to achieve without confidence that overall costs would be stable or decrease. Going beyond health care, the overall recent political priorities in Pennsylvania and especially in the Rendell administration have been economic growth and development, full employment, a favorable business climate, and some tax relief—all highly appropriate issues for Pennsylvania at this historical juncture when population and economic growth have slowed. Indeed, building on the general concerns about economic development in Pennsylvania, the nursing home industry is amassing evidence to show the importance of nursing homes to Pennsylvania’s economy.¹¹

Vision and Values for LTC

The value of community integration and consumer choice was early built into Attendant Care Services Act of 1984 which stated that “recipients of attendant care have the right to make decisions about, direct the provision of, and control their attendant care services. This includes, but is not limited to, decisions about hiring, training, managing, paying and firing of an attendant.”¹² Fueled by various focus groups and opinion studies, in more recent years, the OHCR and other government agencies have clearly articulated that consumers, including older people, prefer care at home, have been explicit in recognizing that Pennsylvania’s system is tilted unduly towards institutions, and have called for “rebalancing,” using that specific term. In an op-ed article in the Philadelphia Inquirer, the OHCR Director and her Senior Executive Policy Analyst Associate emphasized values of choice, dignity, control, and staying at home:

¹¹ For example, see Dobson, A., DaVanzo, J, Sen, Namrata, Shive, D, & Kludzuweit, L (2005). The Economic Impact of Nursing Homes in the Commonwealth of Pennsylvania, Final Report. (Prepared for Pennsylvania Health Care by the Lewin Group, March 31, 2005). Last visited 12/6/2005 on Website: [http://www.phca.org/docs/Lewin_Vol1\(FINAL\).pdf](http://www.phca.org/docs/Lewin_Vol1(FINAL).pdf)

¹² Cited in the summary of the Pennsylvania Cash and Counseling Grant Proposal, last visited 12/06/05 on the Website at <http://www.ohcr.state.pa.us/Cash%20Counseling%20grant.doc>

If you start with the question, "What do Pennsylvanians want when it comes to long-term care?" the answers are the same from Erie to Philadelphia, from Scranton to Uniontown, and everywhere in between. People want to stay in their homes. When that is no longer feasible, they want a setting as residential as possible, where they have privacy, dignity, and a place to move around and call their own but with access to services 24 hours a day.

Take a moment and think about it, if you haven't already, and you will reach the same conclusion. You may come to a point in your life when you need help bathing. But you'd like to take that bath in your own bathroom. You might need some help with meals, but you'd like to eat in your own kitchen. You might need some help keeping track of your medications, but you'd like to take them with water from your own faucet.

That is Gov. Rendell's vision for the future of long-term care and services in Pennsylvania. Our goal is to provide services that help people stay in their homes as long as possible. That means we need to rethink the way we provide long-term care and services.¹³

In an October 2003 press release announcing two Real Choice System Change Grants, Governor Rendell is quoted making the same points as did the above-cited op ed article. The Governor then concludes with specific rebalancing language: "We are committed to an aggressive effort to rebalance our long-term care system, providing opportunities so that people of all ages and all disabilities may live independently in the community. These grants will help us achieve that goal."¹⁴ Although we did not identify any numerical specific numerical goals or timetables for rebalancing, material from the Governor's Office, the OHCR and the key state, agencies consistently evoke the vision of achieving the kind of care citizens want in their own homes and reducing reliance on institutions. The messages are being expressed not only in state documents, but in press releases, speeches, and the media.

The vision of community integration and choices is typically combined with strong statements that such strategies will result in reduced costs. Typically, the message about the

¹³Greco, R & Torregrossa, A. Needed changes in long-term care: PA is trying some out now, in Phila. and elsewhere. Philadelphia Inquirer, April 8, 2004. Also posted on OHCR Website and last visited 12/6/2005 at: <http://www.ohcr.state.pa.us/phillinquireoped.doc>

¹⁴ Found at <http://www.state.pa.us/papower/cwp/view.asp?A=11&Q=435613>, last visited 12/6/06.

value of home care is intertwined with an efficiency argument. The editorial already quoted illustrates this well in its conclusion:

In Pennsylvania, because of our reliance on nursing homes as the primary provider of long-term care and services, we spend the fourth-largest amount of any state in the country per capita on long-term care - 40 percent more than the average in states across the nation.

The Rendell administration is working with advocacy groups; agencies on aging; disability service providers; hospital discharge planners; and consumers to eliminate the barriers that keep people from receiving the long-term care and services they need at home.

Redesigning the system in this way is a double win. First, it likely will save taxpayers millions of dollars. It will give us the opportunity to redirect money to other programs providing health care. And, more important, it will allow Pennsylvanians to receive services in the setting they prefer. Overwhelmingly, that is at home.

In its State Plan on Aging for 2004-2008, developed with much input from stakeholders, the Pennsylvania Department of Aging (PDA) listed 10 priorities (each with outcome measures) as follows: 1) enhancing the role of community centers; 2) health and wellness; 3) civic engagement and volunteerism; 4) raising public awareness of age-related issues; 5) improving transportation for seniors; 6) home and community based care; 7) protecting elders from fraud and abuse; 8) improving availability of affordable housing, including for those transitioning from nursing homes; 9) mental health needs and mental retardation among seniors; and 10) cultural inclusion for the aging network.¹⁵ Although the text indicates that the ordering of priorities is unrelated to their importance, this varied list with HCBS showing as Priority Number 6 has the effect of making rebalancing efforts for seniors seem to be just one priority among many.

On the other hand, the PDA report goes on to state that “older adults overwhelmingly prefer to stay at home rather than enter a nursing home,” and that “in response to this consumer preference, the Department and sister agencies are working to ‘rebalance’ the long-term care system so that a greater amount and percentage of the Commonwealth’s long-term support

¹⁵ Pennsylvania Department of Aging (2004). State Plan on Aging, 2004-2008. Presented by Secretary, Nora Dowd Eisenhower. to

resources are focused on in-home services.” As usual, the financial connection is made: “Rebalancing benefits taxpayers as well, because in-home services can typically be provided at less than one half the cost of nursing home care (all quotes from p. 26).” The PDA plan goes on to emphasize increased waiver slots, easier access, community direction, and consistency among AAAs in implementing the PDA waiver. It also includes a rather original suggestion that “rebalancing may create a higher demand for legal services to protect older adults’ rights, redress acts of fraud and abuse, and advocate for resources to which they are entitled . . . (p. 26).” The outcome measures for Priority # 6 include the number of seniors enrolled in HCBS options, the number of consumers serviced through the PDA waiver; the number of consumers transitioned from nursing homes to HCBS options, and (in keeping with the concern for legal supports) the number of Area Agencies on Aging that provide access to legal services for older adults.

Leadership

Rosemarie Greco, the Director of the OHCR has a 30 year history of leadership in the private sector, including serving as CEO of several large banking corporations. She occupied many voluntary leadership roles in Philadelphia, where she chaired the first Women's Commission, was a member of the City Planning Commission, chaired a special task force which drew the charter for Mayor Rendell's Office for Management, Productivity and Planning, and served as a member of the Executive Committee of the founding Board of Philadelphia's Special Service District. For four years, she was a member of the Board of Education for the School District of Philadelphia. She founded and chaired the School-to-Career Leadership Council, personally recruiting and engaging Chief Executive Officer Colleagues of the City's major corporations to assume leadership responsibility for the Philadelphia School District's 19 Resource Boards. A newcomer to state government, she consciously brings skills and values from the business world

into state government and the arena of health care reform. Her two associate directors for long term living, in contrast, both have long relevant tenures in Pennsylvania government: Dale Laninga with the Department of Aging and staff director of the Intra-Governmental Task Force on Long-Term Care from its creation in 1987, and Ann Torregrossa, JD and consumer advocate who headed up the Pennsylvania Law Project's Philadelphia office, providing legal assistance on Medicaid, resident's rights, health benefits, and related issues. The leadership group at OHCR have effectively developed an agenda and the funding streams (through grants) to develop and test components of system change for long term living.

Many of the key cabinet leaders are new to state government; some were leaders in Philadelphia during the Rendell mayoralty. The Secretary of Aging, Nora Dowd Eisenhower, JD, who was, among other roles, the AARP executive director of Pennsylvania, director of a federal project to combat Medicare fraud operated by CARIE (the Philadelphia-based Center for Advocacy for the Rights and Interests of the Elderly), and a deputy attorney general in the Pennsylvania Bureau of Consumer Protection, has a strong background in prosecuting consumer fraud and advocating for consumer protection. The Secretary of Public Welfare, Estelle Richman, has a long social services career including serving as Director of Social Services for the City of Philadelphia and then, under Mayor Rendell, the managing director for city of Philadelphia, responsible for 13 city departments. The Secretary of Health, Calvin Johnson, MD is pediatrician with a public health background who, prior to his appointment, was on the faculty of Temple University. Donna Cooper, the Governor's Director of Policy, had recently headed up an advocacy organization, Good Schools Pennsylvania, and before that had been Mayor Rendell's Deputy Mayor for Planning. In general, the leadership team at the cabinet level has substantive credentials, though many of the officials are new to state government. At the sub-

cabinet level, many of the leadership group, particularly division heads in the PDA, is comprised of new hires brought in by secretaries, though long-tenured civil servants are also located in key positions in Departments of Aging, Public Welfare, and Health.

State Government Organization for LTC

Figure 2 shows how long-term care policy and program management and administration responsibilities are distributed among several state agencies, in particular the Departments of Aging, Public Welfare, and Health. The figure also shows how responsibility for various HCBS waivers is distributed across Departments, but the Waivers themselves are described in a later section.

The Department of Aging (PDA) is responsible for managing the PDA waiver (i.e. the waiver for beneficiaries age 60 and older), and two state funded programs: the Options program serves people who do not qualify for Medicaid or Medicaid and who do not meet the nursing home level of care criteria; and the Bridges Program serves beneficiaries who meet the nursing home level of care criteria but have income and resources that exceed Medicaid limits. PDA also administers all Older American's Act programs and staffs the Intra-Governmental Council for Long-Term Care (Figure 3).

The Department of Public Welfare (Figure 4) contains three divisions that operate long-term care services programs. The Office of Social Programs manages the Attendant Care Waiver and Act 150 (a state funded attendant care program), the OBRA waiver, and the COMMCARE waiver. The Office of Medical Assistance Programs (OMAP) is the state's Medicaid agency and, as such, is responsible for general oversight of all HCBS waivers, 1115 managed care waivers, and state plan services. OMAP also directly administers the AIDS waiver, the Michael Dallas waiver, and the Elwyn waiver. The Office of Mental Retardation administers the

Consolidated waiver for individuals with mental retardation, the Person/Family Directed Supported Waiver for individuals with mental retardation and a waiver for Infants, Toddlers and Families.

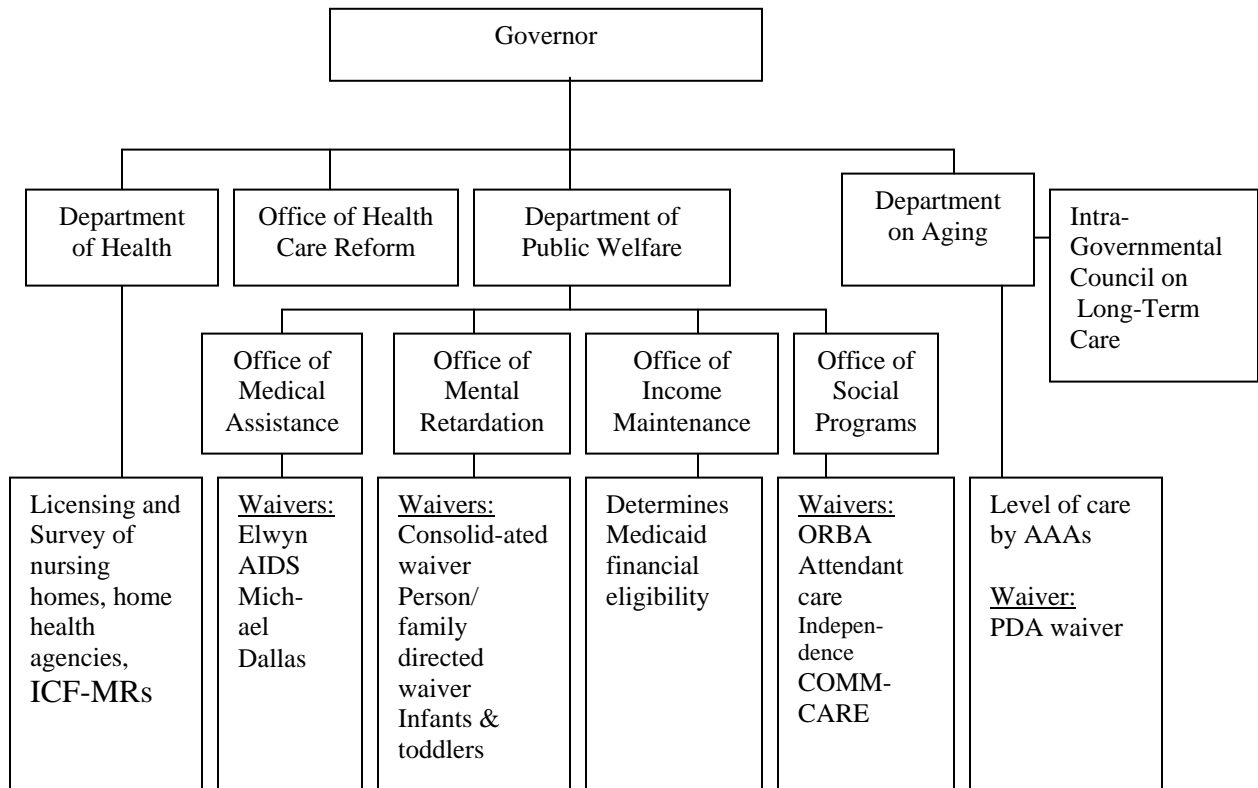


Figure 2. Overview of Pennsylvania Cabinet Structure Related to Long-Term Care, as of July 2005

Organization of Long-Term Care at Local Levels

Programs for different target or age groups are contacted through different entry points. Although the Websites for each Department are well organized to explain the offices, divisions, or programs within each department, and how to access each program, these electronic networks are easier to navigate if the user already knows the organizational structures.

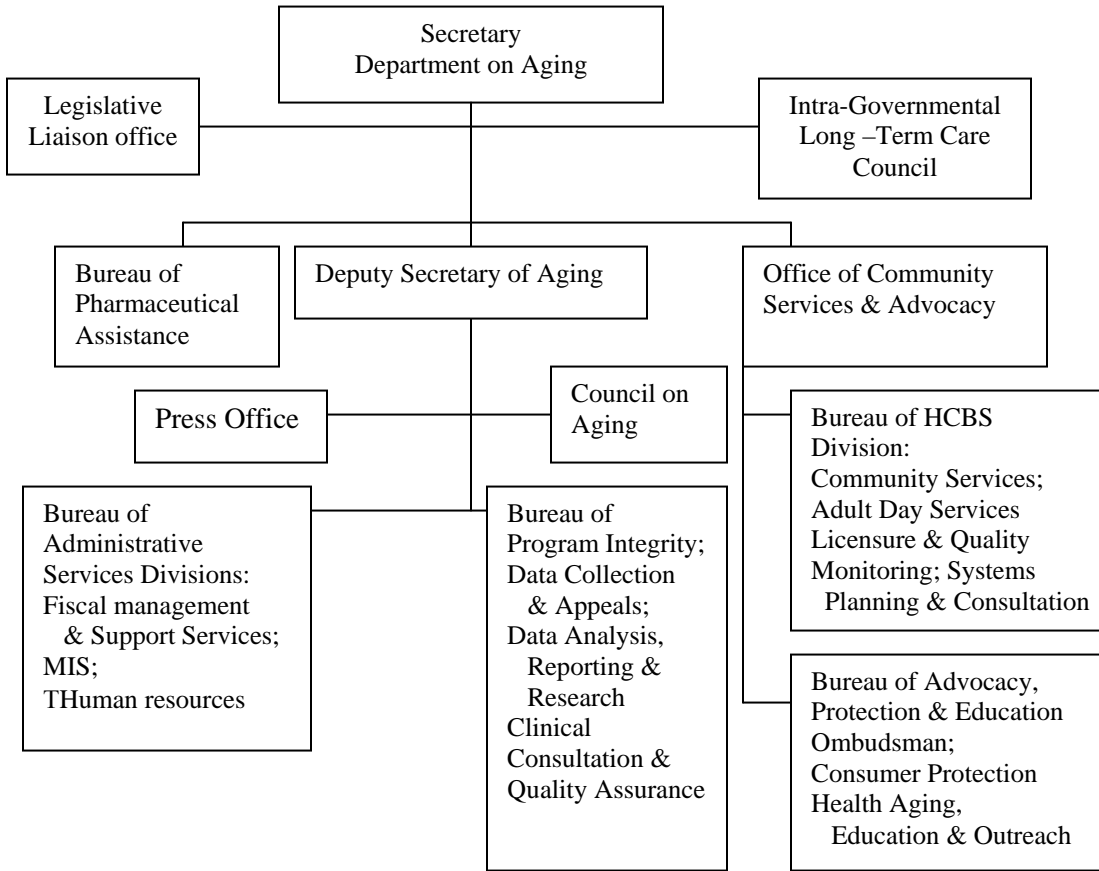


Figure 3. Organization of Pennsylvania Department on Aging

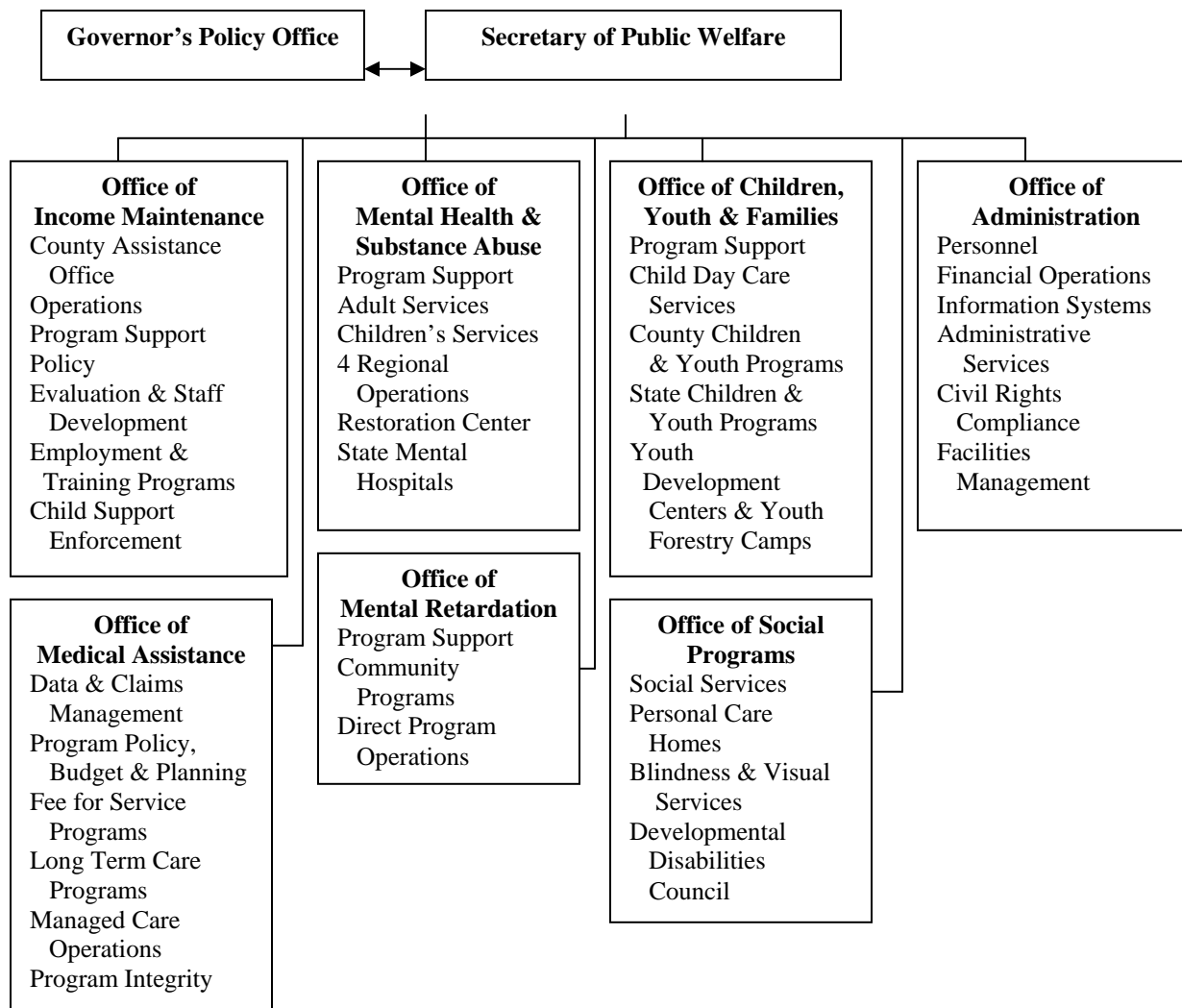


Figure 4. Organization of the Department of Public Welfare

As indicated above, the Aging programs are administered through 52 Area Agencies on Aging (AAAs), comprised of 1 to 4 counties in each planning and service area. Case management is provided through the Area Agencies on Aging, which also contract for services under the large PDA (Pennsylvania Department on Aging) waiver and manage their quality, as well as manage all Older Americans Act services. The AAAs also are involved in the development and monitoring of resources. For example, the large domiciliary care program (Pennsylvania's term for small family homes) is certified by the AAAs, and the AAAs engage in

recruiting and monitoring services. The Pennsylvania Corporation on Aging (PCA), by far the largest AAA in the state and the fourth largest in the United States, is a program of enormous magnitude. To illustrate with statistics developed by PCA in 2004, it funds almost 50 senior centers and satellite programs in Philadelphia's neighborhoods, assists about 100,000 callers a year through its hotline and Information and Referral services, provides between 8000 and 10,000 assessments annually for home care, and arranges home care for more than 12,000 persons a year through a network of more than 100 contracting service providers. More than half the consumers served are minority group members of color, and a third have income below the poverty level. PCA's budget is developed from many sources, but the primary source of funding is still the Pennsylvania lottery dollars allocated through the PCA. The PCA is in itself a repository of substantial leadership and expertise from the state, maintains a relational data base and a research capability, and has a track record of creative collaborations within the community. PCA has been successful in receiving grants and piloting new programs (often in collaboration with the State); some of its efforts are described in Section II and III.

Within the Department of Public Welfare, the Office of Mental Retardation (OMR) is accessed through 46 county OMR Offices, each comprised of one or more counties; 10 areas are comprised of 2 counties; 3 are comprised of 3 counties, and 1 of 4 counties. The multiple county jurisdictions for mental retardation are not coterminous with the multi-county Area Agency on Aging offices. Applicants for OMR services apply to county offices, each of which maintains its own waiting list. Case coordination is either provided directly by county mental retardation officials or by agencies contracting with the county. Two counties provide services directly, whereas all others contract for the services. The OMR county offices also are one front door to

mental health services, but other routes exist to access behavioral health care through managed care vendors.

In contrast, the Office of Social Programs operates the Community Services for Persons with Physical Disabilities through just two agencies, both Centers for Independent Living: Liberty Resources, Inc, based in Philadelphia and covering 20 counties including the populous area around Philadelphia; and United Disability Services, based in Lancaster, PA and covering 47 counties, including the Pittsburgh area. The state as a whole has 17 Centers for Independent living to serve Pennsylvania's 67 counties.

Establishing financial eligibility for any and all Waiver, Medicaid, and Income Maintenance programs is done through contacting County Assistance Offices. One or more such office is found in every county; Philadelphia has central and 20 district offices, and Pittsburgh has a central and 8 district offices.

Advocacy Environment

Pennsylvania has a vigorous consumer advocacy and self-advocacy network for persons with physical disabilities, and for persons with Mental Retardation and Developmental Disabilities. Pennsylvania ADAPT, for example, is particularly well-organized and visible. The Pennsylvania Statewide Independent Living Council (PASILC) with 15 members appointed by the Governor maintains a staff and a vigorous policy advocacy agenda. The Pennsylvania Developmental Disabilities Council, a Governor-appointed body, engages a larger number of advocates on its various communities. The Arc of Pennsylvania has a presence in all counties through its network of 40 affiliates.

As in most states, advocacy for seniors by seniors is less pronounced than advocacy by younger people with disabilities, but the state AARP office is a vigorous one on behalf of protection

for seniors, and CARIE (the Center for Advocacy for the Rights and Interests of the Elderly) is a nationally known advocacy organization for elder rights. (The present Secretary of Aging was Executive Director of the State AARP office.) Historically, many Area Agencies on Aging have played strong advocacy roles for seniors, a thrust that is encouraged by the elder rights and protection thrust of the present Secretary on Aging.

The Department of Public Welfare formed a new consumer group, the Stakeholder Planning Team (SPT) in 2002 to assist in developing system changes to better serve persons in need of home and community based services and supports. This team, which meets 6 times a year, consists of 25 consumers, parents, advocates, providers, and county government representatives. Members are appointed by the Secretary of Public Welfare to serve three-year terms. The Administration looks to this team for advice and help planning all DPW and Medical Assistance-funded home and community based activities. DPW identified achievements of the SPT that include:

- Assisted the Department of Public Welfare in revising and refocusing the [Real Choice Systems Change Grant](#) application that was submitted to CMS last July. The Department received the \$1.38 million award in September. The grant will be used to develop better methods to manage the overall system in support of community living, develop a system of access to HCBS services and supports for people of all ages and disabilities, and to develop expertise and capacity to effectively serve individuals across the broad spectrum of disabilities and long-term illnesses.
- Created and presented Recommendations to the Rendell Administration, a transition document on home and community based services in Pennsylvania that provides "a picture of obstacles faced, a model of what can be achieved when we work together, and a blueprint for a new way forward."

Litigation Related to Rebalancing¹⁶

Of the 8 states in the rebalancing study, Pennsylvania has the largest number of reported legal cases related to re-balancing and care in the most integrated setting. According to the UCSF National Center for Personal Assistance Services, of the 14 cases found in the state, 11 are closed, 2 are open, and the status of one is unconfirmed. In the landmark case, *Pennhurst State School v. Halderman*, which predated the recent spate of suits in the state, the plaintiff, a resident of a state institution for the mentally retarded, brought a class action suit in 1970 in federal court alleging that conditions at the facility violated various federal constitutional and statutory rights of class members as well as their rights under the Pennsylvania Mental Health and Mental Retardation Act of 1966. In 1977, the district court ruled that residents of Pennhurst had a constitutional right to receive an adequate education, training, and ongoing care in the “least restrictive setting.” The genesis of the case involved accusations that the residents were abused and neglected. The court ordered the institution closed and the residents provided with community living arrangements. The 3rd Circuit Court of Appeals affirmed, holding that, in addition to the Constitutional claim, Pennsylvania law also required the state to assure that members of the plaintiff class live in the least restrictive environment. Even though the U.S. Supreme Court reversed (451 US 1 [1981]) on the grounds that, under the 11th Amendment, a federal court lacks the power to order state officials to conform their conduct to state law, the lower court’s opinions had laid the groundwork for the deinstitutionalization movement in the

¹⁶ The cases discussed here are not necessarily inclusive of all Pennsylvania lawsuits in this arena. More details regarding these cases are at: Smith G.A. “Status Report: Litigation Concerning Home and Community Services for People with Disabilities.” Human Services Research Institute. 2005. www.hsri.org/index.asp?id=news and, Kitchener, M. Willmott, M. and Harrington, C. “Home and Community Based Services: Olmstead and Olmstead-Related Lawsuits”. UCSF National Center for Personal Assistance Services. 2005. <http://www.pascenter.org/olmstead/>

years that followed. *Pennhurst* became an important national precedent in establishing a right to community services for people with mental retardation and developmental disabilities.

In *Sabree et al. v. Richman*, a class action filed on behalf of individuals wait listed for ICF/MR services, plaintiffs argued that the state was not providing Medicaid services to eligible persons with reasonable promptness. The federal district court dismissed the suit on the grounds that Medicaid law does not confer to individuals an enforceable right to services and thus lacked standing to bring the suit. The 3rd Circuit Court of Appeals reversed, holding – in line with decisions in other circuits – that Medicaid does confer such individually enforceable rights. The plaintiffs have returned to district court with their original complaint.

Residents of Norristown State Hospital brought suit in *Frederick L. et al. v. Department of Public Welfare et al.* claiming that their continued institutionalization, despite recommendations for community placement, violated the ADA. The district court found that accelerating waiver placements would increase state expenditures and thus amount to a “fundamental alteration” of the state’s long-term care services and programs and therefore denied the complaint. The 3rd Circuit Court of Appeals disagreed, ruling that budgetary considerations alone could not support a fundamental alteration defense, and remanded the case back to the district court. In September 2004, the district court dismissed the case, finding that the state’s existing deinstitutionalizing plan and process were sufficient under the requirements of the ADA. The plaintiffs have appealed this decision.

The 3rd Circuit Court of Appeals issued a similar ruling to their *Norristown* decision in March 2005 in *Pennsylvania Protection & Advocacy v. Department of Public Welfare*. In the PPA suit, residents of a state-operated nursing facility claimed that their continued institutionalization violated the ADA. The Circuit Court vacated the lower court’s ruling in

favor of the state, holding that a “fundamental alternation” defense requires more than a claim of predicted increases in expenditures. The case is back in the district court for further proceedings.

In two suits that pre-dated the Olmstead decision (*Charles Q v. Houston* and *Kathleen S. v. Department of Public Welfare*), the courts ruled in favor of patients with mental illnesses living in Pennsylvania state hospitals who were seeking treatment in the community. In another pre-Olmstead suite, *Helen L. v. Didario*, nursing home residents who had been determined to be able to live in community settings with PAS support sought access to HCB waiver services. The 3rd Circuit Court of Appeals ruled that the state’s failure to provide services in the most integrated setting violated the ADA and that provision of such services to the plaintiffs would not amount to a fundamental alternation of the waiver program, noting that the state’s argument “that it is more convenient, either administratively or fiscally, to provide services in a segregated manner, does not constitute a valid justification for separate or different services” under Title II of the ADA.

Service Provider Environment

As befits a populous state with a history of expenditure on human service programs and aging programs, Pennsylvania has a full array of residential providers and a wide range of HCBS service providers. Through their trade associations, these providers weigh in regularly on public policy issues.

Institutional and Community-Based Residential Providers

Table 3 shows residential care capacity in Pennsylvania, including both institutions and community group residential settings. As the table shows, in 2004 Pennsylvania had 724 nursing homes serving 76, 678 residents. The capacity has declined in the last 5 years; in 2004 there were 48 nursing home beds per 1000 people over age 65. Occupancy rate has been running just

under 90%, and a bit higher than the national average. AARP reported that facility beds decreased 5.9% between 1998-2003, a decrease that is greater than the comparable national figures of 4% and 4.7% declines respectively.¹⁷

Table 3. Supply of Residential Services in Pennsylvania, 2000-2004

Settings	2000		2001		2002		2003		2004	
	Set-Tings	Beds	Set-tings	Beds	Set-tings	Beds	Set-tings	Beds	Set-tings	Beds
Nursing Homes	770	95063	754	82,086	754	93,298	740	90,815	722	89,278
Nursing Home Occupancy Rate	88.2%		87.5%		88.%		89.7%		89.5%	
Nursing Home Residents Per 1000 85+	351.1		331.8		318.4		Not available		Not Available (480 per 1000 over 65+)	
State MR/DD Institutions	8	2,974	7	2,722	7	2,548	6	2,434	6	2,203
Small ICF-MRs (<16 beds)	189	1,146	181	1,063	164	945	164	942	155	912
Large ICF-MRs (16+ beds)	24	1,879	24	1,822	22	1,709	22	1,693	20	1,674
Personal Care Homes	1,830	76,779	1,798	79,803	1,748	76,786	1,726	76,490	1,690	74,721

Notes:

- Nursing Home statistics from AARP Across the Miles reports, cited above, and the American Health Care Association, last visited on website 12/9/05; <http://ahcaweb.org/research/>
- Other statistics were provided by staff at Pennsylvania Departments of Public Welfare and Aging.
- Data on State MR/DD institutions and ICF/MRs are for state fiscal years, and data on residential settings are for calendar years. State-operated institutions for MR/DD included one mental retardation unit on the grounds of a state mental health hospital for fiscal years 2000-2002.
- Data on numbers or ICF/MRs and, State MR/DD institutions and its users are limited to those with Medicaid funding, though that count likely includes most of the supply and residents.
- Services in Personal Care Homes is not covered by Medicaid Waivers in PA, except for a demonstration in the Philadelphia area because licensure rules require that only people “who do not need nursing homes” may be in them.

The majority of nursing homes (55.1%) in Pennsylvania are nonprofit facilities (in 2003, 49.5% private nonprofit and 5.6% publicly owned, compared to 34.5% nonprofit in the United States). The publicly owned sector has downsized over the last few years, but in 2005

¹⁷ Source: Census Bureau Population Projections July 2004 and CMS nursing home supply data December 2004 compiled by the American Health Care Association.

Pennsylvania still had 36 county-owned facilities, 13 city-owned facilities, and 1 state-owned nursing homes. On other parameters, such as payor mix, proportion of chain facilities, and proportion of hospital based facilities, PA was similar to the national average.¹⁸

Regulation of institutional and group residential services is divided among Pennsylvania Agencies. The Department of Health licenses and inspects the Survey and Certification programs for nursing homes and ICF/MRs. The Department of Welfare licenses and inspects Personal Care Homes, the licensure term for a wide variety of non-health facilities, including some that market themselves as Assisted Living. Many consumers with low-incomes use SSI and state supplements for care in Personal Care Homes. Medicaid waivers do not cover such care, and by license Personal Care Homes are prohibited from serving anyone who needs nursing- home level care; the exception is a demonstration project in Philadelphia operated by PCA and a home care organization and providing assisted living services for about 250 consumers in six personal care homes.¹⁹

. Through its Area Agencies on Aging, the PDA registers domiciliary care homes, which are small family settings that originally were limited to 3 people. Domiciliary Care homes are defined as having “homelike settings,” and they still tend to be small but are now allowed to have up to 13 people. The Department has established more stringent rules for any domiciliary care homes with four or more residents. In 2005, about 4000 domiciliary homes were registered in the state. Residents need to be able to transfer out of bed independently to remain in a

¹⁸Statistics here were compiled using OSCAR data by Harrington, C, Carrillo, H, & Crawford, C (2004). Staffing, Residents, and Facility Deficiencies, 1997 Through 2003. San Francisco, CA, Department of Social and Behavioral Sciences, University of California, San Francisco. Available and last visited 12/112/2005 at:

<http://www.nccnhr.org/uploads/CHStateData04.pdf> or at <http://ahcaweb.org/research/>

¹⁹ Mollica, R & Johnson-Lamarche, H (2005). State Residential Care and Assisted Living Policy . (Submitted to U.S. Department of Human Services Office of the Secretary for Planning and Evaluation, Division of Disability, Aging, and Long-Term Care, under contract with Research Triangle, Inc, March 31, 2005). Portland, ME: National Academy for State Health Policy. On website and last visited on 12/12/2005 at:

<http://aspe.hhs.gov/daltcp/reports/04alcom.htm> The Pennsylvania Home Care Association may be visited at <http://www.pahomecare.org/>

domiciliary home. Finally the Office of Mental Retardation licenses group homes and family homes. Staffed group homes serve an average of 2.6 consumers and family homes are limited to serving two people. Homes that are owned by the consumer do not require a license.

Home-Based Service Providers

Home care is provided in Pennsylvania through 321 licensed home health agencies, many of which also provide personal care and private duty services that may be provided without a license. In addition, the Pennsylvania Homecare Association estimated that another 500 agencies provides “non-medical continuous care support” to people in their homes. The Homecare Association supports licensure for this group of agencies, and indicates that legislation is pending in the state senate for that purpose.²⁰ The Pennsylvania Community Providers Association, a provider network of mental retardation and mental health organizations has 40 full and 20 associate members, and maintains an active policy monitoring and educational program. According to data provided by the Department of Public Welfare, 239 Adult Day Care Centers and 231 Adult Training Centers offering Habilitation Services had served as Department vendors in 2004. This overview of service providers, which does not claim to comprehensively include all types of vendors, should give some glimpse of the complex, service-rich environment in Pennsylvania.

Extremely good records are available about all these residential settings and other care providers at the county level. Listings that are updated monthly can be found on the websites of the relevant agencies with information on how many people each residential setting serves and how many residents are on SSI. Although the multiple agencies monitoring the settings makes

²⁰ Information is on Department of Health Website where rules related to home care are posted and lists of agencies can be identified by county. Website last visited 12/10/2005 found at: <http://www.dsf.health.state.pa.us/health/cwp/view.asp?A=189&Q=236834>

the information somewhat fragmented, the data base is stronger that is available in most states. From our spot-checking on websites while preparing this report, it seems that detailed lists of providers of various types can be accessed many ways: from the state regulatory authorities; from local lead agencies such as AAAs, and from various provider associations.

Issues in Service Environment

The usual provider concerns about reimbursement and regulation have been heightened since 2000 because of Pennsylvania's struggles in recent years to reduce or at least contain Medicaid costs. One tactic in the search for cost savings is Medicare optimization proposals. For example, retroactive denials of home health claims under Medicaid or the waivers was suggested if the state believes the consumer could have been eligible for that care under Medicare. This Medicare appeals project affecting 160 home health agencies was under active consideration in 2005, to the anxiety of the agencies and their trade association; in November 2005 (after the period covered in this case study), the Department of Public Welfare decided not to pursue those claims, but raising the possibility should lead home care agencies to seek Medicare coverage for waiver clients whenever a care episode appears eligible. Another recent policy affecting home care reimbursement prohibits clients receiving end-of-life hospice services from receiving services under the aging PDA waiver on the theory that the Medicare home hospice should be providing the necessary services. The home care providers dispute that contention, and the issue is under discussion. Another theme centered around nursing-home reimbursement rates that providers feel are too low and which give a disincentive to admit people with light-care needs. Although such an incentive is appropriate for rebalancing, some HCBS providers worry that they are being expected to provide care to people with higher needs in an under-funded system. One provider described a cycle where HCBS programs attract more people than expected, which

leads to cutting provider rates. Providers would like the state to concentrate on developing a long-term financing mechanism to meet the demand.

Current reimbursement makes it hard to attract capital to renovate nursing homes. According to industry representatives, Medicaid accounts for half of all nursing home revenues. The capital component is based on a replacement cost at \$26,000 per bed while the actual cost is closer to \$70,000. One association representative suggested that the state needs to design a package with seed money and requirements for modernization that require private matching to allow nursing homes to become a hub of HCBS in an area. Under the plan, homes could redesign space for assisted living and personal care, use their kitchen for home delivered meals, and provide space for adult day care.

Advocacy representatives for individuals with mental retardation indicated that the state has made progress over the past 10-15 years toward providing more home and community based services due to the significant influx of funds, a multi-year plan, and additional funding intended to reduce the waiting list by 850 people. Despite this progress, however, over 2,000 people remain on the emergency waiting list, with another 10,000 people on a lower priority list. Stakeholders noted that state officials have to work with a system that is operated by individual counties that may have their own approaches to administering the program. The strong presence of county government makes it difficult to reallocate funds among counties. They noted that OMR may shift from an allocation based method to a contractual method as a strategy to achieve more uniform use of funds.

Historical Evolution of LTC

Pennsylvania has a long history of serving people with disabilities in community settings. In 1966, the state legislature passed a bill assuming responsibility for funding and licensing of

services to individuals with mental retardation. Community services were expanded in 1977 following the court settlement in *Pennhurst* that ordered the closing of large state MR/DD institutions. See table 4 for the historical evolution of the Pennsylvania system.

Since 1972, the state has used proceeds from the state lottery to fund in-home services for people 60 years of age and older through the OPTIONS program. A series of waivers for older adults, adults with physical disabilities and others were implemented during the mid to late 1990s. Between 2000 and 2005, state officials moved aggressively to explore the barriers and opportunities to balancing their long term care system through studies conducted by the Intra-Government Council on Long Term Care and grant proposals to CMS. Pennsylvania has received five Systems Change grants from CMS totaling more than \$4.5 million since 2002, including one of the first Real Choice System Change grants (\$1.35 million) in FY2002, including its Aging and Disability Resource Center grant to establish four centers to assist consumers and family members “who need information, counseling, assessment and assistance in applying for long term care services.”²¹ (This tally does not count an earlier HCFA grant for Transitions from Nursing Homes.) In addition, a three-year Cash and Counseling grant from the Robert Wood Johnson Foundation will further the state’s goal to permit people of all ages with disabilities or limitations to have the right to live in the least restrictive and most integrated setting appropriate to their needs and to receive consumer-centered and consumer-centered services. Cash and Counseling grant model will be implemented in the PDA waiver in 3 waivers for adults with physical disabilities, the Michael Dallas Waiver for technology dependent persons and in a waiver for persons with mental retardation age 3 and older. It is anticipated that the Cash and Counseling model will be selected by well in excess of 10% of persons in waivers for which it is available, which by the end of the grant period will cover at least 1500 consumers.

²¹ ADRC application. Available at <http://www.ohcr.state.pa.us/ADRC%20Narrative.pdf>.

Table 4. Selected LTC Milestones in the State of Pennsylvania

Year	Policy or Programmatic Development
1965	Older American Act funding began
1966	Passage of PA Mental Health/Mental Retardation Act establishing state responsibility for funding and licensing of services
1972	OPTIONS in home services program for persons age 60 and older began
1977	Settlement of Pennhurst suit, ordering closure of large state hospitals for persons with MR
1986	Attendant Care Services Act was passed Intra-Governmental Long Term Care Council established
1987	Michael Dallas waiver implemented for technology dependent persons Family caregiver support program implemented ACT 150 attendant care program implemented
1988	Act 185 codified the Intra-governmental Council on LTC into law
1990	AIDs waiver for persons ages 21-64 implemented
1991	OBRA waiver for persons with severe chronic disabilities implemented
1994	Attendant care waiver for persons 18-59 with a physical disability implemented
1996	Consolidated waiver for persons with MR (age 3 and older) implemented
1997	Independence waiver for persons 18 and older with physical disabilities implemented Office of Mental Retardation develops a multi-year plan to improve consumer direction and quality of services
1999	PDA waiver for persons age 60 and older was implemented Person/Family directed waiver for person age 3 and older with mental retardation implemented
2000	Intra-Government LTC Council issues reports on barriers to community care
2001	PA Transition to Home project implemented Intra-Government LTC Council issues 2 reports on frontline workers
2002	COMMCARE waiver for persons aged 21 and older with traumatic brain injury implemented BRIDGE program for older people with assets exceeding Medicaid eligibility levels implemented Real Choice System Change (RCSC) grant awarded to Department of Public Welfare to develop better access to and management of HCBS services. Intra-Government LTC Council issues third report on frontline workers
2003	Governor's Office of Health Care Reform established Money Follows the Person RCSC grant awarded by CMS QA/QI RCSC grant awarded by CMS Aging & Disability Resource Center RCSC Grant awarded to Governor's Commission for Health Care Reform Intra-Government LTC Council issues "Direct Connections: A Resource Guide for Frontline Workers" Governor's Office of Health Care Reform leads implementation of "Community Choice" to streamline access to home and community based services
2004	Mental Health Systems Transformation RCSC grant awarded by CMS Integrating Long Term Supports with Housing RCSC grant awarded by CMS Cash and Counseling grant awarded PDA and OSP award funds to local groups to support nursing home relocation activities
2005	Worker Resource Center implemented Transition services added to 1915 (c) waivers University of Pennsylvania issues report on a survey of frontline workers for the Intra-Governmental Long Term Care Council

Programs and Services

Pennsylvania operates 11 Medicaid home and community based services waivers. One is managed by the Department of Aging. The Office of Social Programs operates five waivers; two are managed by the Office of Medical Assistance Programs and three are managed by the Office of Mental Retardation.

Seniors and Adults with Physical Disabilities

PDA waiver. The aging waiver (PDA waiver) is administered by the Department of Aging and serves adults age 60 and older. The waiver is administered on the local level by 52 Area Agencies on Aging (AAAs). AAA case managers complete assessments for nursing home and PDA waiver services. Medicaid financial eligibility is determined by the State's County Assistance Offices. The waiver covers attendant care, companion services, counseling, environmental modifications, extended physician services, home delivered meals, home health services, home support services, adult day services, personal care services, personal emergency response services, respite care, specialized medical equipment and supplies, transportation and community transition services. The waiver served 9,786 consumers in July 2004.

OPTIONS and Bridge Program. The Department of Aging administers the OPTIONS and Bridge Programs for elders who are eligible for the Aging waiver. These two state-funded programs cover the same services as the aging waiver program, except for nursing home transition services. OPTIONS services are funded by proceeds from the state lottery. There is no functional eligibility threshold, income or asset limit. Services are capped at \$625 a month. Consumers with incomes below 125% of the federal poverty level do not pay a share of the costs and consumers with incomes that exceed 300% of the federal poverty level pay the full cost of services. In FY 2004, OPTIONS served about 15,000 older adults at a cost of \$207.8 million.

The Bridge Program serves people who meet the nursing home level of care criteria but do not meet the Medicaid income or asset limits. Consumers who have include below 300% of the SSI benefit and assets between \$8,000 and \$40,000. The Bridge program spent \$5.8 million in FY 2004 to serve about 400 participants. The program is being phased out.

Options (Any Willing Consumer)	Bridge (Consumer Assets exceed MA limit)	PDA Waiver (MA Consumers)
Primary Funding State Lottery	Primary Funding Tobacco Settlement Funds	Primary Funding Federal MA, State GGO, IGT
No Functional Limitation (NFCE or NFI)	Functionality Eligible (NFCE) And	Functionally Eligible And
Sliding Fee Financial Requirement	Financially Eligible ≤ 300% FBR and	Financially Eligible ≤ 300% FBR and
Asset Limit n/a	Asset Limit ≥ \$800 ≤ \$40,000 and	Asset Limit ≤ \$8,000
Consumer Share Pays costs > \$625 cap Sliding fee schedule: ≤ 125% FPIG = No costs > 300% FPIG = All costs	Consumer Share Consumer bears 50% Costs When assets ≤ \$8,000 Consumer moves to PDA Waiver	Consumer Share No Consumer Share of Cost



Specifications. All programs provide Assessment, Care Management & Protective Services without additional charge, regardless of income or assets. The costs of the listed services below are included in the cost share calculation and are common to all three programs.
Services. All programs provide counseling, transportation, respite care, adult day services, personal care, companion services, home health, home modifications, home support, expanded physician services, specialized medical equipment and supplies, and personal emergency response system. Only the Bridge Program includes home delivered meals

Figure 5. Waiver, Options, and Bridge Programs of the Department of Aging

Attendant care waiver. The attendant care waivers is administered by the Office of Social Programs and serves adults with physical disabilities between ages 18 and 59. Functional eligibility is determined by AAAs. The service plan is developed by a supports coordinator who is selected by the consumer from a list of contracted providers. Consumers may select an agency model or the consumer directed model. The consumer directed model allows greater flexibility

for delegation. (WHO) The care plan includes a range of options for paying caregivers. The waiver covers in-home personal assistance, supports coordination services, personal emergency response services, and community transition services. This waiver served 2,638 individuals in July 2004.

The Attendant Care Services Act (Act 150). The Attendant Care Services Act, or Act 150, is a state-funded program covering the same services as the Attendant Care Waiver for adults age 18-59 who have a physical disability, 3 functional limitations and do not meet the income or functional eligibility for the waiver. Functional eligibility is determined by AAAs. Eligible consumers chose from 15 contracted providers across the state.

Independence waiver. This waiver is administered by the Office of Office of Social Programs and serves individuals with severe physical disabilities that result in substantial functional limited in there or more of the following: self-care, understanding and use of language, learning, mobility, and self direction and/or capacity for independent living. Covered services include assistive technology (\$10,000 maximum), community integration, community transition, daily living services, educational services, environmental adaptations (\$10,000 maximum), personal emergency response services, respite, service coordination, transportation, therapies and visiting nurse services. The waiver served 789 individuals in July 2004.

COMMCARE waiver. The COMMCARE waiver is administered by the Office of Social Programs and serves individuals over age 21 with a medically determined diagnosis of traumatic brain injury which results in substantial functional limitation in three or more of the following: mobility, behavior, communication, self care, self direction, independent living and cognitive capacity. Waiver participants may live in group settings with six or less people. Thirteen contracted enrolling agencies conduct a brief screen and refer participants who are likely to be

eligible to the AAA for a full eligibility assessment and determination. Once eligible, participants enroll with the enrolling agency and a plan of care is developed. Consumers who select the consumer directed option choose a fiscal intermediary from among 18 organizations.

Covered services include service coordination, respite, prevocational services, educational services, supported employment, community integration, environmental adaptations (\$20,000 maximum), personal emergency response, part time nursing, non-medical transportation, assistive technology (\$10,000 maximum), therapies, personal care services, chore services, coaching/cuing, cognitive therapy, night supervision, habilitation and support, structured day programs, counseling, behavioral specialist consultant, and community transition services. The waiver served 69 individuals in July 2004.

Michael Dallas waiver. This waiver is administered by the Office of Medical Assistance Programs and serves technology dependent persons. The services covered at attendant care, case management, private duty nursing, nutritional supplements, respite care and durable medical equipment. The waiver served 61 individuals in July 2004.

AIDS waiver. This waiver is administered by the Office of Medical Assistance Programs and serves individuals diagnosed with HIV/AIDS and covers home health services, homemaker, nutritional supplements and consultation, specialized medical equipment and nursing home transition services. The waiver served 175 individuals in July 2004.

Elywn waiver. This limited waiver is administered by the Office of Medical Assistance Programs and serves individuals age 40 and older who are deaf or deaf and blind and who live in the Valley View Assisted Living. The waiver served 35 individuals in July 2004.

Developmental Disability

OBRA waiver. This waiver is administered by the Office of Social Programs and serves people with a developmental disability that occurred before age 22 and a severe physical disability that results in functional limitations in three or more ADLs. The services include adult day services, assistive technology/specialized medical equipment and supplies (\$10,000 lifetime limit), community integration services, environmental adaptations (\$10,000 limit per site), personal emergency response services, respite services, service coordination, support employment services, therapies, transportation, visiting nurse and nursing home transition services. The waiver served 538 individuals in July 2004.

Infants, Toddlers and Families waiver. This waiver is administered by the Office of Mental Retardation and serves children up to age 3. Services include habilitation by qualified professionals with family or caregiver participation. The waiver served 2,312 individuals in July 2004.

Consolidated waiver. The consolidated waiver is administered by the Office of Mental Retardation and serves individuals age three and older. Covered services include habilitation (residential, day, prevocational, support employment, homemaker/chore, and adaptive equipment), environmental accessibility modifications, permanency planning services, therapy and nursing care, respite and transportation. The waiver served 13,511 individuals in July 2004.

Person/Family Directed Support waiver. This waiver is administered by the Office of Mental Retardation and provides a limited array of services to individual age three and older that live in their own home or with family members. The covered services are habilitation (residential, day, prevocational and supported employment), respite, environmental accessibility adaptations to a home or vehicle, transportation, specialized therapy and visiting nurse services,

adaptive appliances and equipment, homemaker/chore services and personal support. The waiver served 6,897 individuals in July 2004.

Table 5. Summary of home and community based service programs

Management Agency	Program	Population
Medicaid HCBS waivers		
Department on Aging	PDA waiver	Adults 60+
Office of Social Programs	Attendant care waiver	Adults 18-59 with a physical disability
	COMMCARE waiver	People with traumatic brain injuries
	OBRA waiver	People with severe chronic disability before age 22 and three functional limitations
	Independence waiver	People with severe physical disabilities
Office of Medical Assistance Programs	Elwyn waiver	People age 40 and older who are deaf or deaf and blind and who live in the Valley View Assisted Living
	Michael Dallas waiver	Individuals with a medically determined diagnosis of traumatic brain injury
	AIDS waiver	People with HIV/AIDS
Office of Mental Retardation	Consolidated waiver	Individuals with mental retardation
	Infant, Toddlers and Families waiver	Children birth to age 3 requiring early intervention services
	Person/Family Directed Support waiver	Individuals 3 or older that live in their own home or with family
State funded programs		
Office of Social Programs	Act 150	Adults 18-59 who self-direct
Department of Aging	Options	60+ who do not meet Medicaid financial or functional requirements
	Bridge	60+ who meet Medicaid functional requirements but do not meet financial requirements

Table 6. Summary of services by waiver

Note: prepared by Thomson Medstat											
	Consolidated Waiver	PFDS Waiver	ITF Waiver	OBRA Waiver	COMMCARE Waiver	Independence Waiver	Attendant Care Waiver	PDA Waiver	Elwyn Waiver	Michael Dallas Waiver	HIV/AIDS Waiver
Adult Day Care				•							
Adult Foster Care											
Assisted Living									•		
Assistive Technology	•	•		•	•	•					
Attendant Care							•	•		•	
Behavior Management		•			•						
Case Management										•	
Coaching/ Cueing					•						
Cognitive Therapy					•						
Community Integration Services				•	•	•					
Community Transition Services				•	•	•	•				
Companion Services								•			
Consumer Training				•							
Counseling				•	•	•		•			
Daily Living Services				•		•					
Day Habilitation	•	•	•		•						
Educational Services					•	•					
Environmental Modifications	•	•		•	•	•		•			
Home Delivered Meals								•			
Home Health Care								•			•
Home Support Services								•			
Homemaker/Chore	•	•			•						•
Night Supervision					•						
Non-Medical Transportation	•	•		•	•	•		•			
Nutritional Counseling/Assistance											•
Nutritional Supplements										•	•
Occupational Therapy	•	•		•	•	•					
Permanency Planning	•										
PERS				•	•	•	•	•			
Personal Care					•			•			
Personal Support		•									
Physical Therapy	•	•		•	•	•					
Physician Therapy								•			
Prevocational Services	•	•		•	•						
Private Duty Nursing										•	
Residential Habilitation	•	•			•						
Respite	•	•		•	•	•		•		•	
Specialized Medical Equipment & Supplies				•	•	•		•		•	•
Speech, Hearing and Language Therapy	•	•		•	•	•					
Structured Day Program					•						
Support Coordination				•	•	•	•				
Supported Employment	•	•		•	•						
Visiting Nurse	•	•		•	•	•					
Visual/Mobility Therapy	•	•									

Section II. System Assessment

In this section, we briefly profile selected system functions, using identical headings to those in each state-specific case study. The section that follows details selected Pennsylvania programs or initiatives that are especially noteworthy and innovative management approaches for rebalancing.

Access to Services

Since the late 1970's, the Department of Aging has operated a home care program through area agencies on aging (AAAs) using state general revenues from the lottery. Preadmission screening of Medicaid applicants seeking admission to a nursing home began in the 1980's. Incremental progress followed a series of task force reports. In March 2002, the Intra-Governmental Council on Long Term Care issued a report that identified 22 systemic barriers to home and community based services, some related to information gaps and some to policies and processes that created delays in establishing Medicaid functional and financial eligibility.²² The OHCR gave this issue early priority. Section III highlights those efforts, including the Community Choice pilot in selected counties for expedited processes of eligibility and service initiation.

Array of Services

As the previous material has suggested, a wide range of differentiated services exist in Pennsylvania. The problems lie in the ability of consumers to access these services quickly, and in a cost-effective manner. Here there is some tension between providers' desires for higher payment levels for all types of services, and the policy-makers hopes for more flexible,

²² Pennsylvania Intra-Governmental Council on Long-Term Care (2002). Home and Community-Based Services Barriers Elimination Work Group: Report (Report to the Intra-Governmental Council, Submitted March 2002).

consumer-directed and, they hope, less expensive service provision through a greater use of independent providers.

The array of residentially based services is broad and varied, but the focus of concerns. Personal care homes are often described as a problem area due to a lack of enforcement of quality standards, low rates of payment for SSI residents, and a history of abuse by staff in some facilities. (About 75% of the residents of personal care homes have a history of mental illness). Advocates felt the recent changes in the regulations will improve oversight and quality of care in personal care homes, but providers are not sanguine. Despite their expectation of quality improvement, moreover, consumer advocacy representatives argue against using HCBS waiver funds (a potential vehicle for getting dollars into the system) in personal care homes because it will divert funds from in-home services.

To summarize, the building blocks of a system of services are present in Pennsylvania, and are enhanced by recent efforts to strengthen the quality and availability of the labor force. In some ways, the rich array of provider organizations that will be part of the solution to long-term support also creates problems of vested interests and fixed ideas about how to manage care that could be a deterrent to systemic changes. However, provider stakeholders are at the table and engaged in the planning that has gained momentum in Pennsylvania.

Quality Initiatives

As indicated Pennsylvania received a CMS grant in 2003 to develop and implement new quality management (QM) systems for consumer-centered service planning and provision, and to that end to develop a data base with the capacity for prospective management of the system. The OHCR is the lead organization for the effort, which includes development of new tools to help providers and care managers develop personalized service plans, and training for providers and

consumers on quality issues. Much of this effort is in anticipation of the expansion of consumer directed efforts to populations in aging and developmental disability, and thus the system development includes development of emergency backup for all crucial services. The state targeted having all its systems tested and in place by the third year of the grant, that is the Fall of 2006.

Other quality efforts have been taking place in the state, including a program to encourage improvement of quality of life in nursing homes and financial incentives for expanding private rooms. Also noted as a promising practice, highlighted as a national model,²³ is Pennsylvania's Independent Monitoring for Quality (known as IM4Q), which has been applied in MR/DD. Essentially independent review teams composed of the consumer with the disability, family members, and other concerned citizens independent of the services reviewed collect information using a standardized tool to tap the program participant's satisfaction and the extent to which dignity, rights, respect, choice and control, relationships, and community inclusion are promoted for the consumer. IM4Q data are entered into the NCBS web-based information system and used by the OMR to monitor quality in county programs and design quality improvement projects. Aggregate reports are available on a state-wide and county basis.

Consumer Direction

As indicated, Pennsylvania is embarking on a Cash and Counseling demonstration and hopes to infuse consumer direction into many of its waiver services. In addition to participating in the national planning for Cash and Counseling expansion, Pennsylvania was awarded a grant from the National Association of State Units on Aging (NASUA), called "Promoting Consumer Direction in Aging Services," which was used to assess actual consumer, potential consumer,

²³ MedStat Group (2003). Pennsylvania's Independent Monitoring for Quality (IM4Q). On website at www.hhs.gov/promisingpractices/datareadinessPA/PDF

and provider perspectives on consumer-direction, using questionnaires in a Tool Kit developed by NASUA, which itself received foundation funding to develop a Tool Kit and apply it in selected states. The Pennsylvania results suggest a high receptivity to consumer direction among consumers and providers in the aging network, while also pointing to some areas of confusion and misunderstanding.²⁴

Institutional Downsizing

In 1998, the Department of Public Welfare developed the County Commissioners Association of Pennsylvania – Program for Alternative Community Care (CCAP-PACC) program to create incentives for County funded/operated nursing facilities to develop alternative services by downsizing their existing bed capacity and converting space to other uses, such as renovated or expanded physical therapy departments, independent housing units, adult day care centers or community outreach programs. The Department of Public Welfare funds the renovations, makes transition payments to support the phase-in cost of independent housing units and allocates additional home and community based waiver slots to the Area Agency on Aging.

Twenty nine counties participated in the program. By 2005, 1,582 nursing home beds were de-licensed and 2,322 home and community based services waiver slots allocated. State officials indicated that the program has expanded in-home services, created additional independent housing units, reduced the number of beds per room, and created more home-like environments and increased efficiency by spreading operating expenses, administration and staff costs over fewer units. The renovations have improved safety by installing or upgrading sprinkler and alarm systems, improving heating, air conditioning, electrical and plumbing systems, and removing asbestos. Surveyors noted a decrease in code violations.

²⁴ Pennsylvania Department of Aging (2005). Consumer Direction Report: Consumer Perspective, Pre-consumer Perspective, Human Service Professional Perspective. (Report submitted to NASUA, February 2005).

Data Capacity

Data responsibility is de-centralized in Pennsylvania. Individual programs and the state Medicaid agency collect long term care data on a program-by-program basis. Currently, no comparable measures are available across population group or programs. The state has recently undergone a change in its Medicaid data system, and the Department of Public Welfare and the Department of Aging use two different information platforms. The Department of Public Welfare has adopted the PROMISE system, a copyrighted web-based system that is used by all providers for billing purposes and generated information based on that. The transition into this new system proved to be difficult in 2004-2005, with implementation obstacles, and payment problems. The Department of Aging uses a data system that contains much more information about participants but does not generate service information. Although the state currently does not have a relational database system in place, Pennsylvania has plans to develop this capacity.

Mental Health Linkages

Many stakeholders have identified mental health issues as a key area for attention in Pennsylvania. The high proportion of long-term support clientele with mental health problems has been noted by waiver officials. Personal care homes house many people with mental health or substance abuse problems. In 2004, the Department of Public Welfare received a grant to implement a Certified Peer Specialist program for mental health and substance abuse based on a model developed successfully by the Mental Health Association of Southeastern Pennsylvania in collaboration with the Montgomery County Office of Mental Health/Mental Retardation/Drug and Alcohol services. The plan is to refine the model and train consumers to act as peer specialists in service settings such as targeted Case Management, Community Treatment Teams, and Mobile Psychiatric Rehabilitation programs in an expanded number of counties. If this

initiative is successful, a State Plan Amendment will be sought to reimburse these peer specialists under Medicaid through the Mental Health Rehabilitation option. The Philadelphia Corporation on Aging recently announced a grant from Blue Cross that will allow it to provide case management and services to elderly people with mental health problems.

Acute Care Linkages

As indicated above, the Medicaid program in Pennsylvania is struggling to remain solvent. Other concerns about health care include the high cost of drugs under the state's large program to subsidize medications, and the high number of persons without health insurance in Pennsylvania. Regarding the latter, the OHCR brokered a highly unusual arrangement with the four Blue Cross organizations in Pennsylvania whereby the latter agreed to plow substantial amounts of revenues back into care for the uninsured under an established formula. Depending on the county where they live, Medicaid clientele themselves receive their acute care services through enrolling in a mandatory managed care program (Health Access+) or, in counties where that is not established yet, a voluntary primary care case management programs, called Health Choices.

The Program of All Inclusive Care for the Elderly (PACE) is being implemented in 5 locations under the name Long-term Care Capitated Assistance Program (to avoid confusion with the Pharmaceutical Assistance program, which has the acronym PACE in Pennsylvania). At present the state has 3 full-fledged PACE sites and 2 pre-Pace programs. In the Pittsburgh area where this program is most developed, there had been an active approach to locate PACE sites in publicly subsidized or public housing, in conjunction with investors, contractors, and Housing Finance Agencies. All the projects entail new construction with notions of acquiring tax-exempt bonds and having low income set-asides. The first project Homestead had 40% of its enrollees from the units and the rest from the surrounding neighborhood. Although

experience with this is limited at present, some excitement has been developed over the prospect of using these “PACE” programs to break the stigma of public housing while developing the intensity of service needed to keep people at home. The programs report success in working with limited English-speaking populations. Actuary calculates upper payment limit and uses a blend of NF and HCBS payments. Some analysts envisage “PACE” as an important plank in rebalancing, which combines attention to acute care, long-term supports, and housing (which is the next section.)

Housing Linkages

State and county officials recognize that identifying and sustaining safe, accessible, and affordable housing will be a key determinant in rebalancing a system that relies heavily on nursing homes, and also somewhat heavily on personal care homes and domiciliary facilities. With a Real Choice System Change Grant for \$1,385,000, received in 2002, the OHCR is working with the PA Housing Finance agency to encourage developers to allocate 10% of units as accessible housing in HUD housing expanding Section 8 housing, and developing an inventory of available publicly funded accessible housing. The state proposed to work particularly through Regional Housing Coordinators in five regions and Local Housing Options team in 18 locations to model a strategic plan for housing. Through this effort a data base had now been established on the PA Housing Finance Agencies website that updates housing vacancy data in real time, with links to other county and state agency websites so that case managers and housing managers can better assist their clientele.

Some concerns have been expressed, particularly in the Philadelphia area, about the shrinking of funds for home renovation, which in this particular urban area has also been a key need for some people with disabilities to remain in their homes. The concern over housing was

reflected in the four-year plan prepared by Philadelphia Corporation on Aging for 2004-2008. A focus on housing was listed as its first priority and a wide number of initiatives identified for service, collaboration, and advocacy around that topic. Housing issues were also flagged as one of the 10 priorities of the PDA for the entire state's aging plan.

Section III: Featured Management Approaches

Governor's Office of Health Care Reform

In 2003, a Governor Rendell established the Governor's Office of Health Care Reform (OHCR) to facilitate the analysis of administrative, fiscal and regulatory policies and practices; oversee the design of operation and infrastructure and direct the creation and maintenance of a system to assure the accountability of designated agencies. The Director of the OHCR also chairs the Governor Health Care Reform Cabinet, which consists of the Secretary of Aging, the Adjutant General, the Secretary of Health, Commissioner of Insurance, Secretary of Public Welfare, Director of the Governor's Policy Office, and the Secretary of the Budget.

The OHCR set a goal to develop a long term living system that is efficient and effective (cost and program), is focused on the well-being of consumers and their family members, and operates within the financial wherewithal of the state. The OHCR found that policies tend to be organized around departments rather than the delivery of services. Accordingly, the OHCR developed several key questions to guide future development of long term living services and financing:

- Do we know how much money we spend, should spend and can spend on health and long term care?
- What fact based data do we have to monitor program outcomes of providers?
- What has been, should be, and could be the priority spending patterns on state supported access?

- What should the statutory and regulatory changes be to achieve accessible, affordable care?
- Do we know which socio-economic trends are having and will have the greatest impact on the demographics and the severity of need for state paid health and long term care services over the next five years?

The Intra-Governmental Council on Long Term Care, established by the PA House of Representative's Select Committee on Long-Term Care in 1986, was in some ways the precursor to the OHCR. It was created by a March 1988 Executive Order of the Governor, and finally codified in state law in December 1988 by Act 185. The mission of the Council is to study the long term care system from a funding, operational and consumer perspective and make recommendations to the governor on ways to streamline administration of the system, and develop a full spectrum of options for consumers and their families. The 37-member Council is chaired by the Secretary of Aging and includes three members of the Cabinet, four legislators, providers and consumers. The Council's mandate includes:

- Providing a public forum for discussion on long term care issues;
- Analyzing and assessing the current system, examining options and suggesting recommendations for action;
- Developing a framework for a system of long term care services at the state and local level;
- Seeking short and long range options for financing long term care;
- Expanding efforts to educate consumers about long term care issues and alternatives;
- Examining and making recommendations on the organizational structure of services at the state and local level; and,
- Making recommendations on regulations and licensure of personal care homes.

The Council has issued a series of high-profile reports including a report on the Pennsylvania Transition to Home (PATH) project, one of the initial nursing home transition projects funded by CMS. In 2001, the Council issued a report based on focus group findings about the information consumers need and how they want to be able to access it. Reports on frontline workers were issued in 2001 and 2002 that focused on workers' concerns, thoughts, and opinions about recruitment and retention in long term care and what they felt worked or could be done to improve recruitment and retention.

A report in 2002 presented results from a work group formed to evaluate barriers to accessing home and community based services (Home and Community-based Care Barriers Elimination Work Group Report"). A series of recommendations from that report led to the OHCR's development of the Community Choices program, which now operates in 10 counties and has significantly reduced delays gaining access to services.

Dale Laninga was staff director of the Council and Ann Torregrossa chaired several of its important efforts, which lead to a smooth transition into the long-term living work of the OHCR.

Community Choices

During the term of an interim governor, the Council prepared a transition report that was used by the incoming Rendell administration to set priorities for expanding HCBS. The OHCR wanted to move quickly to identify barriers identified by the Council in their report that could be addressed without legislation or changes in regulation. One priority was to create a "fast track" initiative to reduce the time needed to establish Medicaid eligibility and initiate home and community based services. Other initiatives include a statewide nursing home transition program, better information and coordination of 17 home modification programs, strategies to

address the need for housing with services, and strategies to improve recruitment and retention of direct service workers.

The OHCR approached several counties interested in piloting a new, “fast track” approach to the eligibility process that would expedite access to home and community based services. The approach has been implemented for ten of the state’s eleven HCBS waivers (a waiting list for made it impractical to expedite the eligibility process for the MR/DD waiver). It was guided by two primary goals: changes must focus on consumers and the results should increase consumer choices and options. Planning involving both state and local officials began in July 2003, with the expectation that the changes would be implemented in four counties in Southwestern Pennsylvania by October 2003 and six counties in the Philadelphia area by December 2003. Four state agencies with responsibility for long term living functions formed a core state team – the Departments of Aging, Income Maintenance, and Medical Assistance Programs, and the Office of Social Programs.

During the first year of operation, the Community Choice pilot sites received 8,810 applications. Eighty nine percent of the applicants were 60 years of age or older. Twelve percent of all applications were processed within 72 hours and 5 percent within 24 hours. About 30% of the referrals were made by family members, 19% by hospitals, and 11% by AAA network agencies, nursing facilities, and other service providers. Nearly 75% of applicants were found eligible, about 10% were either financially or functionally ineligible, and another 10% remained pending at the end of each reporting period.

The data indicated that 27 percent of the applicants were diverted from nursing home placement, relocated from a nursing or were referred by a nursing home. The remaining 67 percent accessed services more quickly.

As of July 2005, the Community Choice program, which simplifies and streamlines the process for accessing home and community based services, is operating in ten counties. Expansion to additional counties has been delayed pending the collection of more data on the impact of the process on nursing home utilization. State agencies are adapting existing information systems to determine the impact on nursing home admissions and Medicaid bed days in the demonstration counties

The county based delivery system is being revamped to increase state oversight and consistency across the state. Individuals who apply for waiver services are assigned a priority. Applicants that require immediate services are placed on the emergency list. Those who need services within one year are assigned to the critical list and all other applicants are placed on the planning list. Each county maintains its own waiting list and submits a quarterly report to OMR. New funds are allocated in proportion to each county's waiting list. OMR is considering reviewing a sample of individuals on the waiting list to verify its accuracy.

Care coordination is provided by county workers or organizations that contract with the county. Contracted care coordination organizations are more common in urban areas and counties are more likely to provide care coordination in rural areas. Care plans are not capped except in the Person/Family Directed Support waiver. Two counties provide services directly but all other contract with local provider organizations.

The state team approached local AAAs, service providers, advocates and consumers representing the 10 waivers to form a local core team. Local stakeholders recommended changing the name of the project from "fast track" to Community Choice. The initiative includes the following components:

- A reduction in the Medicaid financial application from 12 pages to four pages;

- Self-declaration of income and assets for applicants under the 300% special income level option;
- Presumptive financial eligibility to facilitate access within 24 hours when necessary;
- Exemption for \$6,000 in assets;
- Exemption for burial plots;
- 24/7 access to assessments and eligibility determination;
- Reduction in the functional assessment form from 30 to five pages; and
- Expedited appeal process for denials.

Nursing Home Transition Program

Pennsylvania received one of the original nursing home transition grants from CMS in 2000. The Pennsylvania Transition to Home Program (PATH) was established “to assist people to transition from nursing homes into the community learn about perceived or real barriers that nursing home residents face when considering alternatives to living in a nursing home.”²⁵ The PATH transition coordinators worked with existing service programs and organizations to help “consumers connect to the services they needed and facilitated the move from institutional living to community living.”²⁶ During a 22 month period, transition coordinators worked with 82 nursing homes in seven counties and successfully transitioned 51 of the 119 consumers referred for relocation assistance. The average length of stay in the nursing home was 18 months. Over half (55%) were female and 47% were 60 years of age or older. Almost half had family members involved with their transition. To ensure that admissions expected to be short term did not become long term stays, transition coordinators worked with the AAAs to ensure clients and

²⁵ PATH: Final Report. Intra-Governmental Council on Long Term Care. March 2004.

²⁶ Ibid.

their families received information about home and community based services, and were contacted by the coordinator to see if they needed assistance with relocation.

Consumers and coordinators faced several barriers. Care plans for several consumers exceeded limits established for waivers with an individual expenditure cap. Waivers with aggregate caps, in contrast, were able to accommodate consumers with more costly care plans. Many consumers did not need attendant care services and were not able to access needed services. Consumers with multiple disabilities, including dual diagnosis or a disability that is not addressed by a waiver program, were especially likely to experience delays in obtaining services.

Delays in obtaining specialized equipment have caused consumers' transitions to be prolonged. PATH transition funding supported several purchases of this equipment, in order to assure a safe discharge in some cases, and in other cases to supplement with equipment not available through Medical Assistance (e.g. specialized lifts.)

Difficulties contacting the assessor or care manager could delay consumers needlessly. However, the PATH program has worked with local AAAs to integrate PATH into the AAA system. In the state's southwestern area, the transition coordinator became an employee, rather than a sub-contractor, of that AAA. Delays have been shortened by integrating the PATH project even further into the existing HCBS system, enabling transition coordinators to see assessors and care managers on a regular basis,. DPW has also addressed this issue (WHAT ISSUE) for consumers under age 60. By incorporating nursing facility transitions into their own HCBS system DPW has also ensured that the professionals handling those transitions are working within a provider agency. The number of communication barriers was reduced from 4 in the first year to 0 in the second year of the project.

The overall lack of affordable and accessible housing was the foremost problem faced by consumers needing an apartment. Several of the counties in the PATH demonstration project had waiting lists (some more than a year long) for accessible units. Also, some housing authorities refused to provide a listing of their individual Section 8 landlords (other than the large apartment buildings), making it difficult for a consumer to search for accessible units and limiting consumer choice.

In response to these difficulties in the PATH program, amendments were submitted to four waivers administered by the Office of Social Programs and the Aging waiver to add transition services as a covered service. Community Transition Services are defined as one-time expenses, not to exceed \$4,000 per consumer. These are “set-up expenses” for individuals who make the transition from an institution to their own home, apartment or family/friend/foster care living arrangement. The funds may be used for necessary expenses in establishing and relocating to a basic living arrangement. The service may not include payment for rent. The following categories of expenses may be covered:

- Equipment, essential furnishing and initial supplies such as including but not limited to food, dishes, chairs, tables, bedding, linens, pots and pans, cutlery, and shelving;
- Moving expenses;
- Security deposits or other such one-time payments that are required to obtain or retain a lease on an apartment, home or community living arrangement;
- Set-up fees or deposits for utility or service access (Examples – telephone, electricity, heating);
- Personal and environmental health and safety assurances, (Examples – pest eradication, allergen control, one-time cleaning prior to occupancy.

Providers of community transition services must comply with the following standards:

- Expenses must be reasonable and necessary for an individual to establish his or her basic living arrangement.
- Providers of Community Transition Services must be able to supply the Transition Services directly, or broker the services from sources in the community.
- The need for Transition Services must be documented by the Area Aging on Aging or the Waiver Implementation Unit of the Division of Long Term Care Client Services.
- Entities providing Transition Services must comply with all reporting requirements as specified by the AAA and/or Waiver Implementation Unit.
- A Transition Services Provider must ensure that the persons delivering transition services maintain a standardized record keeping system. The system must ensure uniformity and consistency in documentation of the service provision, the consumer's response to the service, and other observations made of the consumer.
- Consumer information must be maintained in a confidential manner.
- The Area Agency on Aging may function as a broker of these services as long as their agents are qualified to provide the service.

To continue the coordination activity, the Department on Aging and the Office of Social Programs allocated \$1.4 million approved by the legislature to support transition coordinators. A joint RFP was developed by OSP and PDA. Funds were awarded to organizations in local communities that submitted a collaborative plan.

Institutional Downsizing

Pennsylvania has introduced two strategies to affect nursing home use. In 1997, 81% of all licensed nursing homes participated in the Medicaid program and Medicaid paid for 66% of the occupied bed days.²⁷ An analysis of nursing home admissions in 1996 found that 78% of the individuals admitted were Medicaid beneficiaries on the day of admission or within 60 days of admission, an increase of 20% since 1994. The Department of Public Welfare concluded that the supply of beds exceeded the amount needed to offer Medicaid beneficiaries a choice of settings.

²⁷ Statement of Policy. Pennsylvania Bulletin, Vol 28, No 2, January, 10, 1998.

OMAP introduced a new contracting policy in 1997 when the certificate of need law expired. The policy prohibits nursing homes and ICF-MRs from expanding their capacity without first receiving approval from OMAP.

The Department's statement of policy concluded that there would be a surplus of 5,634 beds by 2000 and spending for nursing home care created an imbalance. About \$2 billion, or 35% of the Medicaid budget, went to nursing home care while only \$76 million was spent on community services. The Department stated that "a policy that results in an unconstrained increase in the supply of nursing facility beds financed at taxpayer expense is unacceptable. The Department believes it is in the best interests of the residents of this Commonwealth with long term care needs to develop a fuller array of long term care supports and services."²⁸ As a result, the Department considers requests for the expansion of existing facilities and approval of new facilities based not on the need for institutional health services, but on whether the Medicaid program needs additional services and the most appropriate way to meet those needs.

Applications are reviewed based on the availability of home and community based services funding in the area, the applicant's willingness to serve Medicaid beneficiaries, willingness to serve technology dependent individuals, past history and the willingness to employ public assistance and medical assistance beneficiaries. Other factors include demographic trends, migration changes, the availability of home and community based services funding, nursing home occupancy rates in the area and waiting lists for nursing home services. No new facilities have been approved since the policy went into effect and Medicaid bed days have declined about 2% a year despite an increase in the population age 85 and older.

The Department's case mix reimbursement system contains financial incentives for nursing homes to admit higher acuity residents rather than lower acuity individuals whose needs could also be met in the community. Key informants reported that nursing home acuity has increased.

Housing Initiatives

Pennsylvania is implementing several initiatives to expand housing resources. The state offers 15 programs that pay for home modifications which are covered by a number of Medicaid waiver and state funded programs. This plurality of programs makes it difficult for consumers and case managers to access the most appropriate services. The Governor's Office of Health Care Reform convened a work group to streamline access to services. A decision tree was developed and will be posted on the OHCR web site that will direct users to the most appropriate program based on answers to a series of questions. Information about the array of programs covering home modifications will be provided to Area Agencies on Aging and Independent Living Centers. These organizations may also be able to access consultation services from physical therapists and occupational therapists to help design or select modifications that will be most effective in supporting consumers.

An affordable and accessible housing data base has been designed. The data base will be managed and maintained by the Pennsylvania Housing Finance Agency (PHFA). Initially, developers that have received financing from PHFA will be required to list vacancies and update the list weekly. Other housing owners will be asked to join the program over time.

PHFA has increased the set aside for accessible units for developers seeking Low Income Housing Tax Credits from five to ten percent of the total number of units supported by tax credits. Finally, a planned study of future housing needs will be expanded to include the housing needs of individuals who will need long term care services. .

Workforce Initiative

In 2000, the Intra-Governmental Council on Long Term Care commissioned surveys of provider agencies and of frontline long-term care workers to understand trends in workforce issues and to develop recruitment and retention strategies that will support the state's effort to balance its long-term care system. The Council found that job vacancy rates for all types of providers had dropped from 11% in an earlier 2000 report to 9.1% in 2004.²⁹ The number of home health agencies reporting moderate to high vacancy rates increased from 20% to 32%. Higher wage rates were associated with lower vacancy rates among home care agencies. Consumers who direct their own care were as likely to report problems finding workers as agency providers. The report recommended increasing training standards, increasing incentives to improve the workplace, funding a demonstration program to test workplace incentives, establish a peer mentoring program, support evidence-based practices in improving wages, benefits and supervision through one-day conferences, and support a social marketing campaign.

The OHCR worked with the Department of Labor and Industries to design and implement a resource center for direct care workers who provide long term care, acute care, mental health and mental retardation services.. In 2005, the Tri-County Patriots for Independent Living, an Independent Living Center, was selected through an RFP to operate the center. The resource center will develop a registry to help consumers find workers. The Center will combine several activities related to recruitment and retention of workers and improve job satisfaction.have the following functions:

Serve as a regional registry of direct care workers and workers and provider agencies. The registry will allow consumers and provider agencies to recruit and interview workers.

²⁹ Diane Brannon, Teta Barry, Joe Angelelli, and Robert Weech-Maldonado. 2004 Pennsylvania Long Term Care Workforce Survey. Pennsylvania State University. University Park, PA. May 2005. Available at <http://www.aging.state.pa.us/aging/cwp/view.asp?a=296&q=252556>.

- Provide entry level to new workers and advanced to training more experienced workers.
- Offer health insurance to individuals and employees of provider agencies.
- Increase the earning potential of workers by allowing workers to combine hours from several consumers or providers, offering scheduling and job sharing assistance, creating career ladders and sponsoring continuing education opportunities.
- Provide administrative functions that support workers such as payroll and health insurance.
- Provide links to affordable day care and supportive services such as mentoring and peer-to-peer discussion groups.³⁰

Department of Aging Level of Care Integrity Project

The Department of Aging has initiated a study of level of care determinations completed by Area Agencies on Aging. The objectives of the study are to determine the percentage of correct and incorrect level of care decisions made by AAAs and any identifiable patterns among incorrect decisions. Two panels will be convened. An expert panel and a peer review panel will review a range of assessments using the criteria that establish whether a person meets the nursing home level of care criteria. The expert panel will review 50 randomly selected assessments and the peer review panel will review 100 assessments.

Section IV. Quantitative Markers of Rebalancing

Markers of Change in Nursing Home Residents

In order to assess the potential effect of HCBS on nursing home use, we examined the MDS data on all Pennsylvania nursing homes for the years 2002, 2003, and 2004. We reasoned that if HCBS was having an effect, the case mix in nursing homes should become higher, i.e., the

³⁰ Request for Proposal. Regional Direct Care Workforce Center, Department of Labor and Industries. Harrisburg, PA. August 9, 2004.

level of disability (both functional and cognitive) should increase. Because nursing homes serve at least two streams of clients, one requiring post-acute care (PAC) after discharge from hospitals and another the more traditional long-term resident, we examined the case mix at two points in time: admission and three months after admission. The former would include the PAC population, but the latter should be a more direct reflection of long-term care HCBS was intended to defray.

Methods

To create the new admission sample we used all MDS admission assessment records in 2002, 2003, and 2004 to calculate the NH Case Mix at admission. The numbers of new admissions in 2002, 2003, and 2004 were 108,371, 105,541, and 97,645 respectively. This included multiple admissions of the same individual in the same or different NH.

For the 3 months after admission sample we used MDS quarterly records in 2002, 2003, and 2004 to calculate NH Case Mix at 3 months after admission. First, we selected all MDS quarterly records into a separate data file. Then we merged this data file with the admission records data files using both a unique resident ID and a unique facilitate ID. Then, we calculated the day-difference between the admission date and the assessment date of the quarterly data file. The first quarter assessments were identified if the day-difference was between 75 days and 105 days. Finally, we used these first quarter assessment records in our case mix analysis

We calculated the ADL score following the method developed by Morris and colleagues for the MDS ADL Long-Form. (Morris, Fries et al. 1999) Specifically, we used variables G1AA (bed mobility), G1BA (transfer); G1EA (locomotion on unit), G1GA (dressing), G1HA (eating); G1IA (toilet use), and G1JA (personal hygiene). The original coding for these variables were between 0 and 4 (0 for independent, 1 for supervision, 2 for limited assistance, 3 for extensive

assistance, and 4 for total dependence) and a number 8 was used when the activity did not occur during the entire 7 days of assessment. We recoded the number 8 (activity did not occur during the entire 7 days) as 4 (total dependence). We finally created a summation score of total ADL dependence by adding the value of these 7 variables. Therefore, the possible score of our ADL variable is between 0 and 28. A higher score means higher ADL dependence.

We used the Cognitive Performance Scale (CPS) developed by Morris and colleagues to measure the cognitive functioning of elders in NH.(Morris, Fries et al. 1994) The CPS was calculated using variables from section B (B1: Comatose; B2A: Short term memory), section C (C4: making self understood), and section G (GHA: eating) of the MDS. The possible score of CPS is between 0 and 6. A higher CPS score means lower cognitive functioning.

Results

Table 7 shows the changes in the NH case mix on admission. Between 2002 and 2004, the functioning level of elders admitted to NHs in PA deteriorated slightly from the average ADL score of 15.69 in 2002 to an average ADL score of 16.16 in 2004. Moreover, the proportion of residents admitted with no ADSL dependencies, or very few, decreased. During the same period of time, the cognitive functioning of elders admitted into NHs improved slightly. The average CPS score went down from 1.64 in 2002 to 1.62 in 2004, and the rate of persons with no cognitive impairment decreased while those with mild impairment increased.

Table 8 shows the NH case mix 3 months after admission for 2002, 2003, and 2004. Here again the ADL functioning at 3 months after admission deteriorated slightly over the 3 year period. The average ADL scores in 2002, 2003, and 2004 were 15.27, 15.49, and 15.60 respectively. The proportion of persons with no or few ADL dependencies also dropped. The CPS scores improved slightly between 2002 and 2004. The CPS score in 2002 is 2.43, dropped

to 2.40 in 2004. While the proportion of residents with no cognitive impairment decreased, the proportion with few cognitive impairment increased. This pattern suggest that HCBS may have achieved part of its goals in deflecting the clients with lower ADL needs to other sources, but the same effect was not seen for cognition.

Table 7: Characteristics of Admittees to Nursing Homes in Pennsylvania, 2002-2004

	2002	2003	2004
ADL score	%	%	%
0	3.0	2.6	2.5
1	0.8	0.7	0.7
2	1.2	1.1	1.1
3	1.1	0.9	0.9
4	1.8	1.5	1.4
5	1.5	1.2	1.1
6	2.1	1.8	1.7
7	1.9	1.7	1.6
8	2.4	2.1	2.0
9	2.2	2.0	1.9
10	3.2	3.0	2.9
11	3.1	2.9	2.9
12	5.4	5.4	5.2
13	5.1	4.9	4.8
14	5.4	5.2	5.1
15	4.8	5.0	5.0
16	5.0	4.9	5.0
17	5.2	5.4	5.6
18	7.5	8.4	8.8
19	7.7	8.5	9.4
20	5.9	6.4	6.7
21	5.2	5.7	5.9
22	3.9	4.1	4.2
23	2.7	3.0	2.8
24	2.5	2.5	2.5
25	1.9	1.8	1.8
26	1.8	1.7	1.7
27	1.8	1.8	1.6
28	4.2	4.0	3.5
Mean ADL	15.69	16.12	16.16
N*	108,341	105,526	97,622
CPS score			
0	40.2	39.1	38.4
1	14.1	14.2	15.3
2	13.5	14.1	14.5
3	18.8	19.5	19.6
4	4.8	5.0	5.1
5	4.8	4.6	4.2
6	3.9	3.5	3.0
Mean CPS	1.64	1.65	1.62
N*	108,308	105,484	97,577

Table 8: Pennsylvania NH Residents 3 Months Post-Admission, 2002-2004

	2002	2003	2004
ADL score	%		
0	5.0	4.5	4.7
1	1.5	1.4	1.3
2	2.3	2.0	2.0
3	1.8	1.7	1.5
4	2.5	2.2	2.1
5	1.7	1.8	1.5
6	2.4	2.3	2.2
7	2.4	2.2	1.9
8	2.3	2.3	2.2
9	2.2	2.4	2.1
10	2.9	2.9	2.6
11	2.9	2.7	2.6
12	3.5	3.6	3.4
13	3.8	3.7	3.7
14	3.7	3.8	3.8
15	4.4	4.6	4.8
16	4.4	4.4	4.4
17	4.7	4.8	5.4
18	6.7	7.4	7.6
19	6.7	6.7	7.9
20	5.2	5.6	6.2
21	5.1	5.2	5.8
22	3.9	4.3	4.1
23	3.0	3.1	3.2
24	2.9	3.0	2.8
25	2.3	2.2	2.2
26	2.1	2.1	1.9
27	2.4	2.2	1.9
28	5.4	5.1	4.5
Mean ADL	15.27	15.49	15.60
N	16,423	21,286	20,867
CPS score			
0	18.4	17.6	17.7
1	13.2	13.5	13.8
2	15.8	16.2	16.2
3	31.2	31.2	31.7
4	7.7	8.2	8.5
5	8.5	8.3	7.7
6	5.3	5.0	4.4
Mean CPS	2.43	2.44	2.40
N	16,420	21,283	20,864

Figure 6 shows the changes in the numbers of clients served under a variety of Medicaid programs. The largest sector of clients is in nursing homes, which decreased slightly in 2004.

The numbers served by the DD waivers have increased steadily since 2000. The numbers in the aging waiver are considerably smaller, but they too have increased steadily since 2001. These figures represent people served at any time during the year; some may not be covered for the full year.

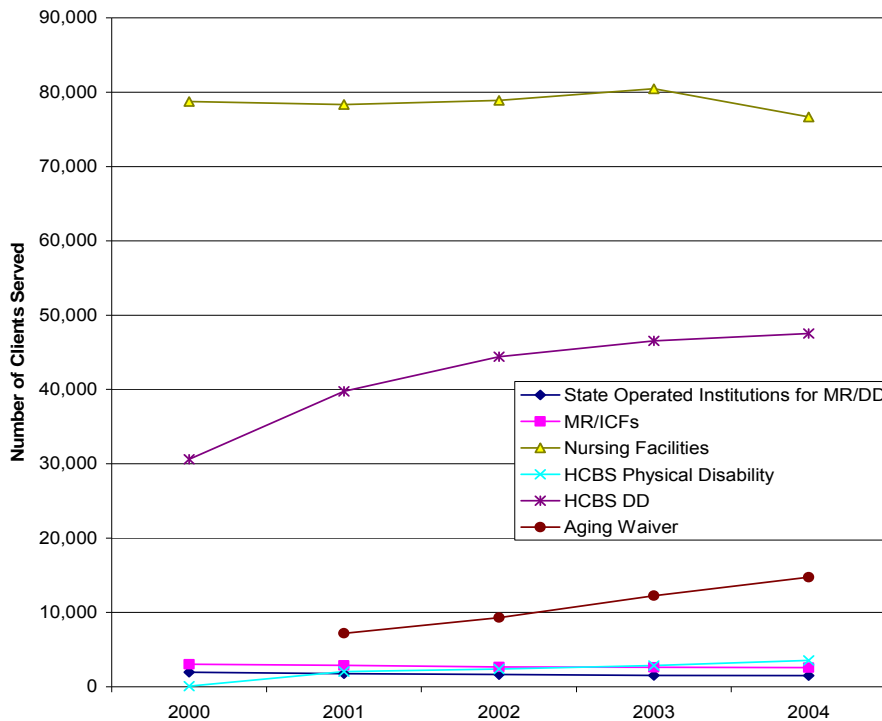


Figure 6. Clients Served in Selected Programs in Pennsylvania, 2000 to 2004.

Figure 7 traces the expenditures. The majority of the money goes to nursing homes, and this figure has increased steadily. The next largest expenditure is on facilities for MR-DD, both state operated and MR-ICFs. These expenditures have remained stable. Waiver funds are modest and steady.

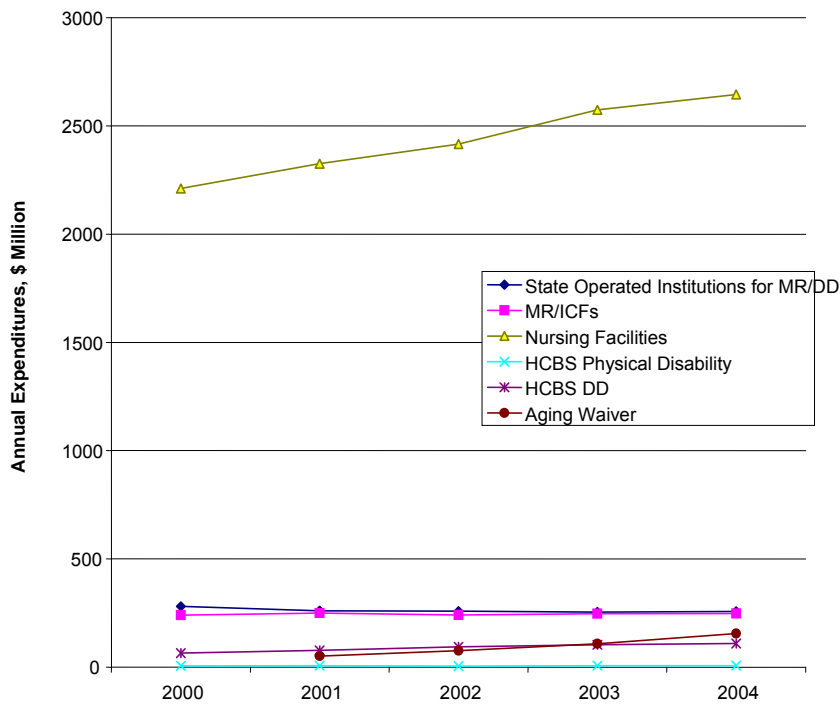


Figure 7. Expenditures for Selected Programs in Pennsylvania, 2000-2004

Figure 8 examines the costs per person served. This figure represents people served at any time during the year; some may not be covered for the full year. The most expensive services are those in institutions for MR-DD, followed by nursing homes. The MR-DD costs per client have grown steadily, much faster than those for nursing homes. The costs per client served for physical disability waivers fell precipitously in 2001 and remained steady thereafter. In general waiver costs per client are much lower than those in institutions.

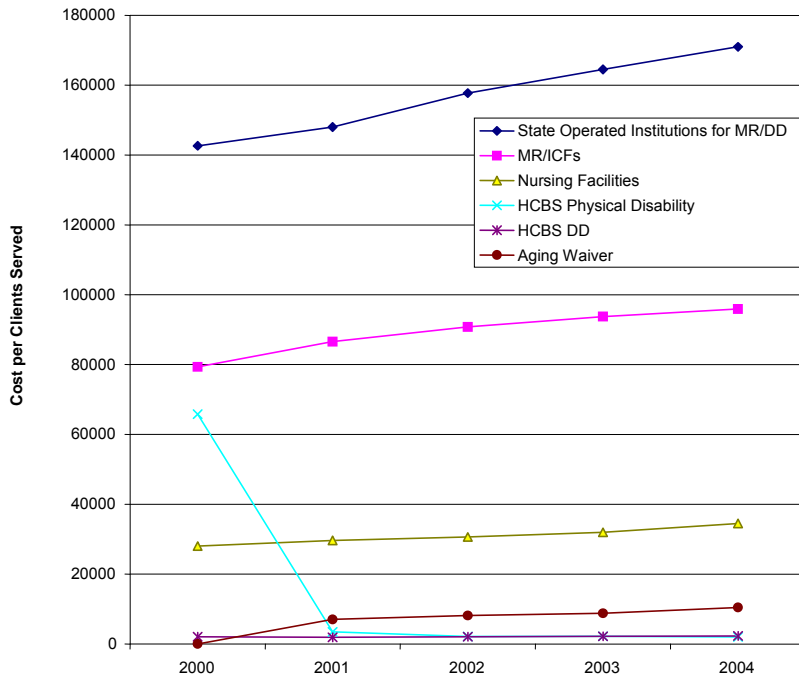


Figure 8. Costs Per Consumer Served in Selected Programs, 2000-2004.

Conclusion

Pennsylvania is working intensively to rebalance a system that has remained tilted to institutions despite a long tradition of community care provision. The challenges have been well identified with the involvement of stakeholders from the advocacy and provider community. The Community Choice demonstration has shown that it is possible to reduce bureaucratic barriers to access, and will be implemented state-wide. Cash and counseling options are scheduled to be added to many waivers. The state is poised to move ahead in reducing dependence on nursing homes and to affect closure of the remaining state institutions in the MR/DD area.

The state's efforts to improve balance in the long term care system were bolstered by a very high level Office of Health Care Reform by the Governor. Under Governor Rendell, OHCR

implemented a Long-Term Care Reform Project with experienced staff to initiate and coordinate policy and program efforts across agencies. Pennsylvania has made progress, but more needs to be done to successfully balance the long-term care system. Quality assurance programs are well developed for nursing homes but less well-articulated in community settings. Although Pennsylvania has multiple home and community based waiver service programs, many are difficult to access, have waiting list, or serve just a small number of consumers.

In this report, we described many of the planning and consolidating processes that have been undertaken in Pennsylvania to lay the groundwork for statewide systemic changes. In our future work, we will examine the extent to which Pennsylvania decides to make structural changes in state government operations to facilitate long-term care reform, the extent to which consumer-directed programs expand, the expansion of Community Choice statewide, and the results of the various housing, mental health, quality management, and managed care initiatives underway. Also of interest is when and if these reforms are achieved, the OHCR recedes as a vehicle in long-term living policy and the efforts revert to the established agencies, however they become changed. And finally, it will be of great interest to track whether these efforts have payoff in terms of rapidly accelerating rebalancing towards community care.

Issues for Future Observation

- How the new quality management efforts develop.
- Whether the state is successful in promoting more affordable accessible housing options and more awareness of existing vacancies.
- Whether a new state governmental structure evolves along functional lines as has occurred in other states.

- How the personal care home sector will evolve in terms of quality and the acuity of those served. At present, advocates' concerns about quality issues in personal care homes is part of the reason why they resist changing the licensure to allow nursing-home certifiable consumers in personal care homes.

The backdrop of fiscal pressures has historically helped some states, including Oregon in the 1980s, move towards enhanced community care when a vision for such care had already been established. Pennsylvania appears to have achieved some clarity on the vision and may now be poised to transform itself to a more balanced system.