

pmpc
Pennsylvania
Medicaid
Policy Center

University of Pittsburgh
A620 Crabtree Hall
130 DeSoto Street
Pittsburgh, Pennsylvania 15261

phone (412) 624-0898
fax (412) 624-3146
www.PAMedicaid.pitt.edu

Long-Term Care in Balance: The Role of Medicaid Policy in Pennsylvania

Howard B. Degenholtz, BA, PhD

Judith R. Lave, BA, PhD

Pennsylvania Medicaid Policy Center
University of Pittsburgh

2007



1	Report
17	Authors
17	Acknowledgments
18	Appendix A
23	Appendix B
26	Appendix C
27	References

Long-Term Care in Balance: The Role of Medicaid Policy in Pennsylvania

Introduction

Long-term care (LTC) accounted for approximately 41 percent of the \$15.8 billion in Medicaid expenditures in the state of Pennsylvania in fiscal year 2005.¹ The Medicaid program is the single largest payer for LTC provided in nursing homes, covering 63.4 percent of all residents and accounting for 49 percent of all nursing home expenditures. LTC represents a substantial component of Medicaid spending, and Medicaid policies have great impact on the lives of people who need services and their families. In Pennsylvania, as in other states, there are major ongoing efforts to shift LTC spending away from nursing homes and toward home and community-based alternatives. The overall goal of such rebalancing policies is to provide people who need LTC and prefer to live in their own homes or with a relative with appropriate financing and services under Medicaid. Rebalancing policies avoid relocating these people to a nursing home or, for those who are mentally retarded, to an intermediate care facility for people with mental retardation (ICF-MR) if they are mentally retarded.

The 1999 *Olmstead* decision by the United States Supreme Court clarified that people with disabilities have a right to receive long-term care services in the most integrated setting possible.² This means that state funding for long-term care through programs such as Medicaid must place high priority on serving people in home and community-based settings, rather than in institutions such as nursing homes. Shifting the balance of long-term care in the state of Pennsylvania away from institutional care, especially for the elderly, is an important step towards compliance with *Olmstead*.¹

This report is divided into two main parts. First, in the background section we provide an

overview of long-term care programs in the state of Pennsylvania. The focus is generally on efforts to provide home and community-based alternatives to institutional care for people with mental retardation or developmental disability (MR/DD) and for disabled elderly. We define long-term care discuss the setting, financing, and some of the demographic trends facing the system, and then we address workforce issues.

In the second part, we introduce and discuss several policy options related to expanding community-based long-term care. For each recommendation, we discuss the rationale and potential costs and benefits. The recommendations range from specific policy changes to adoption of broad principles. Some refer to existing programs that could be expanded and others to initiatives that have been tried in other parts of the country. In summary, the recommendations are:

1. Adopt a uniform client assessment instrument across care settings
2. Consolidate financial and operational management of institutional and home and community-based services (HCBS)
3. Expand opportunities for flexible combinations of housing and services
4. Streamline the eligibility process for accessing HCBS
5. Expand consumer directed home care for the elderly
6. Develop a quality assurance program for home and community-based services
7. Commit additional funding to continue expansion of HCBS

This list of recommendations addresses several aspects of the LTC system in the state of Pennsylvania. Adoption of the recommendations listed in this report will help continue the movement toward a more balanced LTC system, especially for the disabled elderly.

This report concludes that while the state of Pennsylvania provides a substantial level of service in home and community-based settings for people with MR/DD, there is significant room for improvement with regard to disabled elderly. The introduction and rapid growth of the Pennsylvania Department of Aging (PDA) waiver over the past seven years has provided support for many disabled

¹The issues raised by *Olmstead* are central to the evolution of long-term care policy and undergird this report. A detailed discussion of *Olmstead* is included in Appendix C.

elderly to live as independently as possible. However, the overwhelming majority of Medicaid financed LTC for the aged is still provided in the nursing home setting. Significant expansion of the PDA waiver would be needed to reach the level of balance seen in other parts of the country, or even to reach Governor Rendell’s stated goal of 50 percent allocation between home and community-based care and nursing homes (whether measured by expenditures or people served).

Background

WHAT IS LONG-TERM CARE?

Long-term care (LTC) is defined as “assistance and services provided to people who, because of chronic illness or disabling conditions, are limited in their ability to perform basic activities.”³ Disabilities can arise from physical or mental health problems and may develop overtime or be present at birth. People with disabilities may require the assistance of another person to accomplish important tasks necessary for everyday living. These tasks, commonly referred to as basic activities of daily living (ADL) and also referred to as self care or personal care, are: bathing, feeding oneself, using the toilet, getting dressed, and basic mobility (e.g., moving from bed to chair). Another set of activities, referred to as instrumental activities of daily living (IADL), require a higher level of physical capacity and executive function than ADLs. These tasks – using the telephone, taking medications, light housework, money management, meal preparation, and shopping – are considered instrumental because they must be done for the basic ADLs to be possible. For example, a person who is capable of feeding herself may not be able to go grocery shopping or cook. Similarly, a person may be able to dress himself but not be able to do laundry. Both IADL and ADL limitations are used in determining level of disability.

People with LTC needs are commonly divided into two populations based on age and the cause of the disability. People who are elderly (i.e., 65 years old and over) typically have LTC needs due to chronic disease or cognitive impairment due to stroke, Alzheimer’s disease or other neurological disorders. People who are younger (defined as under the age of 65) are much more likely to be disabled as a result of mental retardation or a developmental disorder (MR/DD).

WHERE DO PENNSYLVANIANS RECEIVE LTC?

Nationally, the majority of people with LTC needs (63 percent) is over 65 years of age. The elderly disabled population is more likely to live in an institutional setting than the younger population; 25 percent of disabled elderly live in nursing homes, while only 4.5 percent of disabled younger people live in any type of institution. In Pennsylvania, as shown below on Table 1, the patterns are similar.⁴

In Pennsylvania there were an estimated 512,025 people with a personal care disability who needed LTC in 2006 (see Table 1). This includes residents of nursing homes, people living in personal care homes (PCH), facilities for people with MR/DD, and people who are living in the community.ⁱⁱ The table also shows where people in Pennsylvania who need LTC receive their care. Of the 512,025 people with self-care disabilities, 57 percent are age 65 or older. The elderly population is much more likely to live in an institutional setting: 42 percent compared to 5 percent among the younger disabled.

Table 1: Pennsylvanians with Self-Care Disabilities by Type of Residence

Place of Care	Age < 65	Age ≥ 65
	(N = 219,117)	(N = 292,908)
Community*	207,239	168,928
ICF/MR†	2,581	-
State Center†	1,380	-
Personal Care Home/ Assisted Living‡	-	50,005
Nursing Home	7,917	73,975

Source: *American Community Survey, 2006. US Census Department. † Data are for year 2006-2007, Pennsylvania Budget Document, 2007-2008. ‡Personal Care Home Monthly Statistical Report. <http://www.dpw.state.pa.us/PartnersProviders/LongTermLiving/003670903.htm> (Accessed 10/29/2007).

There are 1,550 licensed PCHs in the state of Pennsylvania with a total of 71,337 beds⁵ (see Appendix B for detailed discussion of PCHs).ⁱⁱⁱ

ⁱⁱ Estimates of the number of people who need long term care and who live in the community come from the 2005 American Community survey (ACS) that is conducted by the US Census.

ⁱⁱⁱ In Pennsylvania, the phrase “assisted living” can be used in marketing materials, but all such facilities must be licensed as Personal Care Homes (PCH). In 2007, legislation created a new

These facilities serve predominantly elderly people^{iv} with self-care disabilities who need daily assistance but do not meet the acuity threshold for nursing home care. In 2005, the last year for which complete data are available, there were 702 nursing homes in the state with 86,224 beds, serving a total of 77,679 residents (see Table 2).

Table 2: Nursing Home Supply and Occupancy, 1999 to 2005.

Year	Facilities	Beds	Residents	Occupancy Rate
1999	750	91,250	81,108	88.9
2000	708	87,320	77,488	88.7
2001	700	86,936	76,267	87.7
2002	694	85,354	76,290	89.4
2003	693	85,522	77,207	90.3
2004	688	85,203	77,209	90.5
2005	702	86,224	77,679	90.0

Source: Harrington, C., Carrillo, H., and LaCava C., *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 1999 through 2005*. September 2006. Department of Social and Behavioral Sciences, University of California, San Francisco.

People under age 65 with disabilities due to mental retardation or developmental disability are primarily served in the community. Historically, in Pennsylvania as in the rest of the U.S., people with disabilities due to mental retardation lived in state-operated facilities. Following national trends that began in the 1960s, there has been a continual increase in the availability of supportive services in the community and a resulting decline in the number of people living in those centers. Between 1996 and 2006, the census at state centers in Pennsylvania decreased 56% from 3,164 to 1,380 individuals. There are currently five state owned centers (Ebensburg, Hamburg, Polk, Selinsgrove, and White Haven) and 204 certified privately owned Intermediate Care Facilities for the Mentally Retarded (ICF/MR). These facilities are mostly small; 185 serve four-eight people and 19 serve more

licensure category for 'assisted living residence'. See Appendix B for a discussion of this issue.

^{iv} Personal Care Homes are open to people over age 18. Although statistical data are not available, very few non-elderly are believed to live in these settings as younger disabled people do not prefer to be housed with elderly, and those with mental retardation live in different housing.

than eight. The Office of Developmental Programs^v supports encouraging privately owned ICF/MR facilities to downsize further and to shift from a medical to a social model.^{vi} Finally, there are 7,917 people under age 65 live in nursing homes; it is not known what proportion of those residents are receiving rehabilitation or post-acute care (short-term) versus custodial care (long-term).

WHO PROVIDES LTC IN THE COMMUNITY?

As shown on Table 1, there were approximately 376,176 people with a self-care (ADL or IADL) disability living in the community in Pennsylvania in 2005.⁶ Of these, 55 percent were under age 65, and 45 percent were age 65 and older. According to national survey data, 78 percent of people who live in the community and who have self-care needs receive assistance from unpaid helpers only. Another 14 percent rely on a combination of paid and unpaid help, and 8 percent have only paid help. Unpaid assistance with ADLs and IADLs is typically performed by close relatives of the person with disabilities, such as a spouse, adult child, or parent. Many also receive assistance from volunteers, neighbors, and friends. The level of assistance can vary considerably, from just a few hours per week to full-time support. A recent study by the AARP estimated that the economic value of family caregiving in the state of Pennsylvania was \$14.5 billion dollars per year, which is the sixth highest of all 50 states.⁷ By way of comparison, total expenditures (all payers) for nursing home care in Pennsylvania were \$7.6 billion in 2004.⁸

WHO PAYS FOR LTC?

Medicaid accounts for 48.7 percent of all expenditures on nursing home care in the state of Pennsylvania. In 2005, the last year for which data are available, Medicaid was the primary payer for 63.4 percent of all nursing home residents in the state

^v Previously name was the Office of Mental Retardation. The name was changed in 2007 and Bureau of Autism Services was added to the portfolio.

^{vi} Shifting from a medical to social model involves placing priority on individual growth and development, well-being and quality of life, in addition to meeting their medical needs. For basic principles of ICF/MR facilities: <http://www.dpw.state.pa.us/PartnersProviders/MentalRetardation/03670034.htm>

of Pennsylvania, while Medicare was the primary payer for only 12.2 percent of the residents. (Medicare does not pay for long-term care, but does pay for rehabilitation or post-acute care provided in a nursing home for up to 100 days; the average number of days per admission in 2006 was 25.6.⁹) Direct payments (either by the resident or the resident's family) were the primary source of payment for the rest of the residents.¹⁰ Table 3 shows the proportion of nursing home residents with different primary payer sources in Pennsylvania and for the US from 1999-2005.

Table 3: Proportion of Nursing Home Residents with Different Primary Payer Sources in the US, Pennsylvania, 1999 to 2005

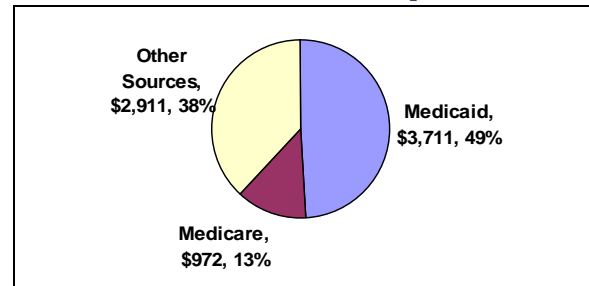
	US			Pennsylvania		
	Medi caid	Medi care	Private/ Other	Medi caid	Medi care	Private/ Other
1999	67.7	8.6	23.7	63.9	8.8	27.3
2000	67.6	9.0	23.4	64.2	8.8	27.0
2001	66.9	9.8	23.3	63.9	9.6	26.6
2002	66.7	10.7	22.6	63.7	10.3	26.1
2003	66.2	11.7	22.0	63.5	11.1	25.4
2004	65.7	12.2	22.0	64.2	11.0	24.8
2005	65.4	13.1	21.6	63.4	12.2	24.4

Source: Harrington, C., Carrillo, H., and LaCava C., *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 1999 through 2005*. September 2006. Department of Social and Behavioral Sciences, University of California, San Francisco

The difference between the proportion of nursing home residents who had Medicaid as their primary payer source and the proportion of nursing home revenues that come from Medicaid is due to two factors. First, Medicaid payment rates are lower than the payments received from other sources. For example, the average reimbursement rate in the state of Pennsylvania in 2004 from Medicare was \$303.75 per day, compared to \$160.70 per day from Medicaid.¹¹ People who pay for nursing home care themselves or with private LTC insurance pay a rate that is slightly less than the Medicare rate. Second, recipients often have more than one source of payment. Residents for whom nursing homes receive Medicaid payments must contribute all of their Social Security payments (and other income if there is some), with the exception of a small personal care allowance, towards their care. As a result, in 2004 the last year for which expenditure data are available,

Medicaid paid for 48.7 percent (\$3.711 billion) of nursing home care in the state of Pennsylvania, Medicare paid for 13 percent (\$972 million), and resident payments and other sources accounted for 38 percent (\$2.911 billion).^{vii 12} Other sources include private insurance (2.46 percent and Veteran's Administration (.86 percent).

Figure 1: Distribution of Nursing Home Expenditures by Payer Type, 2004 (millions). Source: United States Personal Health Care Expenditures. Centers for Medicare & Medicaid Services, Office of the Actuary, National Health Statistics Group.



Medicaid is also a significant payment source for people with disabilities living in the community. The primary financing mechanism is through home and community-based services (HCBS) waivers or waiver programs. (See Appendix A for background on waiver programs and a list of services offered by each type of HCBS waiver in Pennsylvania.) In 2006, Pennsylvania waiver program expenditures for the MR/DD and the elderly disabled populations were \$1.2 billion and \$439 million respectively. Table 4 shows the increase in expenditures in these programs over time. Between 1999 and 2006, expenditures by Medicaid waiver programs for the elderly increased nearly ninefold while those for people with MR/DD more than doubled. The dramatic increase among the elderly is mainly due to growth in the number of people served by the program (see Table 4), while the increase in the MR/DD population is due to modest changes in program size and moderate increases in the expenditures per person.

^{vii}. Note that data are based on a calendar year rather than fiscal year.

Table 4: Medicaid Waiver Expenditures for MR/DD and Elderly Population in Pennsylvania, 1999 to 2006

Year	Mental Retardation/ Developmental Disability		Elderly
1999	\$489,410,573		\$49,694,241
2000	\$659,318,641		\$66,723,641
2001	\$800,525,109		\$99,872,940
2002	\$888,105,157		\$133,637,621
2003	\$1,000,116,107		\$180,848,004
2004	\$1,040,642,422		\$253,535,151
2005	\$1,091,062,813		\$385,919,962
2006	\$1,152,338,340		\$439,840,122

Source: Medstat, 2004, 2007

The number of participants in Pennsylvania Medicaid waiver programs for the MR/DD population increased 180% from 12,501 in 1999 to 34,878 in 2006, the last year for which data are available (recent data are shown on Table 5). Growth has been much faster in the waiver program for the elderly population [known as the PDA waiver], which began in 1999. In 2004, there were 20,495 elderly Medicaid waiver recipients (data for 2005-2006 and 2006-2007 are not available).

Table 5: Medicaid Waiver Participants: Mentally Retarded/Developmentally Disabled and Elderly Disabled Populations, Pennsylvania 2002 to 2004.

Year	MR/DD	Aged
2003-2004	26,736	12,826
2004-2005	31,390	20,495
2005-2006	33,274	n.a.
2006-2007	34,878	n.a.

Source: State of Pennsylvania. MR/DD is Mental Retardation/Developmental Disability and includes the Attendant Care, Personal Family Directed Support, OBRA, Infant, Toddlers and Families, Independence, and Consolidated Waiver programs. Aged includes the Pennsylvania Department of Aging 60+ Waiver. Recent data for Aged waiver participants are not available.

Average expenditures for the MR/DD population are substantially higher than for the aged. In 2004-2005, the average expenditure for all MR/DD waivers was \$33,152. This includes waivers serving all ages of people with MR/DD including residential care (see Appendix A). The PDA waiver that serves the elderly spends about \$12,370 per person annually. (By contrast, the average annual cost of a nursing home is \$55,892.) The dramatic

difference in HCBS expenditures between the MR/DD and elderly reflects the needs of the population and that waiver programs for the MR/DD population were explicitly designed to substitute for large, state-run institutions that provide all-inclusive housing and care for people with limited ability to live independently. By contrast, programs for the aged are intended to support people who have lived independently their entire lives but have experienced decline in function, and they are still expected to pay for their own living costs.

FUTURE DEMAND FOR LTC WILL INCREASE

This section projects what the future demand for LTC will likely be over the next several decades. Since the major factor affecting demand for LTC is the aging of the population, we focus here on predictions of the rate of disability among people over age 65.

The demand for LTC services is expected to increase with the aging of the baby boom generation (i.e., people born between 1946 and 1964, the oldest of whom will reach 65 in 2011). Table 6 shows predictions of the size of Pennsylvania's elderly population from 2000 to 2025. These estimates are based on the 2000 census.^{viii} The percentage of the population over 65 was projected to drop from 15.6 percent in 2000 to 15.4 percent in 2005, then increase steadily from 2006 onward, reaching 21.9 percent in 2025.¹³ The percentage of the Pennsylvania population over age 85 was projected to increase steadily from 1.9 percent in 2000, to a high of 3 percent in 2025. At the same time, the proportion of people under age 65 is expected to fall from 84.6 percent to 78.1 percent placing greater burden on working age people to finance services for the disabled and the elderly. By contrast, the US population is projected to be slightly younger, with 80 percent under age 65.

^{viii} We elected to report projections based on the 2000 census for consistency. Annually updated population statistics from the American Community Survey do not count institutionalized populations or people living in group homes, and are thus not consistent with the projections. The projections for years 2001-2004 are consistent with state vital statistics reports http://app2.health.state.pa.us/epiqms/Asp/SelectParams_Tbl_count.s.asp (accessed 9/12/2007)

Table 6: Population Aging Projection for State of Pennsylvania

Year	Number			Percent	
	Total	65 to 84	85+	65 and over	85+
2000	12,281,054	1,681,598	237,567	15.6%	1.9%
2001	12,295,929	1,663,119	247,377	15.6%	2.0%
2002	12,321,644	1,647,941	255,227	15.5%	2.1%
2003	12,351,381	1,633,821	265,247	15.5%	2.2%
2004	12,391,530	1,619,382	277,949	15.4%	2.3%
2005	12,426,603	1,607,466	289,044	15.4%	2.4%
2006	12,460,844	1,599,004	300,554	15.5%	2.4%
2007	12,493,634	1,599,079	311,569	15.6%	2.5%
2008	12,525,118	1,611,432	320,125	15.7%	2.6%
2009	12,555,469	1,617,098	329,133	15.8%	2.7%
2010	12,584,487	1,618,183	338,052	15.9%	2.8%
2011	12,612,380	1,628,036	345,296	16.1%	2.8%
2012	12,639,226	1,669,216	351,520	16.5%	2.9%
2013	12,664,761	1,709,050	357,129	16.8%	2.9%
2014	12,688,737	1,745,865	360,286	17.1%	2.9%
2015	12,710,938	1,785,684	363,298	17.5%	3.0%
2016	12,731,118	1,827,095	364,942	17.8%	3.0%
2017	12,748,977	1,876,045	364,878	18.2%	3.0%
2018	12,764,432	1,929,028	363,379	18.7%	3.0%
2019	12,777,274	1,984,583	361,158	19.1%	2.9%
2020	12,787,354	2,041,545	361,573	19.6%	2.9%
2021	12,794,939	2,097,299	361,856	20.0%	2.9%
2022	12,800,217	2,155,433	362,468	20.5%	3.0%
2023	12,803,142	2,213,395	364,398	21.0%	3.0%
2024	12,803,729	2,266,802	366,787	21.4%	3.0%
2025	12,801,945	2,318,958	369,823	21.9%	3.0%

It is possible that growth in demand for LTC due to the increasing size of the elderly population in Pennsylvania will be offset somewhat by lower prevalence of disability. For example, in nationally representative data, the prevalence of disability in ADL or IADL among people over age 65 in 1982 was 26.2 percent, but in 1999 the prevalence had decreased to 19.7 percent.^{ix 14} This decline in prevalence is attributed to factors such as improved medical treatments (e.g., arthritis medication, joint replacement), positive behavioral changes (e.g., better diet, reduced alcohol and tobacco use, exercise), widespread use of assistive technology,

^{ix} Note that estimates of disability from this source are different than ACS and Census due to different definitions and sampling methods.

and improvements in socio-economic status among successive cohorts of elderly.

Based on population growth alone, the number of disabled elderly in the state of Pennsylvania is expected to increase by 41 percent by 2025 (assuming 19.7 percent of elderly are limited in one or more ADL or IADL). However, if the prevalence of disability continues to decline at the same rate as was observed from 1982 to 1999, then by 2025 there will be 52,866 fewer disabled elderly in the state of Pennsylvania than expected.^x There is no way to predict whether this trend will continue; indeed, the increasing prevalence of obesity in the adult population may offset these gains. Nevertheless, even under this optimistic estimate, the LTC system in Pennsylvania will still need to accommodate 100,457 (27%) more disabled elderly people than it does today.

As noted, Pennsylvania has a relatively high proportion of elderly, placing Pennsylvania at a comparative disadvantage relative to other states with regard to the aging of the population. According to the American Community Survey (ACS), 26.7 percent of Pennsylvania households had one or more persons aged 65 or older. With respect to the percent of households with one or more person aged 65 or over, Pennsylvania ranked fourth after Florida (29.4 percent), Hawaii (28.2 percent), and West Virginia (27.2 percent). The percentage of Pennsylvania's population that was over age 65 was 15.2 percent in 2006, ranking third highest after Florida (16.8 percent) and West Virginia (15.3 percent). Pennsylvania also ranks high in terms of the proportion of people over age 85 – the population most at risk for nursing home placement. In 2006, Pennsylvania was third highest, with 2.4 percent of its population age 85 or older, just slightly behind Florida and North Dakota (tied with 2.6 percent), and Iowa (2.5 percent).

THE LONG-TERM CARE WORKFORCE

The long-term care workforce is facing several critical challenges that affect Medicaid funded

^x It is not clear, however, whether disability rates will continue to drop in the coming decade. The trends that provided better health for current cohorts of elderly may be offset by increasing prevalence of chronic disease and obesity among working age and near elderly.

programs: there is an impending shortage of workers, turnover rates (which are associated with poor quality of care) are high, and training is inadequate. These problems are faced by all categories of LTC providers. This section describes these issues in greater detail and discusses several initiatives currently underway to alleviate these problems.

There are currently 137,140 nursing assistants, home health aides, and personal care aides in Pennsylvania, and their average wage is \$10.52 per hour.¹⁵ The Pennsylvania Department of Labor and Industry estimates that there will be a need for 45,100 additional direct-care workers in long-term care by the year 2014.¹⁶ However, the pool of people who typically fill these jobs, women aged 25-44, is projected to grow much more slowly than the need for workers. This pattern is reflected nationally.¹⁷ Many employers report vacancies; for example, a 2001 study in Pennsylvania reported that 13 percent of long-term care providers (including nursing homes, home health agencies, personal care homes, adult day centers, and centers for independent living) were experiencing a vacancy rate of 20 percent or higher.¹⁸

Nationally, turnover rates in nursing homes have averaged as high as 45 percent, although some facilities have experienced rates of up to 200% per year. Recruitment and retention are thus considered to be major workforce issues. Other issues facing the LTC workforce include: inadequate initial training and limited continuing education of workers, low levels of compensation, lack of benefits, limited career advancement, poor working conditions, and low job satisfaction. It is physically demanding and dangerous work. For example, the prevalence of workplace injuries among direct-care workers is higher than in the construction, coal mining, and trucking sectors.¹⁹

One major effort to improve the LTC workforce currently underway in Pennsylvania is being led by the Better Jobs and Better Care Coalition (BJBC-PA). The original funding came from a grant by the Robert Wood Johnson Foundation²⁰ to the Center for Advocacy for the Rights and Interests of the Elderly (CARIE), which was the lead organization for a statewide coalition. The goals of that project, described below, are different from other workplace interventions. For

example, typical workplace interventions such as improving salary and benefits place the cost and responsibility on providers who might not have sufficient revenue. States have experimented with policies such as “wage pass-through” to help workers without the increase being siphoned off as profit; such a program clearly requires commitment from the state to increase funding and the evidence is lacking that such policies are effective.

The goals of the BJBC-PA are to demonstrate successful strategies to improve retention, create new training models that better prepare workers for the job, and empower workers to take the lead in promoting their profession. BJBC-PA has produced and pilot-tested a universal core curriculum for direct-care workers that covers the following topics: home care, nursing home, adult day services, assisted living, consumer direction, and death and dying.²¹ The coalition includes 27 different providers who have worked on redesigning and improving aspects of the workplace following a collaborative model between management and direct care workers.²² In addition to these projects, the BJBC-PA advocates for policies that support direct-care workers, such as advanced training for direct-care workers and revision of criminal background check rules.

Other organizations involved in improving the LTC workforce are the Pennsylvania Direct Care Worker Association²³, a membership organization dedicated to providing education, networking, leadership and system improvement, and the Pennsylvania Culture Change Coalition,²⁴ which aims to advocate for transformation across long-term care settings from an institutional model to a “relationship and community focused model of living.”

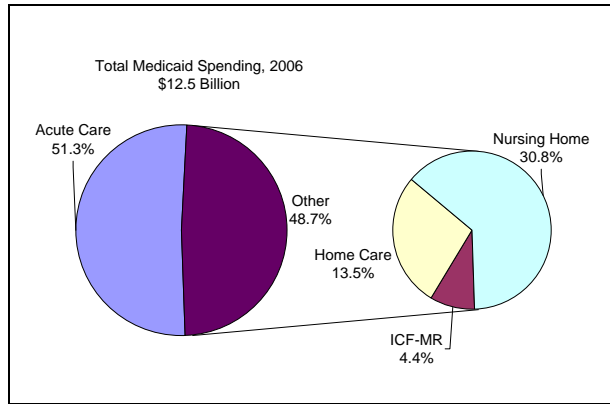
In summary, the implications for Medicaid of continued problems in the direct-care work force are poor quality of care in all settings due to turnover and vacancies. The use of temporary agency staff leads to increased cost. Finally, in HCBS, limitations in the supply of labor will hinder program expansion. Inadequate training raises quality concerns for all settings.

IMPACT OF LONG-TERM CARE ON PENNSYLVANIA'S MEDICAID BUDGET

Expenditures on LTC make up a substantial proportion of Pennsylvania's Medicaid budget (see

Figure 2). In 2006, expenditures on nursing homes (\$3.9 billion), ICF-MR (\$555 million), and home care (\$1.7 billion), accounted for 48.7 percent of all Medicaid expenditures.²⁵

Figure 2: Proportion of Medicaid Spending on Long-Term Care



Source: Medicaid Long-Term Care Expenditures in FY 2006. Thomson Healthcare, Cambridge, MA.

Table 7 shows the actual expenditures for acute and long-term care by Pennsylvania Medicaid and the proportion in each category for the years 2001 through 2006. There are no Medicaid expenditures for assisted living facilities because Medicaid does not pay for assisted living. Under the new assisted living licensure, Medicaid will be able to pay for services provided to people living in assisted living residences, but will not be able to pay for room and board, as with nursing home care. The proportion of

Medicaid expenditures spent on nursing homes decreased from 36.3 percent in 2001 to 30.8 percent in 2006, and the proportion spent on home care services^{xi} over the same time period increased from 9.5 percent in 2001 to 13.5 percent in 2006.²⁶ One possible explanation for the relative decrease in nursing home expenditures is that the state has not adjusted Medicaid payment rates for inflation. Rather, the state has applied a multiplier factor to the case-mix adjusted payment formula that has had the effect of keeping per diem rates relatively flat.²⁷ The other explanation is the increase in spending under the HCBS.

The absolute level of Pennsylvania expenditures on nursing homes increased 18 percent from \$3.6 billion in 2001 to \$4.3 billion in 2005.^{xii} (Data for 2006 are shown, but are not considered reliable due to corrections processed throughout the year.) By contrast, expenditures for BCBS increased 62 percent from \$965 million in 2001 to \$1.7 billion in 2005. Over this same time period, overall Medicaid expenditures (acute and long-term care) increased by about 33 percent. This increase is due in large part to the use of tobacco settlement money for expanding the PDA waiver for the elderly.

^{xi} Home care includes HCBS waivers and Medicaid funded Home Health Care that is provided post-hospitalization.

^{xii} Medical price inflation in the nursing home sector was approximately 19% from 2001 to 2005. Source: Producer Price Industry Data (<http://data.bls.gov/cgi-bin/dsrv>) Accessed 12/3/2007.

Table 7: Medicaid Expenditures on Acute and Long-Term Care, 2001 to 2006 (in 1,000s)

	2001		2002		2003		2004		2005		2006	
	Expenditure s	%	Expenditure s	%	Expenditure s	%	Expenditures	%	Expenditures	%	Expenditures	%
Acute Care	\$5,009,567	49.4	\$5,905,812	51.7	\$6,663,117	53.5	\$6,198,194	50.8	\$7,049,409	52.1	\$6,446,201	51.3
ICF-MR	\$486,149	4.8	\$506,212	4.4	\$511,953	4.1	\$506,685	4.2	\$587,907	4.3	\$555,408	4.4
Home Care	\$965,156	9.5	\$1,083,812	9.5	\$1,239,008	10.0	\$1,358,078	11.1	\$1,565,254	11.6	\$1,693,224	13.5
Nursing Home	\$3,684,030	36.3	\$3,933,228	34.4	\$4,036,788	32.4	\$4,135,470	33.9	\$4,337,387	32.0	\$3,861,854	30.8
Total	\$10,144,901		\$11,429,064		\$12,450,866		\$12,198,426		\$13,539,958		\$12,556,687	

Source: Thomson Healthcare, 2007. Note: Home Care includes Home and Community Based Services Waivers for Mentally Retarded and Developmentally Disabled (MR/DD) and elderly.

THE BALANCE BETWEEN INSTITUTIONAL AND COMMUNITY-BASED SERVICES

The expansion from 2000 to 2005 in home and community-based services for the elderly in Pennsylvania has shifted the balance of where people who need LTC services are served (see Table 8). However, Medicaid expenditures on LTC for the elderly are still heavily tilted toward nursing homes, whereas the reverse is true for the MR/DD population. One way to express this is to examine the ratio of expenditures on community-based services to that of institutional services. As shown on Table 8, the ratio for the MR/DD population is lower than one, indicating that expenditures are higher for community-based services. By contrast, the ratio for the elderly is much higher than one, indicating that for every \$1 spent on community-based services nearly \$12 is spent on institutional care.

Table 8: Ratio of Expenditures on Institutional to Community-based LTC Services.

Year	MR/DD	Elderly
2000	.75	56.94
2001	.61	39.15
2002	.57	30.96
2003	.52	23.20
2004	.51	17.47
2005	.56	11.55

Source: Medstat. Notes: For the MR/DD population, comparison is waiver services to ICF-MR. For the Elderly, comparison is waiver services to nursing home.

From 2000 to 2005, the time period that HCBS for the elderly were expanding, the Pennsylvania nursing home population was basically unchanged, decreasing slightly from 87,320 to 86,224.²⁸

Although the overall elderly population in the state declined somewhat from 1.68 million to 1.6 million, the population over the age of 85, which is most at risk for LTC needs, actually increased from 237,567 to 289,044. Analysis of nursing home admission data suggests that the level of functional impairment among new admissions increased slightly during this time period, implying that some elderly with slightly lower levels of disability were diverted away from nursing homes.²⁹ However, it is also possible that the expansion of HCBS for the elderly has served people who otherwise would not have chosen to live in a nursing home.

Policy Options for Expanding Community-Based Long-Term Care

It is widely recognized that people with disabilities, regardless of age and their families, prefer that LTC services be provided in home and community-based settings rather than in institutions. The experience for people in the MR/DD population is quite different than that of the disabled elderly, however. The state of Pennsylvania has had a long tradition of providing community-based services for the MR/DD population (see Appendix A); Medicaid spending on institutional care is only about half of the spending on home and community-based services. However, although some progress has been made towards providing elderly disabled people with the opportunity to receive services in their setting of choice, institutional spending for the elderly outstrips home and community-based services by a factor of more than 10. In 2005, Pennsylvania ranked 47th in terms of the balance of Medicaid expenditures between institutional and community-based services for the elderly, with only 9.5 percent of expenditures on LTC services going toward community-based

services, and 90.5 percent going towards institutions.³⁰ Selected states that ranked near the top with respect to reducing the proportion of Medicaid LTC expenditures going to community-based services include: Oregon (1st, 53.7 percent), Washington (4th, 51.3 percent), Texas (6th, 45.8 percent), Minnesota (8th, 40.0 percent) and Vermont (11th, 34.8 percent). The success of these states in reducing the reliance on nursing homes has been credited, at least in part, to policies that could be considered or expanded in Pennsylvania.

Next, we discuss several policy recommendations related to expanding home and community-based long-term care services. The rationale for each recommendation is presented, and potential benefits and cost implications are presented.^{xiii} (A detailed cost/benefit analysis of each recommendation is beyond the scope of this report.) Where possible, we have identified and drawn on examples from other states; however, many of the initiatives described below have not been formally evaluated, and thus the experience and implications for the state of Pennsylvania cannot be estimated.

1. ADOPT A UNIFORM ASSESSMENT INSTRUMENT ACROSS CARE SETTINGS:

The state should consider adopting a uniform assessment instrument that can be used to compare health status and quality of care across long-term care settings.

The state of Pennsylvania does not have a statewide instrument for assessing eligibility for both home and community-based services and nursing homes.³¹ A standardized assessment instrument would make it possible to assure fairness and objectivity in both eligibility determination and care planning. In addition, it would be possible to make reliable comparisons of people served in each setting and track outcomes using a consistent metric. Such an instrument would enable the state to examine LTC costs while adjusting for acuity and also to distribute resources more efficiently and equitably.

The state of Washington has made strides in this area with the development and implementation of

^{xiii} In developing these recommendations, we reviewed and synthesized several recent reports; these are referenced as appropriate.

the Comprehensive Assessment and Reporting Evaluation (CARE) system. The CARE incorporates all elements of the nursing home Minimum Data Set (MDS)^{xiv} along with direct consumer assessments, making it possible to compare client characteristics across programs and settings including nursing homes.³² The CARE system determines functional eligibility and calculates resource allocations for each client. The state uses these data to monitor the quality of care; the state can examine and report quality based on the type of setting where the person lives, or the case manager, field office, or region. In addition, the state uses data on caseloads to generate forecasts to assist in planning and budgeting.

The state of Pennsylvania has an opportunity under the new Assisted Living Residence legislation to introduce a standardized instrument for home and community-based services waivers, assisted living residents, and nursing home residents. Specifically, under the new law, the state must conduct a comprehensive assessment on all Pennsylvania residents who receive services paid for by HCBS waivers. This assessment must use “an instrument that provides comparable data elements and at comparable time intervals as specified by the state for Medicaid for nursing facilities.”³³ **The state should consider adopting an instrument for HCBS such as CARE or the one produced by the developers of the nursing home Minimum Data Set (MDS).** InterRai,^{xv} the developer of the nursing home MDS has developed compatible versions for home care and assisted living. The home care version (MDS-HC) has established reliability and validity in the US and abroad,³⁴ and MDS-HC has been adopted statewide in Michigan³⁵ and by the Veteran’s Administration.³⁶

The state of Pennsylvania could adopt an existing assessment tool with some modification as described above, or it could decide to develop an

^{xiv} The nursing home Minimum Data Set (MDS) is the data generated by the federally mandated Resident Assessment Instrument (RAI). The RAI must be completed at admission, upon a significant change in resident health status, and every 90 days for all residents of US nursing homes that accept Medicaid payments. Additional assessments must be conducted for residents who are receiving Medicare funded skilled nursing services. MDS data are transmitted by nursing homes to state agencies and the Federal government for payment, quality assurance, and research.

^{xv} <http://www.interrai.org>

entirely new system as has been done in other states. The benefit of adopting an existing assessment tool would be the established validity and reliability of the instruments themselves. In addition, state policymakers and analysts would be able to compare LTC in Pennsylvania to other states using the same instrument, as is currently possible in nursing home care. By contrast, a new system developed specifically for Pennsylvania could address specific needs that are not met in existing tools. For example, the wide range of programs in the state of Pennsylvania might make it difficult to adopt a single instrument. The cost of developing a new assessment would be significantly higher than that of modifying an existing instrument. In either case, there would be substantial transition costs (e.g., training, infrastructure, lost productivity) associated with implementing any new assessment system. While potentially substantial, this has not deterred other states from moving in this direction. Benefits include improved data for planning, analysis and quality monitoring, as well as improved transparency and equity in care planning and service allocation.

2. CONSOLIDATE FINANCIAL AND OPERATIONAL MANAGEMENT OF INSTITUTIONAL AND HCBS SERVICES:

The state of Pennsylvania should continue efforts to realign the management structure for long-term care under the leadership of the Long Term Living Council.

In Pennsylvania, financial responsibility for both nursing homes and home and community-based waivers lies with the Department of Public Welfare, Office of Medical Assistance Programs (OMAP), making it potentially possible to reallocate savings from reduced institutional services. However, operational control of programs for the elderly rests with the Department of Aging. The Department of Aging has decision-making authority over who is eligible for nursing home care and waiver services, but no budgetary oversight, making it difficult to plan effectively. A similar division of authority exists in programs for the MR/DD population. This structural division potentially limits the potential to target home and community-based services most cost-effectively.³⁷ For example, eligibility for waiver services is tied to need for institutional care, limiting the state's ability to serve individuals who could benefit from in-home services but are not facing

immediate risk of nursing home placement. Since the overall budget and individual care plan limits for waiver beneficiaries are set by one agency, while the need is assessed by a separate agency, care plan limits may be driven by budgetary requirements that do not match clinical needs. Another factor is that quality assurance and licensure of institutional and residential providers are based in separate agencies. This poses a challenge to development of policies such as pay-for-performance. The state of Pennsylvania has made efforts to consolidate and realign the management structure for long-term care under the leadership of the Long Term Living Council. **These existing efforts should continue with efforts to integrate the Long-Term Living Council with budgetary authority and oversight of institutional and residential providers.**

Other states such as Minnesota, Washington, and Texas have developed a consolidated fiscal management structure that allows reduced expenditures on institutional care to be re-allocated to home and community-based services. For example, in Washington, the Aging and Disability Services Administration can expand waiver services without seeking a supplemental appropriation from the legislature.³⁸ Vermont has used a Section 1115 waiver to create an entitlement for HCBS for elderly and adults with physical disabilities. In most state Medicaid programs, there is an entitlement for nursing home care, but HCBS is limited to a fixed number of slots. The Vermont program, which became operational in 2005, eliminates the requirement that Medicaid waiver participants be eligible for nursing home care to access HCBS, which is then allocated based on a comprehensive assessment. Instead, the same set of criteria is used for eligibility and allocation of services.^{xvi 39}

In Pennsylvania, the use of multiple waiver programs to finance services for the MR/DD program contributes to management and planning difficulties. **The state should consolidate existing waiver programs into as few as possible and avoid creating new waivers for specific populations.** Consolidating waiver program funding streams can lead to greater administrative flexibility and

^{xvi} Detailed analysis of the impact of this program on Medicaid spending in Vermont is not available.

efficiency. For example, waiver participants would not have to change funding sources if they relocate from their family home to a residential setting or reach a certain age (see Appendix A).^{xvii} Similarly, waivers for elderly living in assisted living residences should come from the same funding stream as people living in their own homes. People would be able to relocate without losing eligibility, and the state would be able to re-allocate funding based on demographic trends and preferences without the funding being locked into statutory categories. The legislation authorizing the use of Medicaid waiver dollars in assisted living residences did not include funding for services. Creating a new waiver program specifically for assisted living residences with new, dedicated funding, avoids the risk of cannibalizing the existing PDA waiver slots. However, this arrangement means that a PDA waiver resident may not be able to relocate to an assisted living residence and continue to receive services. The only alternative for such a person would likely be a nursing home. The money would not follow the person; instead the funding would continue to be tied to the place where care is delivered.

3. EXPAND OPPORTUNITIES FOR FLEXIBLE COMBINATIONS OF HOUSING AND SERVICES:

The state should increase the supply of high quality, low cost housing and reduce barriers to providing supportive services to elderly living in subsidized housing. In addition, the state should use waiver programs to serve elderly in subsidized housing and assisted living residences.

Limitations on where Medicaid recipients can live to receive HCBS waiver services is a significant barrier to providing alternatives to nursing home care for the disabled elderly in Pennsylvania. Disabled elderly people who are not able to maintain a household, but who do not require the level of nursing care and supervision of nursing homes have historically had few options for receiving community-based long-term care services. This is especially the case for less affluent elderly who cannot afford to pay for in-home assistance

^{xvii} It is not clear what happens to waiver participants who lose their eligibility due to age or relocation. Since the number of slots in each waiver program is tightly managed, people may face waiting lists if they switch to a different funding stream.

themselves and have limited ability to rely on family caregivers. A hallmark of states that have successfully shifted their LTC systems away from institutional care is that they have had the flexibility to provide services to people in group living environments, such as senior high-rises, retirement housing, and assisted living.

Potential barriers to integrating housing and services include turf issues between different agencies and incompatible eligibility rules.^{40 41} In general, housing policy is not concerned with health needs or disability of residents, and, conversely, long-term care programs cannot provide assistance with rent. Furthermore, the goal of preventing relocation to a nursing home is not typically part of housing policy. Indeed, housing providers may be concerned with liability if elderly tenants with cognitive limitations leave the stove on or bother other residents. There are often few linkages between LTC service providers and housing operators; improving those relationships can increase appropriate referrals.

One option is for housing operators to develop LTC service capacity as a licensed provider, for example as a subsidiary business. This could achieve economies of scale that are not available to an independent provider. For example, residents could receive Medicaid waiver services from an agency that is based in their housing unit or campus. Such an arrangement could provide a lower-cost alternative than assisted living, which is difficult to provide for low-income elderly, and could fall under the traditional waiver program. Another example in Pennsylvania is the Program of All-Inclusive Care for the Elderly (PACE, known as Community LIFE in Pennsylvania) has had success by locating a day-health site in a subsidized housing facility in the Pittsburgh region. The new Assisted Living Residence licensure category in Pennsylvania (see Appendix B) will potentially make it possible for less affluent elderly living in assisted living to receive publicly financed services; however, many may be unable to afford market rent.

Reducing barriers to integrating housing and services will make it possible for disabled people to receive services in a community setting to as great an extent possible. The alternative is that people with LTC needs will have not options aside from moving

to a nursing home. Although the move to a nursing home would be covered by Medicaid, it entails the loss of dignity and independence associated along with giving up one's home or apartment.

4. STREAMLINE THE ELIGIBILITY PROCESS FOR HOME AND COMMUNITY-BASED SERVICES:

The state should expand the Community Choices program of expedited intake for waiver services and continue to emphasize nursing home transition by providing resources to facilitate return to the community or to suitable housing.

Many frail elderly people require some level of restorative or supportive services after a hospitalization. A common trajectory for people who have been discharged from hospitals is nursing home placement for short-term rehabilitation, which is often followed by long-term placement. Several states that have shifted the provision of LTC to home and community-based settings have implemented systems to establish Medicaid eligibility rapidly to develop a service plan for people upon hospital discharge or shortly after admission to a nursing home for post-acute care. States such as Washington and Oregon have used expedited intake as a tool for avoiding nursing home placement.^{xviii} In addition, case managers in Washington assigned to each nursing home in the state identify and support residents who have the potential to return to the community.

The state of Pennsylvania's Community Choices program is designed to reduce delays in obtaining service for Medicaid waiver programs.^{xix} When contacted, an intake person meets with a prospective participant in the hospital or in her own home within 24 hours, if needed. Staff is on call seven days a week, 24 hours a day. This program has the potential to direct waiver services resources to people who are at imminent risk of nursing home

placement. **The state should expedite the intake process for waiver services, expand the current program statewide, and institute performance standards and benchmarks for intake workers.**

Related to expedited intake, the state of Pennsylvania has experimented with enabling nursing home residents to transition back into home or community-based settings. Pennsylvania received a grant in 2000 from the Centers for Medicaid and Medicare Services (CMS) to establish the Pennsylvania Transition to Home program (PATH). The goal of this program was to identify and relocate people who are inappropriately placed in nursing homes and to prevent people who go to nursing homes for short-term needs (e.g., post-hospital care) from becoming permanent residents. The program was designed to assist people in transitioning from nursing homes to the community, and in particular, to identify and address barriers that nursing home residents may face when considering leaving the facility. This type of program can play a crucial role in shifting the locus of care away from nursing homes for people with the potential to live more independently and has been used successfully in other states such as in Oregon.

The PATH program involved transition coordinators who worked with Area Agencies on Aging (AAA) to ensure that people who were identified as potentially able to leave the nursing home and their families received information and received any needed assistance. The initial PATH demonstration program only enrolled a small number of people – only 51 participants were successfully transitioned out of the 119 referred. Barriers to successful implementation of this program included poor communication between the PATH transition coordinator and the case manager for the HCBS waiver program and a lack of accessible and affordable housing. It was also difficult to identify people early enough in their nursing home stay for transition planning to take place. Furthermore, it was difficult to discharge people because they required modifications to their homes to provide an adequate level of safety (e.g., grab bars, ramps, wheelchair access) and in-home services such as meals, medication assistance, and financial management. These services were not available in the community.

^{xviii} A related strategy is to have a "single point of entry." That refers to consolidation of information about eligibility, benefit levels as well as personnel who conduct financial and need-based assessment.

^{xix} The program operates in the following counties: Allegheny, Chester, Cumberland, Dauphin, Perry, Delaware, Lancaster, Montgomery, Philadelphia, Fayette, Greene, and Washington. <http://www.dpw.state.pa.us/Disable/HomeCommServices/003670971.htm>

One result of this demonstration program was that “transition services” was created as a service category for several of the state’s Medicaid waiver programs. This service provides one-time expenses to set up a home or apartment, including equipment, furnishings, moving expenses, security deposits, and set-up fees for utilities and other services. This program was subsequently expanded statewide, and the state reports that 600 people have been transitioned back into the community in 2006. Currently, each AAA receives the names of all residents admitted to a nursing home biweekly in their region. Staff from each AAA is responsible for visiting all newly admitted nursing home residents and providing counseling on long-term living options and community-based services.⁴² **The state should continue to emphasize nursing home transition and provide resources to facilitate return to the community or to suitable housing.** Some individuals who do not own their own homes may no longer have an apartment to return to after spending more than a month in a nursing home. Others may require modifications to make their home accessible. To be successful, the transition program needs to have the resources and flexibility to find suitable housing and make necessary renovations.

5. EXPAND CONSUMER DIRECTED HOME CARE FOR THE ELDERLY:

The state of Pennsylvania should pursue development of cash and counseling as a Medicaid plan option in addition to offering it as a service category under existing waivers.

Under Pennsylvania’s state funded Attendant Care program and the Attendant Care Medicaid waiver program,^{xx} people aged 18 to 59 with disabilities are given the opportunity to hire, train, direct, and fire their own worker. This model follows the philosophy of consumer direction, embodied in what are termed Cash & Counseling programs. Although Cash & Counseling has had a long history in the MR/DD population in Pennsylvania, the

^{xx} The state-funded Attendant Care program serves adults people with disabilities who do not meet income eligibility for the Attendant Care waiver program. Statistics for these programs are combined. In fiscal year 2004-2005, there were 6,255 people served and expenditures were \$47,031,000. In fiscal year 2005-2006, there were 7,046 people served and expenditures were \$60,751. Source: Department of Public Welfare Budget.

implementation of such programs for disabled elderly is relatively recent.

Pennsylvania received a planning grant from the National Association of State Units on Aging (NASUA) in 2003⁴³ and is currently a recipient of a demonstration grant from the Robert Wood Johnson Foundation⁴⁴ to develop and implement a Cash & Counseling model in other waiver programs for other populations, including the elderly. These grants build on the experience of three states (Arkansas, Florida, and New Jersey) that participated in the original Cash & Counseling demonstration project funded by Robert Wood Johnson Foundation and the Federal Department of Health and Human Services. Central to the Cash & Counseling model is giving the participant both the resources to pay for needed services and advice on how to use those resources, including options for the level of support they can receive in managing their own care.

The experience in the three states that were part of the original RWJF demonstration project showed that nursing home expenditures were reduced, satisfaction was higher, and health and safety were not adversely affected. Participants had fewer unmet needs for assistance with personal care and greater access to paid services. The demonstration also highlighted the need for administrative services to assist clients with record keeping, money management, bill paying, and taxes.

Under the Deficit Reduction Act (DRA) of 2005, it is now possible for states to offer Cash & Counseling as a special Medicaid plan option rather than as a waiver program, making it easier administratively to create these new programs. Unique to Cash & Counseling, the DRA allows states to set eligibility and benefit levels and control the size of the program, much as with waiver programs, giving states the greater flexibility and managerial control than with an entitlement. **The state of Pennsylvania should pursue development of cash and counseling as a plan option in addition to offering it as a service category under existing waivers.**

6. ASSURING THE QUALITY OF HOME AND COMMUNITY-BASED SERVICES:

The state of Pennsylvania should adopt an outcomes based model for HCBS waiver

programs serving the elderly based on the Independent Monitoring for Quality (IM4Q) program.

Expansion of HCBS raises the important question of quality of care. In contrast to institutional care, the home setting is not regulated or licensed; thus, concerns about the safety of the environment are common. There is a wide range of services and types of providers that fall under the category of home and community-based services (see Appendix A), potentially diffusing responsibility and accountability for outcomes. For example, HCBS refers to services provided in the home such as personal care, homemaker/chore, companion, and delivered meals. HCBS also refers to home health care – which includes medically oriented services such as wound care, medication administration, therapy, and other nursing care. In addition, HCBS can refer to services delivered outside of the home such as transportation, adult day care⁴⁵ and congregate meals. Because there are so many services, it is difficult to attribute client outcomes to one particular provider as opposed to the overall plan of care.

Pennsylvania has a nationally recognized program in the Office of Mental Retardation in the Department of Public Welfare for quality management in the MR/DD population. The Independent Monitoring for Quality (IM4Q)⁴⁶ program uses independent review teams who interview people receiving services and their families about the quality of services in the context of their daily lives. Participants in each county are sampled for the interview process from among eligible service recipients living in state licensed community residences, in ICF-MR, living independently or with family. The reports are shared with the local county program to assure that problems are addressed in a timely way. **The general approach used in the IM4Q program can be adapted for the elderly population. The key features of the IMQ4 program include independent data collection, focus on satisfaction, and client perceptions of quality.**

7. COMMIT ADDITIONAL FUNDING TO CONTINUE EXPANSION OF HCBS:

To justify the increased cost, the state of Pennsylvania should adopt clear goals and

benchmarks for expanding home and community-based services for the elderly beyond shifting the locus of care away from institutions.

Home and community-based services (HCBS) are less expensive on a per unit basis than institutional LTC. Pennsylvania estimates that the cost of one year of nursing home care is \$55,892, compared to \$22,775 for one year of HCBS.⁴⁷ However, many HCBS users are not people who are being diverted away from nursing homes. Instead, they are people who have been living with disabilities and not receiving sufficient assistance. A system that places highest priority on consumer choice and also takes seriously the requirements of the *Olmstead* decision will have to serve some individuals who may be either more expensive to support in the community than in a nursing home or who might face significant risk to their health and safety. Although current policies have been developed to support the principle of self-determination and independence, the state also has an obligation to maintain the health and well-being of the people being served. A central question is who decides what level of risk is acceptable for a person to remain living in the community: whether it is the choice of the individual or the case manager who authorizes the care plan. This is complicated by fiscal pressures and equity concerns. For example, while it may be possible to serve some highly disabled individuals in the community, the cost of their care would deplete the resource available for other clients.

Governor Rendell's 2007-2008 budget requests funding for an additional 2,200 individuals in the PDA waiver program. However, for Pennsylvania to just maintain the current distribution of expenditures between institutional and HCBS, additional funds would be required just to keep pace with the projected increase in the number of disabled elderly. There are currently about 78,000 nursing home residents in the state of Pennsylvania and 20,000 PDA waiver participants. The number of disabled elderly is expected to grow between 27% and 41% by 2025. Further shifts in the overall balance between institutional care and HCBS will require substantial expansion of current programs. If reductions in use of institutional LTC can be re-allocated to HCBS, then the impact on the Medicaid program will be mitigated.⁴⁸

Expansion of home and community-based services raises several policy questions. First, do publicly funded services displace care that people would otherwise receive from family members? The research literature on whether this occurs is mixed. Some older studies found that informal caregiving is a substitute for paid home care, while several recent analyses have found that little substitution in fact has taken place.⁴⁹ Second, although the cost of home and community-based services are often compared to nursing home care as a benchmark, home care and nursing homes are not always substitutes for each other. In other words, not every recipient of HCBS would have gone to a nursing home if those services had not been available. On the one hand, if the goal of the HCBS program is to substitute for nursing home care, eligibility will need to be very narrowly targeted to those individuals who would otherwise choose to go into a nursing home. In fact, such careful targeting is very difficult to accomplish. On the other hand, if the goal of expanding HCBS is to improve the quality of life of disabled elderly and their families and support consumer preferences and decisions, then the programs should be evaluated on other factors than impact on costs.

The state of Pennsylvania should identify and adopt quantifiable program objectives related to the health and well-being of LTC users that are responsive to the type of services and setting where people live. For example, program objectives could include reducing unmet need for personal care, preventing injury, helping to manage chronic disease, improving quality of life, and allowing family members to return to the paid labor force. By focusing programs on these types of objectives, the state can align program incentives with broader goals of aging in place and serving people in the most integrated (community-based) setting.

Conclusion

The state of Pennsylvania provides a substantial level of service in home and community-based settings for people with MR/DD. These programs reflect a long-standing commitment to that population. Current policies support providing services in small (fewer than 8 beds) ICF/MR facilities and in family homes. By contrast, there is significant room for improvement with regard to disabled elderly. The introduction and rapid growth of the Pennsylvania

Department of Aging (PDA) waiver over the past seven years has provided support for many disabled elderly to live as independently as possible. However, the overwhelming majority of Medicaid financed LTC for the elderly is provided in the nursing home setting. The state of Pennsylvania has several policies in place that can help serve the growing population of elderly in home and community-based settings, and potentially enable some nursing home residents to move to more residential settings. Creative approaches to integrating housing and services with separate funding streams can enable low-income individuals to live in safe, high-quality residential environments without the threat that the only way to receive supportive care is in a nursing home. However, without explicit commitment of dedicated funding through the waiver mechanism, the entitlement to nursing home care under Medicaid will serve to maintain the current imbalance.

Authors

Howard B. Degenholtz, PhD is Associate Professor of Health Policy & Management, Department of Health Policy & Management, University of Pittsburgh Graduate School of Public Health; Faculty, Center for Bioethics and Health Law

Judith R. Lave, PhD is Professor of Health Economics and Chair, Department of Health Policy & Management, University of Pittsburgh Graduate School of Public Health; Director, Pennsylvania Medicaid Policy Center

Acknowledgments

The Pennsylvania Medicaid Center was established with initial support from the Pew Charitable Trusts. We also received funding from the Jewish Healthcare Foundation, the North Penn Community Health Foundation, the Brandywine Foundation, and the Pottstown Area Health and Wellness Foundation.

Many people helped in the development of this report. In particular, we thank Monica Costlow, JD and two external reviewers.

Appendix A

Medicaid Home and Community Services (HCBS) Waiver Programs

In 1981, Congress passed legislation that allowed states to provide expanded HCBS as an alternative for people who would otherwise need nursing home care. Section 2176 of the Omnibus Reconciliation Act of 1981 (OBRA '81) provided the Health Care Financing Authority (now the Centers for Medicare and Medicaid Services (CMS) the authority to 'waive' several statutory requirements for states wishing to provide HCBS for disabled Medicaid beneficiaries. These programs are often referred to as '1915(c) waivers' based on the section of the Social Security Act that authorizes them. Key to the design of waiver programs, was that states could limit the amount of money that would be spent each year by restricting the number of people served and the amount of services per person, rather than be committed to an open-ended entitlement as with other Medicaid benefits.

Prior to 1981, Medicaid did not cover in-home services for assistance with activities of daily living except through the optional personal care benefit. State concern over the entitlement nature of Medicaid and the medically oriented definition of personal care under the benefit were cited as reasons for generally low use of that program. Notable exceptions were New York, California and Texas. Currently, 36 states offer the personal care benefit.

The OBRA '81 established a method for states to provide HCBS for disabled persons who would otherwise require institutional care. The goal was to prevent or postpone institutionalization by providing services that can help disabled people live independently. A broad array of services can be targeted to carefully defined populations. Because states specify the number of people who can be served on each waiver (i.e. the number of 'slots'), waivers are an attractive way to cover these sub-groups with lower financial risk.

There are three Medicaid requirements that may be waived: state-widenedness, comparability, and financial eligibility. Dropping the state-widenedness requirement enables states to cover services in specific regions, making it possible to experiment with small-scale programs before expanding them or

develop different approaches in different parts of the state. Waiving the comparability requirement means that services do not have to be comparable in scope, duration and amount for different groups of eligible persons – thus states can carve-out hard to serve individuals or subgroups and tailor programs to their needs. For example, people with mental illness, physical disabilities, older people, persons with HIV/AIDS, or individuals suffering traumatic brain injury. Finally, states are allowed to use the institutional financial eligibility requirements for a community-based population. Thus, most states use the 300% of the SSI institutional eligibility level. Estate recovery requirements apply to waiver programs.

When the waiver authority was established, there was concern that offering alternatives to institutional care would increase rather than decrease (or keep constant) total costs due to increased demand (the 'woodwork effect'). Waiver programs therefore had to demonstrate 'budget neutrality' in order to be approved. According to the law, the average cost of serving beneficiaries under the waiver can not exceed the average cost of care in an institution. Operationally, this means that the average Medicaid cost cannot exceed the cost of nursing home care or ICF/MR care, depending on the population. In addition, states were required to document that for each waiver beneficiary there was an empty or closed bed in an institution. This last stipulation was eventually dropped.

Currently, waiver programs exist in all 50 states.^{xxi} In the state of Pennsylvania, there are 11 separate waiver programs. The following descriptions and data are taken from the Department of Public Welfare website.^{xxii}

Consolidated Waiver for Persons with Mental Retardation. The Consolidated Waiver for Individuals with Mental Retardation provides services to eligible persons with mental retardation so that they can remain in the community. Participants live in group homes of 3 or fewer.

^{xxi} Arizona is an exception because it's entire Medicaid program operates under a Section 1115 demonstration waiver).

^{xxii} <http://www.dpw.state.pa.us./Disable/HomeCommServices>
Accessed March, 2007.

Personal Family Directed Support Waiver. The Person/Family Directed Support Waiver provides services to eligible persons with mental retardation so that they can remain in the community. Participants live in their own homes or with family.

Infant Toddlers & Families Waiver. The Infants, Toddlers, and Families Waiver (Early Intervention) provides services to children from birth to age three who are in need of early intervention services and would otherwise require the level of care provided in an intermediate care facility for persons with mental retardation or other related conditions (ICF/MR-ORC).

OBRA Waiver. The OBRA Waiver is a Home and Community-Based waiver program that provides services to people with developmental physical disabilities to allow them to live in the community and remain as independent as possible.

COMMCARE Waiver. The COMMCARE Waiver is a Home and Community-Based program developed for individuals with a medically determined diagnosis of traumatic brain injury (TBI). COMMCARE prevents the institutionalization of individuals with TBI and helps them to remain as independent as possible.

Independence Waiver. The Independence Waiver is a Home and Community-Based waiver program that provides services to persons with physical disabilities to allow them to live in the community and remain as independent as possible.

Attendant Care Waiver. The purpose of the Pennsylvania Attendant Care Program is to enable individuals with physical disabilities to perform activities of daily living. Consumers have ultimate control of their attendant care services including the right to recruit, hire, train, supervise, pay and, if necessary, terminate their attendants.

Pennsylvania Department on Aging (PDA) Waiver. The Pennsylvania Department of Aging (PDA) 60+ Waiver provides home and community based services to eligible person's age 60 or older that are clinically eligible for nursing facility care.

Elwin Waiver. The Pennsylvania Elwyn Waiver Program provides home and community-based services to eligible persons age 40 and older who are deaf, blind or deaf and blind.

Michael Dallas Waiver. The Michael Dallas Waiver provides home and community based services to eligible persons of any age who are technology-dependent. Technology dependence is defined as requiring technology to sustain life or replace vital bodily function and avert immediate threat to life.

AIDS Waiver. The AIDS Waiver is a home and community-based waiver program that offers additional services to those living with symptomatic HIV or AIDS, in order to provide an alternative to hospitalization or institutional care.

Figure 1. Description of Waiver Eligibility Requirements

Waiver	Financial	Target Population	Notes
Consolidated Waiver ^{xxiii}		<ul style="list-style-type: none"> • Age 3 or older • Mental Retardation 	<ul style="list-style-type: none"> • Participants live in group homes (3 or fewer)
Person/Family Directed Service (PFDS) ^{xxiv}	<ul style="list-style-type: none"> • \$2,000 Resource Limit (does not apply to children under 21) • Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> • Age 3 or older • Mental Retardation • Does not require Office of Mental Retardation licensed community Residential Services 	<ul style="list-style-type: none"> • Individual expenditure limit of \$21,000 • Participants must live in their own home or family's home
Infant, Toddler s and Families (ITF) ^{xxv}	<ul style="list-style-type: none"> • Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> • Birth until 3rd birthday • Need for early intervention services • ICF/MR level of care for mental retardation and related conditions 	

^{xxiii} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671640.htm>

^{xxiv} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671641.htm>

^{xxv} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671639.htm>

Waiver	Financial	Target Population	Notes
OBRA ^{xxvi}	<ul style="list-style-type: none"> \$8,000 Resource limit (does not apply to children under 21) Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> Developmental disability onset prior to age 22 Severe physical disability likely to continue indefinitely and results in substantial limitation in three or more major life activities Need for ICF/MR level of care Primary diagnosis not mental health or mental retardation 	<ul style="list-style-type: none"> Counties served: Berks, Bradford, Bucks, Carbon, Chester, Delaware, Lackawanna, Lehigh, Luzerne, Monroe, Montgomery, Northampton, Philadelphia, Pike, Schuylkill, Sullivan, Susquehanna, Tioga, Wayne, and Wyoming.
COMMCARE ^{xxvii}		<ul style="list-style-type: none"> Age 21 and older Diagnosed with TBI Require Special Rehabilitative Facility (SRF) level of care Disability must result in limitation in three or more major life activities: mobility, behavior, communication, self-care, self-direction, capacity for independent living and cognitive capacity (judgment, memory and reasoning) 	<ul style="list-style-type: none"> TBI is a sudden insult to the brain or its coverings, not degenerative, congenital or post-operative Expected to be indefinite Individuals living in community settings Limited service area^{xxviii}
Independence ^{xxix}		<ul style="list-style-type: none"> Age 18 or older Severe physical disability which is likely continue indefinitely Substantial functional limitation in three or more major life activities Requires nursing facility level of care Primary diagnosis not mental health or mental retardation Not ventilator dependent 	<ul style="list-style-type: none"> Limited service area (see 1)
Attendant Care ^{xxx}		<ul style="list-style-type: none"> Ages 18 to 59 Mentally alert Physically disabled Capable of selecting, supervising, firing attendant Managing financial and legal affairs Require nursing home facility level of care 	<ul style="list-style-type: none"> Waiver offers services above state funded Attendant Care Act 150 Program Available in all counties
Pennsylvania Department of Aging (PDA) ^{xxxi}	<ul style="list-style-type: none"> \$2,000 Resource Limit Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> Age 60 or older Skilled Nursing Facility level of care 	
Elwin ^{xxxi}	<ul style="list-style-type: none"> \$2,000 Resource Limit Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> Age 40 or older Deaf, blind or deaf and blind Skilled Nursing Facility level of care 	<ul style="list-style-type: none"> Resident of Delaware County
Michael Dallas ^{xxxi}	<ul style="list-style-type: none"> \$2,000 	<ul style="list-style-type: none"> Any age 	

^{xxvi} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003670916.htm>

^{xxvii} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003670179.htm>

^{xxviii} Two service areas: (1) Adams, Allegheny, Armstrong, Beaver, Bedford, Blair, Butler, Cambria, Cameron, Centre, Clarion, Clearfield, Clinton, Columbia, Crawford, Cumberland, Dauphin, Elk, Erie, Fayette, Forest, Franklin, Fulton, Greene, Huntingdon, Indiana, Jefferson, Juniata, Lancaster, Lawrence, Lebanon, Lycoming, McKean, Mercer, Mifflin, Montour, Northumberland, Perry, Potter, Snyder, Somerset, Union, Venango, Warren, Washington, Westmoreland, and York. (2) Counties Served: Berks, Bradford, Carbon, Chester, Delaware, Lackawanna, Bucks, Luzerne, Monroe, Montgomery, Northampton, Lehigh, Philadelphia, Pike, Schuylkill, Sullivan, Susquehanna, Tioga, Wayne, and Wyoming

^{xxix} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003670931.htm>

^{xxx} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003670176.htm>

^{xxxi} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671492.htm>

^{xxxi} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671491.htm>

^{xxxi} <http://www.dpw.state.pa.us/health/accesshealthcare/suppservwaivers/003671490.htm>

Waiver	Financial	Target Population	Notes
	Resource Limit (does not apply to children under 21) <ul style="list-style-type: none"> Income limit 300% of Federal Benefit Rate 	<ul style="list-style-type: none"> Technology dependent Meet Special Rehabilitation Facility level of care 	
AIDS^{xxxiv}		<ul style="list-style-type: none"> Age 21 or older with AIDS Unable to work Require hospital, skilled nursing facility or intermediate care facility level of care Not in hospice 	<ul style="list-style-type: none"> Eligible for Medical Assistance or trying to obtain Medical Assistance in conjunction with the AIDS waiver application

Figure 2. Services Available Under Each Waiver Program

	Consolidated	PFDS ^{xxxv}	ITF ^{xxxvi}	OBRA	COMMCARE	Independence	Attendant Care	Elwin	Michael Dallas	AIDS	PDA
Adult Day Services			✓								
Behavioral Specialist Consultant					✓						
Coaching/ Cueing					✓						
Cognitive Therapy					✓						
Community Integration & Transition			✓		✓	✓					
Companion											✓
Counseling (Consumer and/or Family)					✓			✓			✓
Daily Living			✓			✓					
Durable medical equipment & supplies								✓	✓	✓	✓
Education			✓		✓	✓					
Environmental Accessibility Modifications	✓	✓		✓	✓	✓					✓
Habilitation:											
Residential	✓	✓	✓		✓						
Day	✓	✓	✓								
Prevocational	✓	✓	✓	✓	✓						
Supported Employment	✓	✓	✓	✓	✓						
Homemaker/ Chore	✓	✓	✓							✓	
Adaptive Equipment	✓	✓	✓	✓		✓			✓		
Home Delivered Meals											✓
Night Supervision					✓						
Nutritional consultations										✓	
Older Adult Daily Living Centers											✓
Permanency Planning	✓										
Personal Care					✓		✓	✓			✓
Personal Emergency Response Systems			✓		✓	✓	✓				✓

^{xxxiv} <http://www.dpw.state.pa.us/health/hivaidsserv/aidswaiverprogram/003674813.htm>

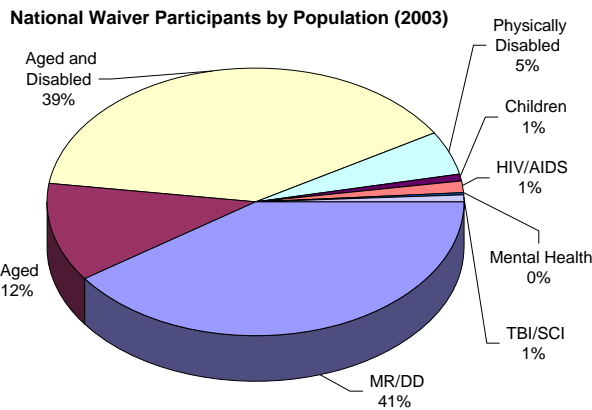
^{xxxv} Person/Family Directed Services Waiver

^{xxxvi} Infant, Toddlers and Families Waiver

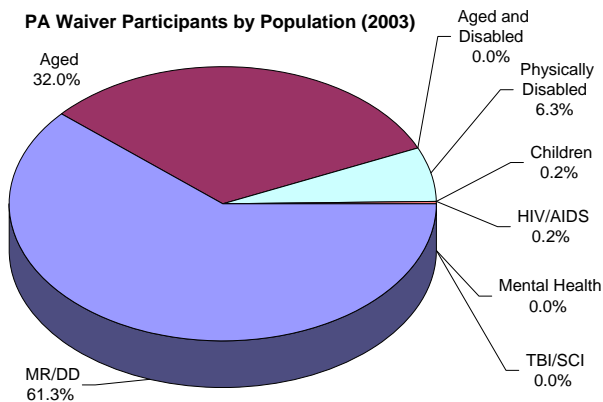
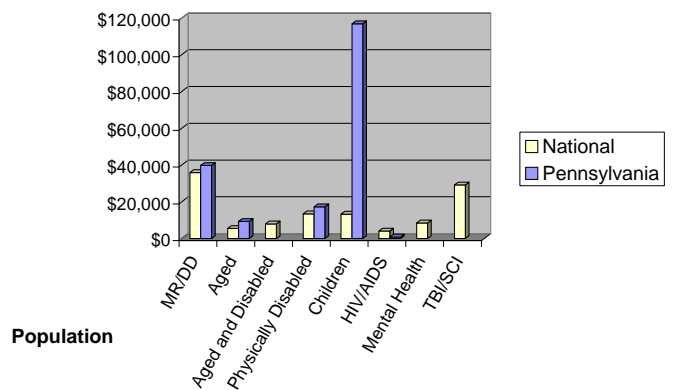
	Consolidated	PFDS xxxv	ITF xxxvi	OBRA	COMM CARE	Independence	Attendant Care	Elwin	Michael Dallas	AIDS	PDA
Personal Support		✓									
Respite Care	✓	✓		✓	✓	✓					
Service Coordination					✓	✓	✓		✓		
Specialized Therapy											
Structured Day Program					✓						
Supplemental home health								✓		✓	✓
Supplemental skilled nursing										✓	
Therapy:											
Physical	✓	✓		✓	✓	✓					
Occupational	✓	✓		✓	✓	✓					
Behavioral				✓		✓					
Speech, Hearing and Language	✓	✓		✓	✓	✓					
Therapeutic Social and Recreational Programming								✓			
Transitional services									✓	✓	✓
Transportation	✓	✓		✓	✓	✓		✓			✓
Visiting Nurse	✓			✓	✓	✓			✓		

The following figure shows the distribution in terms of population served, both nationally and in Pennsylvania. The pie charts show that the MR/DD population makes up a greater proportion of waiver participants in Pennsylvania than nationally.

Nationally, the most expensive population on a per capita basis is the mentally retarded/developmentally disabled (MR/DD). Pennsylvania follows the same pattern except for the 'children' category.



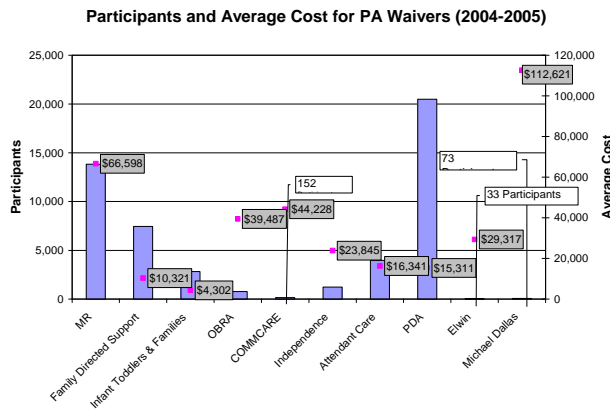
Average Expenditures per Waiver Participant (2003)



The preceding charts are based on data from CMS Form 372, which is used by states to report on the waiver participants programs to the Federal Government. The population categories are therefore standardized for national comparisons.

Data from 2004-2005 obtained from the Pennsylvania agencies that oversee the waiver

programs provides an additional level of detail.^{xxxvii} The PDA waiver has the most participants, however the Michael Dallas Waiver has the highest cost per person followed by the MR waiver.



Appendix B

Personal Care Homes and Assisted Living Residences

Nursing homes are licensed by the Department of Public Health as domiciles for people who require nursing services. Personal Care Homes are licensed by the Department of Public Welfare as domiciles for people who do not require nursing home level of care (see Box). While many PCHs are marketed as assisted living facilities, until recently, this term did not exist in state law as a licensure category.

The number of PCH beds has grown from 53,673 in 1996 to 71,029 in 2007, while the supply of nursing homes has declined and occupancy has decreased. The growth of PCHs in Pennsylvania and across the country was dramatic up until the year 2000, after which growth rates have leveled off.^{xxxviii} This growth was based on market demand and in large part on the guiding philosophy of independence and dignity. Assisted living ideally offers an ‘apartment’ style residence with private rooms with a lockable door, and food storage and preparation (e.g., a small refrigerator and microwave oven). This allows the resident to store snacks, leftovers, or heat their food without needing to go to a communal dining room for every meal. Many facilities do not offer the full range of amenities, however.

PCHs in Pennsylvania can have as few as 4 residents, and range in structure from modified homes to apartment buildings to institutional structures that resemble nursing homes. The rent in a PCH typically covers room and board and some basic assistance with daily living, and can vary considerably based on the level of services and amenities. Facilities range from very modest places that offer only the bare essentials for daily living to ‘upscale’ accommodations with resort-like features and activity programs.

People who require more than basic assistance can either purchase additional services from the facility or can hire an outside provider. Facilities that agree to accept Supplemental Security Income (SSI)

^{xxxviii} Mollica, R., Johnson-Lamarche. (2005) *State Residential Care and Assisted Living Policy: 2004*. National Academy of State Health Policy. Prepared for the Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services.

^{xxxvii} Data for this are abstracted from reports by Thomson Medstat.

eligible residents cannot charge more than the monthly SSI payment, less a personal living allowance, for room and board and basic personal care services. In Pennsylvania, 18% of PCH residents rely on SSI as their only income source. Many low income elderly living in PCHs might be eligible for Medicaid Waiver services based on functional and income/asset criteria. However, there is a conflict between state and federal law regarding eligibility. The federal requirement states that waiver participants must meet nursing home level of care, while the state regulations exclude such residents from living in a PCH, and require that they be discharged. This restriction makes PCH unaffordable for many low income elderly who need extensive personal care or cannot afford a visiting nurse. It is also difficult, therefore, for less affluent people to age in place. Aging in place refers to the concept of bringing additional services to the individual as their needs change rather than require the individual to change to another setting. In Pennsylvania PCH, residents needing more care are at risk of being forced to relocate to a nursing home at the expense of Medicaid.

The ‘bright line’ between the populations served by nursing homes and PCHs is blurred by two factors: the growth of PCHs that specialize in dementia care and the desire of many residents to ‘age in place.’ Many people with dementia, especially in the early stages, do not have significant medical problems that require nursing care, and mainly require supervision and assistance with daily tasks. Existing PCHs have developed units with dementia specific programs. In addition, PCHs have been built that serve people with Alzheimer Disease or other dementias that traditionally had no other option besides a nursing home.

Assisted Living Residence Licensure. On July 14, 2007, the PA legislature approved Senate Bill 704 (Printer number 1272), and forwarded it to Governor Rendell to sign. This bill embraces widely accepted tenets of ‘assisted living philosophy’ and would create a new licensure category for assisted living called ‘assisted living residences.’ The language used in the bill is intended to define a category of people who require medically oriented services who would otherwise require services of a “licensed long-term care facility, including immobile persons” to

live in an assisted living residence, with the caveat that appropriate “supplemental health care services are provided...and the design, construction, staffing and operation...allows for...save emergency evacuation.”^{xxxix}

One apparent goal of the new law is to distinguish Assisted Living Residences from PCHs that provide only minimal supportive services. This approach has been praised by the Pennsylvania Health Care Association which represents the for-profit nursing home providers.^{xi} While the law seems to permit a wider range of people to live in assisted living residences than could previously, the language leaves considerable discretion to the administrator, the medical director or a physician or nurse practitioner to “certify that a consumer may not be admitted or retained”^{xli}

The bill states that “Prospective or current residents for whom placement in a skilled nursing facility is imminent shall be given priority for assisted living residence services funded through a home-and community-based waiver.”^{xliii} This implies that Medicaid HCBS Waiver services will become available to assisted living residents for the first time in Pennsylvania, although it is not explicitly addressed. However, the bill does not increase financing for the waiver programs, thus the existing level of funding will need to be allocated to people living in their own homes and those living in assisted living residences. While the bill allows more disabled persons to remain in assisted living residence, there is no provision for financing the additional level of medically oriented services a low-income resident may require to avoid being discharged, and there is no restriction on the rent that facilities can charge.^{xliiii} Thus it is not clear that these bills will dramatically impact the current distribution

^{xxxix} SB 704, PN 1272, Amending Section 1057.3 (b) of the Health Care Facilities Act.

^{xi} “PHCA Commends Senators Vance, Erickson for Reporting Out Assisted Living Bill” Press Release 4/25/2007. <http://phca.org/docs/042507press.pdf>

^{xli} _____ . Amending Section 1057.3 (f)

^{xliii} _____ . Amending Section 1057.3 a. (3.1)

^{xliiii} Except, of course through HCBS waivers. However, increasing waiver slots to serve assisted living residents is not addressed in this legislation.

of long-term care between nursing homes and other settings.

Approaches to Assisted Living in Other States.

Assisted living plays an important part in the spectrum of long-term care services, filling a niche for people who are unable to maintain their own home but do not require or desire to live in a nursing home. Eligibility and financing affect the viability of assisted living as an alternative to nursing homes. States vary in how broadly the eligible population is defined. Some allow facilities to serve people with a wide range of needs, but leave some discretion to providers to determine whether the residents needs exceed the available services.

Figure 3. Examples of Assisted Living Admission/Retention Policies in Two States

Oregon	Vermont
<p>Facilities may care for individuals with all level of care needs, but a resident may be asked to leave if the individual:</p> <ul style="list-style-type: none"> (1) Has needs that exceed the level of ADL services the facility provides; (2) Exhibits behaviors or actions that repeatedly and substantially interfere with the rights or well-being of other residents; (3) Is unable to respond to verbal instructions, recognize danger, make basic care decisions, express need, or summon assistance; (4) Has a medical condition that is complex, unstable, or unpredictable and treatment cannot be appropriately developed and implemented in the facility; (5) Has not paid for services; (6) Exhibits behavior that is an immediate danger to self or others; (7) Requires 24-hour, seven-day a week nursing supervision; or (8) Is unable to evacuate according to fire safety code. 	<p>Residents may be discharged if they pose an immediate threat to themselves that cannot be managed through a negotiated risk agreement or to others, or if their needs cannot be met with available support services and arranged supplemental services. However, if a facility is able to, it may retain residents who need:</p> <ul style="list-style-type: none"> (1) 24-hour on-site nursing care; (2) Are bedridden for more than 14 consecutive days; (3) Are dependent in four or more activities of daily living; (4) Have severe cognitive decline; (5) Have Stage III or IV pressure sores; or, (6) Have a medically unstable condition.

Source: National Center for Assisted Living State Regulatory Review 2007. March 2007. Washington, DC.

Other states stipulate that specific categories of people that cannot live in assisted living or who have to be discharged. This type of exclusion is often framed in terms of need for daily nursing care. Exclusions are also often framed in terms of capability for self-evacuation. For example, in Ohio:

Facilities may admit or retain individuals who require skilled nursing care beyond the

supervision of special diets, application of dressings, or administration of medication only if the care is on a part-time/intermittent basis for not more than a total of 120 days in any 12-month period.^{xliv}

In terms of financing, 39 states, including New Jersey, Ohio, Oregon, Vermont, and Washington, allow assisted living residents to receive services paid for by Medicaid Waivers.^{xlv} In addition, other states permit residents to receive state-plan financed personal care.^{xlvi} Some states provide multiple levels of Medicaid payment for services based on the needs of the resident (i.e., more disabled residents would be able to receive additional services). However, it should be noted that Medicaid cannot pay for room and board through the waiver.

^{xliv} National Center for Assisted Living State Regulatory Review. (2007) Washington, DC.

^{xlv} National Center for Assisted Living State Regulatory Review. (2007) Washington, DC.

^{xlvi} Collica, R., Johnson-Lamarche. (2005) *State Residential Care and Assisted Living Policy: 2004*. National Academy of State Health Policy. Prepared for the Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services.

Appendix C

The Supreme Court *Olmstead* Decision

In June of 1999, the Supreme Court issued an ground-breaking decision in disability law, *Olmstead v. L.C.*^{xlvii} In *Olmstead*, the plaintiffs were two women with mental retardation and psychiatric conditions who were patients in a Georgia state psychiatric hospital. The plaintiffs remained in the psychiatric hospital for multiple years even after professionals determined that they were ready for discharge to a community setting. In a 6 to 3 opinion, the Supreme Court ruled that the plaintiffs had the right to receive care in the most integrated setting appropriate and that unnecessary institutionalization of persons with disabilities is a form of discrimination prohibited by Title II of the Americans with Disabilities Act.^{xlviii}

In *Olmstead*, the state of Georgia asked the Supreme Court to decide “(w)hether the public services portion of the federal Americans with Disabilities Act (ADA) compels the state to provide treatment and habilitation for disabled persons in a community placement, when appropriate treatment and habilitation can also be provided in a state institution.” The *Olmstead* Court relied on the statutory language of the ADA. Title II of the ADA provides that, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”^{xlix} Also taken into consideration by the Court were the “coordination regulations” applicable to recipients of federal financial assistance under Section 504 of the Rehabilitation Act.¹ The coordination regulations contain an “integration mandate” that states, “(r)ecipients shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”^{li}

The Supreme Court concluded that where a person with a disability could appropriately live in a community setting, Title II required a state or other public entity to provide community-based treatment unless doing so would fundamentally alter the states’ services and programs.^{lii} States may generally rely on the reasonable assessments of their own professionals to determine whether a person is appropriate for discharge to the community.^{liii} In particular, the *Olmstead* ruling greatly impacts state Medicaid policy because the ADA applies to all public bodies and the use of public funds.

Application of the *Olmstead* ruling in long-term care systems requires states to make adjustments to place preference on delivering care in the most “integrated”, or community-based setting. Compliance with the *Olmstead* ruling can be demonstrated by a state producing a “comprehensive, effectively working plan” to increase community-based services and reduce institutionalization, and by ensuring that waiting lists for services move at a “reasonable pace.”^{liv} As of October, 2006, 29 states had created *Olmstead* Plans and 15 others were pursuing other strategies to comply.^{lv}

Currently, Pennsylvania does not have a formal plan or an alternative strategy outlined, however, it has made progress towards complying with the *Olmstead* ruling through several planning efforts. The federal government has supported states efforts to comply with the *Olmstead* decision by encouraging states to expand HCBS waiver programs and the New Freedom Initiative grants. These are grants are offered by CMS to state agencies to support planning efforts and demonstration projects. Pennsylvania has been successful in obtaining several grants under this program.

^{xlvii} *Olmstead v. L.C.*, 527 U.S. 581 (1999)

^{xlviii} *Id.* at 595

^{xlix} 42 U.S.C.A. § 12132 (2001).

¹ 42 U.S.C.A. § 12134(a) (2001)

^{li} 28 C.F.R. § 41.51(d) (1979); *Olmstead*, 527 U.S. at 592.

^{lii} *Olmstead*, 527 at 606

^{liii} *Id.* at 602.

^{liv} Smith, J.D.E. and Calandrillo, S.P. (2001) Forward to Fundamental Alteration: addressing ADA Title II integration lawsuit after *Olmstead v. L.C.* Harvard Journal of Law & Public Policy, vol. 24, Summer, 695.

^{lv} See Appendix X.

References

- ¹ Thomson Healthcare, Medicaid Long Term Care Expenditures FY 2006, 8/10/2007 (Cambridge: 2007).
- ² US Supreme Court (1999) *Olmstead v. L. C.* (98-536) 527 US 581 (1999) 138 F.3d 893.
- ³ Kane, R. A., & Kane, R. L. (1987). *Long-term Care: Principles, Programs, and Policies*. New York: Springer Pub. Co.
- ⁴ Rogers, S., and Komisar, H. "Who Needs Long-Term Care" Georgetown University Long-Term Care Financing Project. May, 2003.
- ⁵ Pennsylvania Department of Public Welfare, Personal Care Homes Monthly Statistical Report. (accessed October 29, 2007) <http://www.dpw.state.pa.us/Disable/PersonalCareAssistedLiving/003670903.htm>
- ⁶ 2005 ACS.
- ⁷ AARP. Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving. (Washington, DC: 2007).
- ⁸ Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group (Baltimore: 2007).
- ⁹ MedPac, June 2007 *Databook*. (Washington, DC: 2007)
- ¹⁰ Harrington, C., Carrillo, H., and LaCava C., Nursing Facilities, Staffing, Residents and Facility Deficiencies, 1999 through 2005. September 2006. Department of Social and Behavioral Sciences, University of California, San Francisco.
- ¹¹ Long-Term Care 2006 Statistics and Information. Pennsylvania Non Profit Healthcare Association (PANPHA). (Mechanicsburg, PA: 2007)
- ¹² Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group (Baltimore: 2007)
- ¹³ US Census.
- ¹⁴ Manton, K. G., Corder, L., & Stallard, E. (1997). Chronic disability trends in elderly United States populations: 1982-1994. *Proc Natl Acad Sci U S A*, 94(6), 2593-2598; Manton, K. G., Gu, X., & Lamb, V. L. (2006). Change in chronic disability from 1982 to 2004/2005 as measured by long-term changes in function and health in the U.S. elderly population. *Proc Natl Acad Sci U S A*, 103(48), 18374-18379; Waidmann, T. A., & Liu, K. (2000). Disability trends among elderly persons and implications for the future. *J Gerontol B Psychol Sci Soc Sci*, 55(5), S298-307. Wolf, D. A., Hunt, K., & Knickman, J. (2005). Perspectives on the recent decline in disability at older ages. *Milbank Q*, 83(3), 365-395; and 65+ In the United States: 2005, US Department of Health and Human Services Current Population Reports.
- ¹⁵ <http://www.directcareclearinghouse.org> and Bureau of Labor Statistics, US Department of Labor, 2007.
- ¹⁶ Pennsylvania Department of Labor and Industry (2007) "PA Industry Employment: Estimated 2004 Projected 2014" <http://www.paworkstats.state.pa.us/gsipub/index.asp?docid=399>
- ¹⁷ Assistant Secretary for Planning and Evaluation. (2003) *The Future Supply of Long-Term Care Workers in Relation to the Aging Baby Boom Generation: Report to Congress*, May 14, 2003.
- ¹⁸ Leon, J., Marainen, J., Marcotte, J. (2001) *Pennsylvania's Frontline Workers in Long Term Care: The Provider Organization Perspective*. Polisher Research Institute, Jenkintown, PA.
- ¹⁹ Davis, M, Dawson, S. (2003) *Pennsylvania's Care Gap: Finding Solutions to the Direct-Care Workforce Crisis*. Paraprofessional Healthcare Institute: Bronx, New York.
- ²⁰ <http://www.bjbc.org>
- ²¹ BJBC-PA Universal Core Curriculum. http://bjbc-pa.org/about/progserv_core.php.
- ²² BJBC-PA Creating Supportive Workplaces – Project by Joint Teams. http://bjbc-pa.org/for_longterm/assistance.php
- ²³ http://www.bjbc-pa.org/for_directcare/feature_forming.php
- ²⁴ <http://www.paculturechangecoalition.org/>
- ²⁵ Thomson Healthcare, 2007.
- ²⁶ Thomson Healthcare, 2007

27

<http://www.dpw.state.pa.us/omap/provinf/ltc/omapltc rates.asp>

28 Harrington, C.

29 Kane, R A., Kane, R. L., Priester, R., Spencer, D., Lakin, K. C., Lum, T. (2005) Rebalancing Long-Term Care Systems in Washington: Experience up to July 31, 2005. Abbreviated Report Submitted to the Centers for Medicare and Medicaid Services.

30 Thomson Healthcare, 2007.

31 Home and Community-based Services Reform and Rebalancing Feasibility Analysis: Final Report. Thomson Medsatat: Cambridge, March 24, 2006.

32 Kane, 2005. and CARE Overview. 2005

33 _____ . Amending Section 1057.3 a. (3.2)

34 Morris, J. N., Fries, B. E., Steel, K., Ikegami, N., Bernabei, R., Carpenter, G. I., et al. (1997). Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc*, 45(8), 1017-1024.

35 Hirdes, J. P., Fries, B. E., Morris, J. N., Ikegami, N., Zimmerman, D., Dalby, D. M., et al. (2004). Home care quality indicators (HCQIs) based on the MDS-HC. *Gerontologist*, 44(5), 665-679.

36 Hawes, C., Fries, B. E., James, M. L., & Guihan, M. (2007). Prospects and pitfalls: use of the RAI-HC assessment by the Department of Veterans Affairs for home care clients. *Gerontologist*, 47(3), 378-387.

37 Thomson MedStat, 2007.

38 Kane, R A., Kane, R. L., Priester, R., Spencer, D., Lakin, K. C., Lum, T. (2005) Rebalancing Long-Term Care Systems in Washington: Experience up to July 31, 2005. Abbreviated Report Submitted to the Centers for Medicare and Medicaid Services.

39 Kane, R A., Kane, R. L., Priester, R., Spencer, D., Lakin, K. C., Lum, T. (2005) Rebalancing Long-Term Care Systems in Vermont. Report Submitted to the Centers for Medicare and Medicaid Services.

40 Pynoos, J., Liebig, P, Alley, D., & Nishita, CM (2005). Homes of Choice: Towards More Effective Linkages between Housing and Services. New York:

Center for Home Care Policy & Research. Policy Brief 24.

41 Feldman, P., Ahrens, J. (2005) Linking Housing and Long-Term Care Services for Older Adults. New York: Center for Home Care Policy & Research. Summary Report: Information Brokering for Long-Term Care.

42

<http://www.aging.state.pa.us/aging/cwp/view.asp?a=3&q=252633>; and Kane, R., Priester, R., Kane, R. L., Spencer, D., A Year in State Management Practices for Rebalancing Long-Term Care Systems: Update of Activities in 8 States, July, 2005 to July, 2006. University of Minnesota.

43 http://www.consumerdirection.org/stat_pa.php

44

http://www.cashandcounseling.org/about/participating_states/pennsylvania

45 Also commonly referred to as adult day living or adult day health.

46

<http://www.dpw.state.pa.us/Disable/MentalRetardationServices/003670114.htm>

47 Pennsylvania Cares. 2007-2008 Executive Budget, Edward G. Rendell, Governor.

48 Cite PHCA Report

49 Penning, M.J., (2002) Hydra Revisited: Substituting Formal for Self-and Informal In-Home Care Among Older Adults with Disabilities. *The Gerontologist*. 42(1):4-16. and Li, Lydia W., (2005) Longitudinal Changes in the Amount of Informal Care Among Publicly Paid Home Care Recipients. *The Gerontologist*. 45(4): 465-473.

Opinions expressed in this report are those of the authors and do not necessarily reflect the views of our funders or the people who reviewed the document.