

Follow the Money: Financing Home and Community-Based Services

Joshua M. Wiener, PhD
Wayne L. Anderson, PhD

Pennsylvania Medicaid Policy Center
University of Pittsburgh

2009



1	Executive Summary
3	Report
24	Authors
24	Acknowledgments
25	References

Executive Summary

Home and community-based services, such as personal care, home health, adult day care, respite care, adult foster homes, and assisted living facilities, are a growing component of long-term care services, but a major institutional bias remains. Nursing homes still dominate Medicaid financing for long-term care for older people and younger adults with physical disabilities. With the aging of the population, especially the rapid projected growth in the population aged 85 and older, demand for long-term care services, including home and community-based services, is sure to grow substantially, raising questions as to what should be the balance between institutional and noninstitutional services.

Despite the preference by older people for care in the community rather than in institutions, most long-term care expenditures are for nursing home care. For example, in 2007, only 31 percent of Medicaid long-term care expenditures for older people and younger persons with physical disabilities were for home and community-based services. Creating a more balanced delivery system by expanding home and community-based services and reducing reliance on institutional care where possible is a major goal for virtually all states and the Centers for Medicare & Medicaid Services.

Increase Funding for Home and Community-Based Services

One approach to financing the expansion of home and community-based services is simply to spend more on these services. Arguably, this has been the primary strategy taken by other countries and most states to date in their attempts to balance the long-term care system. In particular, additional funds have been provided for home and community-based services without explicit efforts to link the expansion to a decline in nursing home use. In part, it is often believed that the expansion of home and community-based services by itself would reduce nursing home use without any additional intervention. With the economic recession, simply increasing funding for home and community-based services may become a difficult strategy to implement.

At the state level, states can expand home and community-based services by liberalizing eligibility and coverage for Medicaid and by increasing funding for state home care programs. At the national level, federal policymakers can expand these services by increasing funding for Older Americans Act programs, raising the Medicaid matching rate for these services or mandating their coverage by states, and by liberalizing coverage of home health and other services.

Minimize the Cost of Expanding Home and Community-Based Services

Given recent problems in the economy and the future increase in demand for long-term care services in the future, adding funding to both home and community-based services and nursing home services may strain the financial resources of many states. In addition to meeting the preferences of people with disabilities to remain in the community if at all possible, consumer advocates and state and some federal officials support expansion of home and community-based services because they believe that people with disabilities can be served at lower cost in the community and that expanding services will result in less costly systems of care. In particular, they hope to substitute home and community-based services for nursing home care. While the research base for the claim for cost savings is weak, most of the studies are based on data more than 20 years old.

To reduce the incremental costs of home and community-based services, states are using a number of techniques to substitute home and community-based services for nursing home care and to provide services at lower cost. These strategies include the following and are discussed in the remainder of the paper:

- *Improve program linkages between home and community-based services and institutional care.* This strategy includes administrative reorganization and consolidation of departments and programs that address long-term

care and the use of global budgets that facilitate the reallocation of funding from institutional to noninstitutional services.

- *Improve targeting to people who would otherwise be institutionalized.* This strategy refines eligibility criteria for Medicaid and state-funded home and community-based services to target people at high risk of institutionalization. Money follows the person, for example, targets people who are already in institutions.
- *Structure financial incentives to increase use of home and community-based services and decrease use of nursing homes.* These initiatives include two very different strategies. The first is to consolidate funding for nursing homes and home and community-based services into a single capitated payment to managed care organizations, providing a financial incentive for the plans to use lower cost services. The second strategy is to provide financial incentives to nursing homes to reduce their number of beds or to convert to assisted living facilities or other types of care.
- *Provide information and single point of entry systems to give consumers more choices.* This strategy provides consumers with more information about long-term care service and financing options and conducts functional (and sometimes financial) eligibility determinations for a wide range of public programs, facilitating the ability to put together a package of services that will maintain people in the community. The premise is that by leveling the playing field a higher percentage of consumers will choose home and community-based services over nursing home care.
- *Administer Medicaid and state-funded home and community-based services more efficiently.* This strategy attempts to manage home and community-based services more efficiently and equitably by standardizing assessments and systematizing and standardizing care plans. This strategy assumes that by carefully standardizing the resource allocation process that overall utilization will decline.
- *Provide a range of lower-cost home and community-based services.* This strategy offers consumers a wide range of lower-cost home and community-based services as alternatives both to nursing home care and to higher cost community services. These initiatives include consumer-directed home care and residential care facilities.

Follow the Money: Financing Home and Community-Based Services

Introduction

Home and community-based services, such as personal care, home health, adult day care, respite care, adult foster homes and assisted living facilities, are a growing component of long-term care services, but a major institutional bias remains. Nursing homes still dominate Medicaid financing for long-term care for older people and younger adults with physical disabilities. With the aging of the population, especially the rapid projected growth in the population aged 85 and older, demand for long-term care services, including home and community-based services, is sure to grow substantially, raising questions as to what should be the balance between institutional and noninstitutional services.

Creating a more balanced delivery system by expanding home and community-based services and reducing reliance on institutional care where possible is a major goal for virtually all states and the Centers for Medicare & Medicaid Services (CMS). Advocates for changing the balance between institutional care and home and community-based services argue that there are four rationales for doing so (Wiener et al., 2004):

- People with disabilities strongly prefer home and community-based services to institutional care. In a 2007 survey conducted for the Henry J. Kaiser Family Foundation, 81 percent of older people responded that they preferred to receive care in their own home or in assisted living facilities if they were unable to care for themselves for an extended period of time; only 4 percent of older respondents reported that they would prefer to be cared for in a nursing home (Henry J. Kaiser Family Foundation, 2007). In one widely cited study, 30 percent of older people indicated that they would rather die than move to an institutional setting, with an additional 26 percent “very unwilling” to move (Mattimore et al., 1997).
- People with disabilities living in the community have substantial unmet needs for personal care and other home and community-based services. These unmet needs often lead to higher rates of adverse events, including discomfort, weight loss, dehydration, falls, burns, skin problems, missed meals, inability to follow special diets, missed doctor visits, and having to wear dirty clothes, factors that affect quality of life for persons with long-term care needs (LaPlante et al., 2004).
- A key element in the preference by people with disabilities for home and community-based services is the assumption that quality of care for these services is superior to that of nursing home care. In particular, older people associate the ability to stay in their own homes through home and community-based services with retention of independence and control over care decisions (AARP, 2003). However, much less is known about the quality of home and community-based services, in part because there is less government oversight, especially by the federal government. Although people who use home care typically report high levels of satisfaction, measuring quality of care in the home and community setting is at a fairly early level of development compared with nursing home care (Khatutsky, Anderson, & Wiener, 2006).
- Policymakers often assume that home and community-based services are a less costly way of providing long-term care, particularly for those who require custodial care. Thus, the presumption is that home and community-based services can better meet the preferences of people with disabilities while achieving savings for states and the federal government. This remains a controversial argument, and more research is needed (Wiener, Brown, Gage et al., 2004). Examining this issue will be a major focus of this paper.

The movement toward more home and community-based programs has been further bolstered by the 1999 ruling of the U.S. Supreme Court in *Olmstead vs. L.C. & E.W.* (521 U.S. 581, 119 S.Ct.2176). Interpreting the

Americans with Disabilities Act, the court ruled that states must make reasonable modification in their long-term care programs and activities to make home and community-based services available to those with disabilities (Rosenbaum and Teitelbaum, 2004; Wiener, Stevenson, and Kasten, 2000).

Balancing the long-term care delivery system by expanding home and community-based services enjoys remarkable political consensus across the political spectrum—liberals view these initiatives as a way of empowering an underclass and conservatives view them as a way of promoting market solutions. The funds to implement this goal lag in most states, but the direction is clear. To finance this change in the delivery system, there are two broad strategies. After providing some background on the financing of home and community-based services, this paper explores these two broad strategies:

- Policymakers can simply provide more public or private funds for home and community-based services by expanding Medicaid coverage and state-funded home care programs, or, at the federal level, by liberalizing Medicaid and Medicare coverage, or by increasing funding for Older Americans Act programs.
- Policymakers can implement a variety of initiatives designed to reduce the incremental cost of home and community-based services, in large part by maximizing the substitution of noninstitutional services for nursing home care.

The paper concludes by summarizing these initiatives and drawing implications for the future financing of home and community-based services.

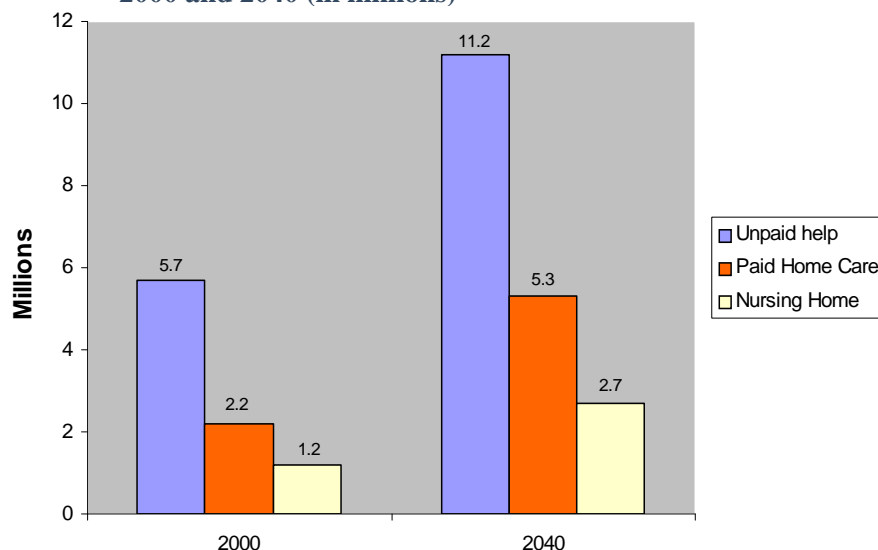
Background

Most people with disabilities, even severe disabilities, live in community settings, not nursing homes. As of 2002, 51.2 million Americans of all ages reported having a disability (Steinmetz, 2006), but only 1.5 million people lived in nursing homes (American Health Care Association, 2007).

The great majority of elderly persons receiving care in the community receives unpaid services in community settings from family, friends, or neighbors, rather than paid home care. In 2002, only 14 percent of older people with disabilities received paid home care; in fact, even among people with severe disabilities (three or more problems with activities of daily living [ADLs]), only 37 percent of older persons received any paid home care (Johnson and Wiener, 2006).

With the aging of the population, demand for unpaid and paid care is likely to increase dramatically. Between 2000 and 2040, even without any changes to the long-term care financing system, one study projected that the use of unpaid care, paid home care, and nursing home care would more than double among persons aged 65 and older (Johnson, Toomey and Wiener, 2007) (*Figure 1*). With the expected increase in long-term care services, the proportion of the Gross Domestic Product likely to be spent on long-term care is also projected to roughly double between 2000 and 2048 (Wiener, Illston, and Hanley, 1994).

Figure 1: Number of Older Adults Receiving Long-Term Care Services, by Type of Service, 2000 and 2040 (in millions)



Source: Johnson, Toomey and Wiener, 2007.

Despite the preference by older people for care in the community rather than in institutions, most long-term care expenditures are for nursing home care (*Table 1*). In 2004, only 32 percent of total long-term care expenditures for older people were for home and community-based services rather than nursing home care (U.S. Congressional Budget Office, 2004). If expenditures for Medicare skilled nursing facility and home health care, which are more accurately characterized as post-acute rather than long-term care, were excluded, the percentage of long-term care expenditures for home and community-based services would fall to 24 percent.

Table 1: Long-Term Care Expenditures for Older People, by Source of Payment, 2004 (in Billions of dollars)

Payment Source	Institutional Care	Home Care	Total
Medicaid	36.5	10.8	47.3
Medicare	15.9	17.7	33.6
Private insurance	2.4	3.3	5.6
Out-of-pocket	35.7	8.3	44.0
Other	2.0	2.5	4.4
Total	92.4	42.5	134.9

Source: Congressional Budget Office, 2004.

This overall institutional bias in financing is reflected in Medicaid spending for home and community-based services. In FY 2007, 42 percent of total Medicaid long-term care expenditures (including services for people with intellectual disabilities) were for home and community-based services, ranging from 73 percent in New Mexico to 13 percent in Mississippi (Burwell, Sredl, and Eiken, 2008). Nationally, between FY 2000 and 2007, the percentage of total long-term care expenditures for home and community-based services increased by 51 percent from 28 percent to 42 percent (Burwell, Sredl and Eiken, 2003; Burwell, Sredl and Eiken, 2008). In Pennsylvania, the percentage of total long-term care expenditures for home and community-based services increased from 16 percent in FY2000 to 28 percent in FY2007 (Burwell, Sredl and Eiken, 2003, 2008), an increase of 83 percent over the same period.

Examining trends in total Medicaid home and community-based services, however, obscures the vast difference between financing for older people and younger persons with physical disabilities on the one hand and people with intellectual disabilities on the other. Although the proportion of Medicaid long-term care expenditures for home and community-based services among older people and younger persons with physical disabilities increased from 11 percent in 1992 to 31 percent in 2007, the percentage for services for people with intellectual disabilities increased from 11 percent in 1992 to 63 percent in 2007 (Burwell, Sredl and Eiken, 2008). While a large majority of Medicaid expenditures for long-term care for people with developmental disabilities is for home and community-based services, a similarly large majority of spending for older people and persons with physical disabilities remains for institutional care. **Table 2** presents the percentage of Medicaid long-term care expenditures for older people and younger persons with physical disabilities that are spent for home and community-based services and for nursing home care for each state. According to these data, Pennsylvania ranks 45th among the states in the percentage of its Medicaid long-term care expenditures for older people and younger persons with disabilities that are home and community-based services.

Table 2: Distribution of Percentage of Medicaid Long-Term Care Expenditures for Home and Community-Based Services and Institutional Care, by State, FY 2007

State	Community-Based LTC Services	Institutional LTC Services
	% of Medicaid LTC	% of Medicaid LTC
Arizona ¹	64.0	36.0
New Mexico	60.7	39.3
Oregon	56.5	43.5
Washington	55.6	44.4
California ²	52.1	47.9
Alaska	50.6	49.4
Minnesota ¹	46.6	53.4
Texas ¹	44.3	55.7
North Carolina	42.7	57.3
Idaho	40.4	59.6
New York ¹	39.3	60.7
Kansas	35.2	64.8
Nevada	35.1	64.9
Washington DC	34.9	65.1
Colorado	34.9	65.1
Missouri	31.1	68.9
Wisconsin ¹	30.7	69.3
Montana	29.3	70.7
Oklahoma	28.7	71.3
Vermont ³	28.5	71.5
Louisiana	26.8	73.2
Virginia	26.8	73.2
Maine	26.6	73.4
Massachusetts ¹	26.4	73.6
Iowa	26.2	73.8
Arkansas	25.9	74.1
Illinois	24.9	75.1
Georgia	24.0	76.0
West Virginia	23.4	76.6
South Carolina	23.0	77.0
Nebraska	22.3	77.7
New Jersey	21.0	79.0
Ohio	20.8	79.2
Connecticut	20.7	79.3
Wyoming	20.4	79.6
Michigan	19.0	81.0
Kentucky	18.9	81.1
Hawaii	17.8	82.2
Florida ¹	17.5	82.5
Maryland	15.9	84.1
Indiana	14.5	85.5
New Hampshire	14.4	85.6
Delaware	13.7	86.3
Alabama	13.1	86.9
Pennsylvania	12.7	87.3
Rhode Island	12.6	87.4
South Dakota	11.5	88.5
Utah	10.7	89.3
North Dakota	6.3	93.7
Mississippi ⁴	2.2	97.8
Tennessee ⁵	1.3	98.7
United States	31.0	69.0

Institutional services include nursing home services. Community-based services include personal care, home health, HCBS waiver services for older adults and people with physical disabilities, Section 1115 Waivers that provide HCBS targeting older adults and people with physical disabilities, and HCBS authorized under Section 1929.

Nursing home data for several states include expenditures for Medicaid Upper Payment Limit programs.

Please see the accompanying report for additional information regarding these data.

¹ Data for Arizona, Florida, Massachusetts, Minnesota, New York, Texas, and Wisconsin do not include managed LTC expenditures.

² California's reported expenditures will likely increase as the state submits prior period adjustments. For FY2002 through FY2005, adjustments increased community services expenditures by \$500-\$800 million.

³ Vermont data do not include a program that covers both long-term and acute care because long-term care spending data are not available.

⁴ Mississippi Aged/Disabled waiver data are not available because the state did not report target population information for HCBS waivers.

⁵ Data for Tennessee do not include home health provided in a managed acute care program

Source: Burwell, Sredl, and Eiken, 2008.

The United States is not alone in facing an aging population that will accelerate the need for long-term care services. France, Germany, Japan, Sweden, and the United Kingdom already have considerably higher percentages of their populations that are aged 65 and older than does the United States (Organisation for Economic Co-operation and Development, 2005). As a percentage of their Gross Domestic Product, several countries, including Germany, the Netherlands, Norway, Sweden, and the United Kingdom, spend more on home and community-based services than does the United States (Organisation for Economic Co-operation and Development, 2005) (*Table 3*). Interestingly, some of the countries that spend more on home and community-based services also spend more on institutional care than does the United States. For example, in 2000, as a proportion of Gross Domestic Product, Sweden spent about twice as much for home and community-based services as did the United States, but it also spent about twice as much for institutional care. Germany and Japan, as part of their transition from programs limited to the low-income population to universal social insurance programs, planned to spend more money on home and community-based services, which they thought were underused (Cuellar and Wiener, 2000; Ikegami and Campbell, 2000).

Table 3: Total Expenditures for Long-Term Care as a Percentage of Gross Domestic Product, by Type of Service and Country, 2000

Country	Home Care	Institutions	Total	% for HCBS
Germany	0.47	0.88	1.35	34.8
Netherlands	0.60	0.83	1.44	41.7
Norway	0.69	1.45	2.15	32.1
Sweden	0.82	2.07	2.89	28.3
United Kingdom	0.41	0.96	1.37	29.9
United States	0.33	0.96	1.29	25.6

HCBS = home and community-based services.

Source: Organization for Economic Co-operation and Development, 2005.

Increase Funding for Home and Community-Based Services

One approach to financing the expansion of home and community-based services is simply to spend more on these services. Arguably, this has been the primary strategy taken by other countries and most states to date in their attempts to balance the long-term care system. In particular, additional funds have been provided for home and community-based services without explicit efforts to link the expansion to a decline in nursing home use. In part, it is often believed that the expansion of home and community-based services by itself would reduce nursing home use without any additional intervention. With the economic recession, simply increasing funding for home and community-based services may become a difficult strategy to implement.

At the state level, states can expand home and community-based services by liberalizing eligibility and coverage for Medicaid and by increasing funding for state home care programs. At the national level, federal policymakers can expand these services by increasing funding for Older Americans Act programs, raising the

Medicaid matching rate for these services or mandating their coverage by states, and by liberalizing coverage of home health and other services.

MEDICAID

The attraction to state policymakers of Medicaid over wholly state-funded home care programs is that it provides states with federal matching dollars, reducing net state costs. In Pennsylvania, every dollar spent by the state is matched by \$1.18 in federal funds. This money, however, comes at the price of conformity with federal rules and regulations.

States provide Medicaid home and community-based services primarily through two main methods (Wiener, Tilly and Alecxih, 2002), although the Deficit Reduction Act of 2005 added to the range of methods. First, under federal law states must cover home health and may, at their option, cover personal care and a few other services through the regular Medicaid program. For example, some states cover adult day health programs as a clinic service. Offering optional services under the regular Medicaid program can be done with administrative ease, but has important constraints. States must offer home health care, personal care, clinic, and other services as an open-ended entitlement—a legal obligation on the part of government to provide services to individuals who meet preestablished criteria, regardless of the cost to the government. This characteristic makes states potentially vulnerable to large expenditure increases because of increased demand by the high percentage of people with disabilities in the community who are not receiving paid services. Moreover, these optional services are fairly narrow in scope and may not effectively maintain people with disabilities in the community.

The potential fiscal exposure involved in the use of the regular Medicaid program has prompted states to rely instead on Medicaid home and community-based services waivers because waivers offer states greater control over expenditures. Currently, all states, including Pennsylvania, operate waiver programs for older people and younger persons with physical disabilities.¹ Under Section 1915(c) of the Social Security Act, states may apply to the U.S. Department of Health and Human Services for Medicaid home and community-based services waivers designed to give states greater flexibility to meet the needs of community dwelling persons with disabilities. Unlike personal care offered through the regular Medicaid program, states must limit waiver programs to beneficiaries who meet the state's level-of-care criteria for nursing homes, intermediate care facilities for people with mental retardation, or hospital services. The federal government imposes this requirement because the waivers are intended to substitute home and community-based services for institutional care. In addition, states must establish in advance how many people they will serve during the course of a year. In contrast to the regular Medicaid program, states may establish waiting lists for these waiver programs; thus, the waivers are not entitlements, although they operate within a program that is normally an entitlement. States may also provide Medicaid eligibility to persons in the community with incomes up to 300 percent of the federal Supplemental Security Income level, which far exceeds regular Medicaid income eligibility limits.

In addition, average Medicaid expenditures for waiver beneficiaries must be the same or less than they would have been without the waiver. As a practical matter, for older people and younger adults with physical disabilities, this means that average expenditures have to be equal to or less than the average cost of Medicaid nursing home care. States may cover a very wide range of services, including case management, homemaker, home health aide services, personal care services, adult day health care, habilitation, respite care, nonmedical transportation, home modifications, adult day care, and other services approved by the Secretary of the Department of Health and Human Services. Although services in congregate residential facilities, such as assisted living facilities, may be covered, room and board are excluded from Medicaid coverage. Room and board may only be covered by Medicaid in nursing homes, intermediate care facilities, and hospitals.

¹ Arizona and Vermont provide Medicaid home and community-based services through a research and demonstration waiver rather than through home and community-based services waivers.

The Deficit Reduction Act of 2005 established a new option for states to offer home and community-based services under the Medicaid program (Crowley, 2006; Disability Policy Collaboration, 2006; U.S. Congressional Research Service, 2006). Under Section 6086 of the 2005 Deficit Reduction Act, states are allowed to offer through the regular Medicaid program some of the home and community-based services that were previously permitted only by waiver. On the one hand, unlike Medicaid home and community-based services waivers, states do not have to demonstrate that the costs will be less than in an institution or limit eligibility to people who meet the nursing home or other applicable institutional level of care. Indeed, needs-based eligibility must be less than for institutional services. On the other hand, consistent with the waivers, the benefit does not have to be offered statewide and states may limit the number of persons they enroll. While financial eligibility limits may exceed normal Medicaid limits, they must not exceed 150 percent of the federal poverty level. States may allow consumer-direction of services under which the participant or an authorized representative directs or controls the amount, duration, scope, provider, and location of services.

Importantly, the provision does not allow states to waive the Medicaid requirement for “comparability,” thus all beneficiaries must be offered the same package of services. This provision may make use of this option less widespread because states do not want to be required to offer the same package of services to all enrollees, for example, the package of services designed for people with intellectual disabilities to people with traumatic brain injury or frail older people.

STATE-FUNDED PROGRAMS

While Medicaid dominates financing for home and community-based services for older people and for younger persons with disabilities, most states also have at least one state-only funded home and community-based services program. A 2007 study found state-funded home and community-based programs in 47 states and the District of Columbia (Kitchener et al., 2007b). Although small compared with Medicaid, these programs are not insignificant, with one survey reporting total expenditures of \$1.4 billion in 2002 (Summer and Ihara, 2004). These programs are not entitlements and are limited to the amount of funds appropriated.

State-funded home and community-based service programs are often designed to complement or supplement the state’s Medicaid services. In some cases, the programs can provide support for people waiting for Medicaid services. In other cases, the programs serve those who do not meet Medicaid functional or financial eligibility criteria. A smaller number of state-funded programs provide services that supplement those provided by Medicaid to participants.

While state-funded home and community-based programs vary from state to state, there are several areas of commonality in their operations:

- A large majority of state-funded home and community-based programs provide homemaker support, adult day or respite services, personal care assistance, care coordination, transportation, home-delivered meals, home repairs and modifications, and chore services. Some programs provide one service, but many programs provide multiple services. The programs serve populations ranging from a few dozen to more than 200,000.
- Financial support for most state-funded home and community-based programs comes from state general revenues. A number of states also use funds from specific sources, including tobacco taxes, casino revenue, state lottery income, and revenue from sales of unclaimed property.
- Most state-funded home and community-based programs serve people aged 60 and older, although a few serve only those aged 65 and older. Most programs do not have a financial eligibility requirement. Some programs have additional criteria for eligibility, including Alzheimer’s disease and risk of nursing home placement, or target those in minority communities, in rural areas, or with low incomes.

- Participants in state-funded home and community-based programs tend to be older than the minimum age for participation; available data indicate that they tend to be aged 75 or older. The majority of participants are women, and they often live alone.
- States use three main strategies to control the per person cost of these programs. The most common strategy is cost-sharing, in which participants are required to make a copayment to receive a service. Those programs using this strategy generally employ a sliding scale based on the participant's income. Another, less common strategy is to place a limit on the amount of service a participant may receive, such as a maximum number of visits or hours of service. States may also place a cap on the total expenditures for services to one participant during a particular month or quarter.

PRIVATE LONG TERM-CARE INSURANCE

In lieu of expanding public programs, a very different strategy is to increase private spending for home and community-based services by increasing the number of people with private long-term care insurance. A viable private long-term care insurance market, primarily sold on an individual basis, has existed since the mid-1980s. In 2005, approximately 7 million policies were in force, covering about 3 percent of the total American population aged 20 and older; about 10 percent of older people have private long-term care insurance, but only 0.2 percent of people aged 20–49 (Feder, Komisar, and Friedland, 2007). Most policies have substantial limitations in terms of length of covered benefits, inflation adjustments, and benefits in case of lapse.

Among the reasons that relatively few people have private long-term care insurance are that people think that Medicare covers long-term care services, denial of the potential risk, medical underwriting of policies, and the existence of a public safety net in Medicaid. Perhaps the greatest obstacle to purchase, however, is that private long-term care insurance is expensive, especially for older people on relatively fixed incomes (Feder, Komisar, and Friedland, 2007; Wiener, Illston, and Hanley, 1994). In 2008, the average premium among three major private long-term care insurance carriers for policies providing a \$150 daily benefit, 3 years of coverage, a 90-day elimination period, and 5 percent compound inflation protection, but no nonforfeiture benefit was \$2,329 per year if purchased at age 60 and \$4,515 if purchased at age 70 (Coronel, 2004). However, the median income for households headed by persons aged 65–74 was \$34,243 in 2004, and declines sharply with increasing age (U.S. Census Bureau, 2006). Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is very expensive for most older people.

The limitations of the unsubsidized, individual private long-term care insurance market has led to a number of proposals and initiatives to “jump start” the private long-term care insurance market, primarily by finding ways to make policies more affordable. At the federal level, qualifying long-term care insurance premiums are tax deductible only to the extent that taxpayers' medical expenses exceed 7.5 percent of adjusted gross income. At the state level, modest deductions or tax credits for the purchase of private long-term care insurance were offered by 29 states and the District of Columbia in 2008 (Henry J. Kaiser Family Foundation, 2008). However, in most cases, these tax incentives provide only a few hundred dollars in tax benefits, making it unlikely that they will substantially change the affordability of policies.

Another approach is the so-called long-term care partnerships. A number of analysts have suggested promoting private long-term care insurance by providing purchasers of state-approved private long-term care insurance policies easier access to Medicaid. In these public-private partnerships, which have been tried for more than 10 years in California, Connecticut, Indiana, Iowa, and New York, policyholders are allowed to keep more of their financial assets than is typically permitted and still receive nursing home and home care benefits under Medicaid. For example, in Connecticut, persons with a state-approved private long-term care insurance policy that pays \$150,000 in benefits can keep \$150,000 in financial assets and still qualify for Medicaid. This strategy allows the insured to obtain lifetime asset protection without having to buy an insurance policy that provides lifetime coverage, reducing the price of the private insurance policy needed. At its core, this approach offers asset protection as its inducement to purchase insurance.

Although the Omnibus Budget Reconciliation Act of 1993 had limited this strategy to the initial four states, the Deficit Reduction Act of 2005 removed those restrictions, and generally lowered the standards of the policies that had been set by the original four states. For example, all of the original four states required policies to have automatic compound inflation adjustment; the Deficit Reduction Act of 2005 eliminated that requirement and replaced it with less strict requirements.

Although this approach is a favorite of policy analysts because it melds the public and private sectors, only modest numbers of partnership policies have been sold in the four states in which the initiative has been tried, despite more than a decade of active promotion and marketing by the respective states. In 2006, after 10 years of promoting the policies, there were only about 200,000 partnership policies in force in the original four states, about 2.6 percent of the older population in the four states (Alliance for Health Reform, 2007; U.S. Census Bureau, 2006). Currently, 22 states, including Pennsylvania, are selling long-term care partnership policies (Long-Term Care Partnership Program, 2009). Depending on who purchases these policies and who eventually needs long-term care, partnership policies may not reduce Medicaid costs, and conceivably could even increase them because some people who would not otherwise be eligible for Medicaid may become so (U.S. Government Accountability Office, 2005).

Minimize the Cost of Expanding Home and Community-Based Services

Given recent problems in the economy and the future increase in demand for long-term care services in the future, adding funding to both home and community-based services and nursing home services may strain the financial resources of many states. In addition to meeting the preferences of people with disabilities to remain in the community if at all possible, consumer advocates and state and some federal officials support expansion of home and community-based services because they believe that people with disabilities can be served at lower cost in the community and that expanding services will result in less costly systems of care. In particular, they hope to substitute home and community-based services for nursing home care.

The primary argument for the cost savings potential of home care rests on a comparison of the average per person Medicaid expenditures for people in the community and in nursing homes. The average annual Medicaid expenditures for home care for older people and adults with physical disabilities (\$8,355 in 2004) per person are dramatically less than average annual Medicaid expenditures (\$27,650 in 2004) per person for nursing home care (CMS, 2008; Kitchener, Ng and Harrington, 2007). This comparison, however, is incomplete because it does not address differences in disability levels, use of acute care services, and the exclusion of housing and room and board costs from home care expenditures. Thus, it is not strictly an “apples to apples” comparison.

Perhaps the most controversial difference in costs relates to the so-called “woodwork effect.” Because a high proportion of people with disabilities do not use paid home and community-based services (Johnson and Wiener, 2006) and because some of the services are inherently desirable (e.g., homemaker services), making these services more widely available can dramatically increase the number of people who use them, enrolling people who would not otherwise be institutionalized.

Although virtually all of the studies on this topic are based on dates more than 20 years ago and do not incorporate more recent state experiences with Medicaid home and community-based services waivers, most research evaluating demonstration projects expanding home and community-based services finds that expanding home care increases rather than decreases total costs. Grabowski (2006) reviewed the potential cost savings of newer home and community-based services models of care such as Medicaid waiver programs, consumer-directed care, capitated care, and case management and subsidized community services for individuals with dementia. Generally, these new care models were associated with increased costs, but greater client and caregiver welfare. Both capitated care and consumer-directed care were identified as potential mechanisms to provide care more efficiently. Generally though, the evidence on potential cost savings of these newer models is weak because of limitations in research design.

This finding of increased costs results primarily from targeting decisions; in these demonstration projects, most persons receiving home care would not have entered a nursing home without the services. In other words, while home care provided a desirable service to people with real needs, it was primarily a supplemental service and did not substitute for nursing home care in most instances. In some cases, the average cost per person in the community, while less than nursing home costs, was not dramatically less than nursing home costs. Thus, in these studies, the costs of large increases in home care use more than offset modest reductions in nursing home use. Although not directly addressing the issue of cost-effectiveness, a recent study of Medicaid long-term care spending patterns found that total long-term care expenditure growth was greater for states offering limited noninstitutional services than for states with large, well-established home and community-based services programs (Kaye, LaPlante, and Harrington, 2009).

To minimize the cost of expanding home and community-based services, states are using a variety of techniques to substitute home and community-based services for nursing home care and to provide services at lower cost. These strategies include the following and are discussed in the remainder of the paper:

- *Improve program linkages between home and community-based services and institutional care.* This strategy includes administrative reorganization and consolidation of departments and programs that address long-term care and the use of global budgets that facilitate the reallocation of funding from institutional to noninstitutional services.
- *Improve targeting to people who would otherwise be institutionalized.* This strategy refines eligibility criteria for Medicaid and state-funded home and community-based services to target people at high risk of institutionalization. Money follows the person, for example, targets people who are already in institutions.
- *Structure financial incentives to increase use of home and community-based services and decrease use of nursing homes.* These initiatives include two very different strategies. The first is to consolidate funding for nursing homes and home and community-based services into a single capitated payment to managed care organizations, providing a financial incentive for the plans to use lower-cost services. The second strategy is to provide financial incentives to nursing homes to reduce their number of beds or to convert to assisted living facilities or other types of care.
- *Provide information and single point of entry systems to give consumers more choices.* This strategy provides consumers more information about long-term care service and financing options and conducts functional (and sometimes financial) eligibility determinations for a wide range of public programs, facilitating the ability to put together a package of services that will maintain people in the community. The premise is that by leveling the playing field a higher percentage of consumers will choose home and community-based services over nursing home care.
- *Administer Medicaid and state-funded home and community-based services more efficiently.* This strategy attempts to manage home and community-based services more efficiently and equitably by standardizing assessments and systematizing and standardizing care plans. This strategy assumes that by carefully standardizing the resource allocation process overall utilization will decline.
- *Provide a range of lower-cost home and community-based services.* This strategy offers consumers a wide range of lower-cost home and community-based services as alternatives both to nursing home care and to higher cost community services. These initiatives include consumer-directed home care and residential care facilities.

IMPROVE PROGRAM LINKAGES BETWEEN HOME AND COMMUNITY-BASED SERVICES AND INSTITUTIONAL CARE

State administrative and budgeting structures that coordinate and integrate responsibilities for nursing homes and home and community-based services can encourage reallocation of resources from institutional to noninstitutional

care by highlighting the trade-offs between these two types of care and by focusing attention of high-level officials on the programs, policies and procedures needed to successfully maintain people in the community (Anderson, Wiener, and O’Keeffe, 2006; Fox-Grage, Coleman and Milne, 2006; Kane et al., 2006). Most states, however, do not have integrated administrative and budget structures. Instead, administrative responsibilities for long-term care financing, budgeting, program development and policy, reimbursement, provider entry, operations, and quality assurance are typically allocated across many different state agencies, resulting in fragmented policy development and accountability. Moreover, most states do not pool the numerous long-term care funding streams and rigidly budget home and community-based services separately from nursing home care, even within the Medicaid program. Thus, for example, Medicaid home and community-based services waivers may be administered by the Department of Public Welfare, while home and community-based services funded by Title III-B of the Older Americans Act may be administered by the Department of Aging, with little coordination between the two programs, even though the two agencies may pay for similar services to overlapping populations.

The potential advantages of greater consolidation of administrative and budgeting functions include more consistent goals for the long-term care system, enhanced accountability for decisions and outcomes, more consistent policymaking, enhanced ability to move funds from institutional to noninstitutional services, and improved access to services (Fox-Grage, Coleman and Milne, 2006). Barriers to consolidation can include difficulty serving multiple populations with different issues and funding streams, agency turf battles, consumer and policymaker fears of big government, and some resistance from consumer groups who fear losing their relationships with established bureaucracies.

State initiatives to improve administrative coordination and decisionmaking can be classified into three models—cabinet, umbrella, and consolidation (Armour-Garb, 2004):

- Under the cabinet model, existing cabinet-level agencies (e.g., aging, health, public welfare, human services) retain their long-term care responsibilities, but work with an official interagency coordinating committee. This structure, as in Pennsylvania, requires the least amount of administrative reorganization, but its success depends on personal effort and consensus, since no one person is empowered to make decisions.
- In the umbrella model, all long-term care services are provided under one single organization, usually a department of health and social services. Different long-term care programs and functions operate in various divisions within the umbrella department. However, organizational units are usually not organized in such a way as to put all long-term care functions in one agency within the department. Each program may have its own independent department-like functions, often linked to funding requirements (e.g., Older Americans Act, Medicaid). Typically, there is a secretary who is administratively over the individual agencies, but he may or may not have substantial decisionmaking authority. Moreover, this official has authority over many different program areas and is not focused on long-term care.
- In the consolidation model, all or almost all long-term care responsibilities, both institutional and home and community-based, are located within one new agency or a division of a larger department. The consolidation model usually requires major governmental reorganization. This model is used in Oregon, Washington, Texas, and Vermont. In this model, the head of this organization, by definition, focuses on long-term care issues and has the authority to make almost all decisions related to long-term care (subject to budget constraints). The underlying assumption is that consolidating authority and responsibility in a single organizational structure substantially enhances administrative efficiency and accountability.

Closely aligned with the organizational changes are state budgeting issues. State legislatures usually appropriate separate budgets for Medicaid institutional services and for Medicaid home and community services programs, as well as for home and community services financed solely with state funds or federal block grant and Administration on Aging funds. Money in these separate budgets cannot be used for other purposes, and are sometimes managed by different state agencies with different accounting, reimbursement, case management, and

service delivery systems and providers. States that do not allow transfers from Medicaid institutional services to home and community-based services budgets may have waiting lists for noninstitutional services. To address this problem, a few states such as Oregon and Washington use “global budgeting” to provide a single budget appropriation for all Medicaid long-term care services, including both home and community-based services and nursing home care. This unified spending authority allows a state agency to avoid the “silo” approach of separate line-item budgets for institutional services or home and community-based services and instead to move funds among various long-term care services depending on demand and policy choices.

TARGETING OF SERVICES TO PEOPLE WHO WOULD OTHERWISE BE INSTITUTIONALIZED

A large majority of persons with disabilities do not receive paid home care. Even among older adults living in the community with severe disabilities and with income below 100 percent of the federal poverty level, 53 percent did not receive paid home care in 2002 (Johnson and Wiener, 2006). Over the last 20 years, states have increasingly targeted services to people with more severe disabilities. In part, this reflects the statutory requirements of Medicaid home and community-based services waivers that limit eligibility to people who meet the state’s institutional level of care criteria. By targeting persons with disabilities who would otherwise be institutionalized, states can limit the size of the eligible population (thus limiting the “woodwork” effect) and, thus, expenditures for home and community-based services and increase the substitution of home and community-based services for institutional care. While by no means an accurate measure of the number of people who would otherwise be institutionalized if they did not receive paid home care, in 2002, out of 10.7 million older people with disabilities living in the community, only 2.0 million had severe disabilities (have limitations in 3 or more ADLs) (Johnson and Wiener, 2006).

Research suggests that states interested in increasing the substitution of home and community-based services for institutional care should target people with the most severe functional and cognitive impairments because they are the ones most likely to otherwise enter a nursing facility. However, functional status alone does not result in the need for nursing facility care. Age, living alone, not having an informal caregiver, poor cognitive functioning, high number of prescription drugs, and prior hospitalizations are all positively associated with institutionalization (Ashok et al., 2004; Miller and Weissert, 2000; Yael and Cooper, 2006). One study estimated that doubling state home and community-based services expenditures per person aged 65 or older would reduce the risk of nursing home admission among childless seniors by 35 percent (Muramatsu et al., 2007). Limiting services only to persons who truly would be institutionalized without the services may result in serving a relatively small number of people with disabilities.

At their core, money follows the person and nursing facility transition initiatives rely on highly effective targeting to save money by reducing nursing home use and providing home and community-based services instead (Anderson, Wiener, and O’Keeffe, 2006). Money follows the person and nursing facility transition programs identify people already in nursing homes who wish to return to the community and help them to do so, providing them with Medicaid home and community-based services in the community after discharge. By definition, people already living in nursing homes have a high risk of nursing home use. Thus, they rate well on targeting. These initiatives rest on the assumptions that without these interventions, these nursing home residents would continue to live in the nursing home and that providing care in the community will be less expensive than providing care in the nursing home.

To explore this concept more deeply, the Deficit Reduction Act of 2005 allocated \$1.75 billion over 5 years for a demonstration of this concept, with the funds earmarked for enhanced federal Medicaid match for services provided to people transitioning out of nursing homes and other institutions as an enticement for states to participate in the demonstration. Thirty-one states, including Pennsylvania, are participating in CMS’s Money Follows the People grant program.

On the one hand, transitioning individuals with intellectual disabilities from institutions to the community has been a central component of long-term care policy for that population for more than three decades. On the other

hand, identifying people in nursing homes who want to live in the community and actively working to transition them out of the institution is a radical change in approach for older people and younger persons with physical disabilities. For the past 25 years, the overwhelming focus has been on preventing admissions to nursing homes, not discharging residents from them. This new strategy takes as its premise that there are people living in nursing facilities that want to return to the community and can do so at a reasonable cost, and that some people admitted to nursing facilities improve rather than decline in functional status and may desire to return to the community. Nursing facility transition programs also reflect an increasingly widespread view that people of all ages with severe disabilities can successfully live in the community with the proper supports, thus challenging the notion of a strict continuum, in which each service is reserved for persons of a particular disability level.

Three factors may prevent states from realizing substantial savings from money follows the person initiatives. First, it is not known how many long-stay Medicaid nursing home residents, in fact, could be transitioned to the community. For example, Pennsylvania plans to transition only about 1,900 older people or younger adults with physical disabilities from nursing homes over the demonstration period, a small proportion of the total number of residents in nursing homes. Transitioning individuals is difficult because entirely new households need to be established with new furniture and complex service packages. In many cases, individuals were institutionalized because the informal care network could no longer provide the support needed. In fact, under the federal demonstration, most states plan to transition small numbers of nursing facility and intermediate care facilities for the mentally retarded/developmental disabilities (ICF/MR) residents. Thus, even if cost savings are possible on an individual basis, the initiatives may not serve many people.

Second, home care costs of people transitioned from nursing homes may be higher than costs of the average Medicaid home and community-based services waiver beneficiaries. For example, in Wisconsin, while Medicaid home and community-based services costs of nursing facility residents transitioned to the community are 77 percent of institutional costs, these costs do not include Supplemental Security Income, food stamps, housing subsidy, or Medicare and Medicaid acute care services (Anderson, Wiener, and O’Keeffe, 2006). In addition, transition services for getting people out of facilities may be costly.

Third, nursing home utilization may not decline. Savings from money follows the person strategies assume no excess demand for nursing home beds, and that once residents transition from the facility, the nursing home beds will remain empty. That assumption may or may not be true, depending on the particular geographic location, but it is very different from the assumptions that have characterized nursing home use for most of the last 30 years where supply-induced demand was thought to be common (Wiener, Stevenson and Goldenson, 1999). In fact, median occupancy rates in nursing facilities have remained relatively stable from 2000 to 2008 (American Health Care Association, 2008). Further, even empty beds may result in costs to Medicaid if the capital and operating costs of empty beds are built into the Medicaid rate.

STRUCTURE FINANCIAL INCENTIVES TO INCREASE USE OF HOME AND COMMUNITY-BASED SERVICES AND DECREASE USE OF NURSING HOMES

This strategy includes two very different approaches. The first uses capitation to create financial incentives within managed care organizations to substitute home and community-based for nursing home care. The second approach provides direct financial incentives to nursing homes to downsize or to convert to assisted living or other types of residential care facilities.

Coordinated Care for People with Long-term Care Needs

People with disabilities currently receive care in a splintered and uncoordinated financing and delivery system. Financing for acute care is largely the responsibility of Medicare and the federal government, while long-term care is dominated by Medicaid and state governments. Within long-term care, financing comes from a variety of sources, including Medicare, Medicaid, the Older Americans Act, and a number of state-funded programs. In terms of service delivery, fragmentation exists both within and between the acute care and long-term care systems.

Federal initiatives to integrate acute and long-term care date to the 1980s and early 1990s, although some states have more recent projects. Almost all of these initiatives depend on managed care taking responsibility for both acute and long-term care services. Under these models, capitated organizations have financial incentives to avoid both the functional decline that can result from unmet needs and the unnecessary costs associated with providing services in needlessly expensive settings. The hypothesis is that this coordinated approach will produce savings in acute care because lower-cost long-term care services will substitute for more costly hospital and physician services and that home care will substitute for more expensive nursing home care. The best known and most extensively researched of these projects are the Social Health Maintenance Organizations (S/HMOs), the Program of All-inclusive Care of the Elderly (PACE), and the Arizona Long-Term Care System (ALTCS), but other examples include Texas' STAR+PLUS program, the Minnesota Senior Health Options (MSHO), New York's Medicaid Long-Term Care Capitation Program, and Wisconsin's Family Care program. Social HMOs, a demonstration project of the 1980s and 1990s, extended the traditional concept of HMOs by adding a modest amount of long-term care to the benefits covered by Medicare (Leutz and Capitman, 2005). A coordinated case management system authorized long-term care benefits for those who met the established eligibility criteria. Social HMOs were intended to serve a cross section of the older population, including both people with and without functional impairments. While all enrollees were eligible for Medicare, relatively few Medicaid beneficiaries were enrolled.

Also starting as a demonstration project, PACE provides a comprehensive set of acute and long-term care services in an integrated financing and service setting (Eng et al., 1997). Although PACE became a part of the regular Medicare and Medicaid programs as a result of the Balanced Budget Act of 1997, there were only about 60 programs in 2008 (National PACE Association, 2008). While Social HMOs targeted a broad range of people with and without disabilities to pool risk, enrollment in PACE is limited to people who are disabled enough to meet nursing home admission criteria. Because expenditures per person are so high, very few people can afford to pay an actuarially fair premium. As a result, almost all enrollees are dually eligible for Medicare and Medicaid. PACE sites operate as geriatrics-oriented, staff model HMOs, with primary care physicians as employees of the organization. A hallmark of the program is heavy use of adult day health programs, which are integrated with primary care.

The Arizona Health Care Cost Containment System (AHCCCS) is a statewide demonstration project that finances medical services for the Medicaid population through prepaid contracts with providers (McCall, 1996). Beginning in 1989, the Arizona Long-Term Care System (ALTCS) program incorporated Medicaid long-term care services into the AHCCCS program (Weissert et al., 1997). Arizona is the only state to provide for capitated acute and long-term care services on a statewide basis. Participation is limited to individuals who are certified to be at risk of institutionalization. ALTCS covers Medicaid acute care services (but does not include Medicare payments), nursing facilities, intermediate care facilities for people with mental retardation, and home and community-based services.

While Social HMOs, PACE, and ALTCS seek to integrate acute and long-term care services and financing, Wisconsin's Family Care Demonstration focuses solely on integrating long-term care, including both a wide range of home and community-based services and institutional care (Alecxi et al., 2003). Family Care has two major components—aging and disability resource centers and care management organizations. The resource centers offer a wide range of information and counseling on long-term care services and providers, assist with enrollment into a care management organization if desired by the client, and conduct functional assessments for Family Care. Resource Centers seek to be “single point of entries” to the entire long-term care system for persons of all income levels.

Care management organizations serve as capitated, managed care organizations for institutional and home and community-based long-term care services. Funding for long-term care from Medicaid state plan services, the Medicaid home and community-based services waivers, and state and county-funded programs are consolidated into a single monthly capitated payment to care management organizations. The goal is one “pot” of money that can be used to create a seamless system in which individuals' needs dictate service provision, rather than program

demarcation. To consumer advocates, a major advantage of Family Care is that it provides an entitlement to an array of flexible home and community-based services to everyone who meets certain criteria. Thus, its goal is to end Wisconsin's long waiting lists for home and community-based services.

Rightsizing Nursing Homes

States working to rebalance their long-term care systems not only need to increase the supply of home and community-based services, but also “rightsize” their nursing home capacity. By adjusting downward their nursing home capacity, states limit potential supply-induced demand, increase incentives to keep less disabled persons in the community, and reduce any Medicaid payments for excess capacity that may be built into the reimbursement formula. The concept of supply-induced demand suggests that, largely because of the availability of third-party payments, health care providers can generate demand independent of the need for services. Thus, a nursing home bed is likely to be a filled nursing home bed, and one largely filled by Medicaid beneficiaries. Historically, there has been an extremely strong relationship between the number of nursing home residents and the supply of nursing home beds (Wiener, Stevenson, and Goldenson, 1999). However, sharply falling nursing home use rates over the last 20 years suggest that excess demand is much less prevalent than it was in the past. For example, although the number of people age 75 and older increased by 54 percent between 1985 and 2004, there was only a 10 percent increase in the number of elderly nursing home residents (Alexciv, 2006; U.S. Bureau of the Census, 1995, 2008).

Other states are at various points in developing, implementing or completing rightsizing or conversion projects to modify the supply of their nursing home beds. Rightsizing is not a new idea. Wisconsin and Nebraska started before 2000 with rightsizing initiatives. Minnesota, Indiana, Iowa, and North Dakota began rightsizing programs in the early to mid-2000s. New York and Michigan are still in the planning stage. We categorize the initiatives in each of these states and supply information on the type of initiative, financial incentives used, and any information about the number of beds closed or converted to other uses, drawing heavily on a previous report on rightsizing issues by Morris (2007).

States use four methods for rightsizing their nursing home capacity—permanent bed closure, temporary bed closure, reducing dual occupancy rooms to single occupancy, and converting beds, wings, or whole facilities for another use such as assisted living (Morris, 2007). **Table 4** summarizes the use of these methods in eight states.

Table 4: Rightsizing Initiatives and Related Financial Incentives

Method	Incentive type	States	Number of beds affected
Permanent closure	Rate adjustment	Minnesota	4,800+
	One-time payment	Indiana, North Dakota	286 in North Dakota
Temporary closure	Rate adjustment	Minnesota	2,800+
	No license fee	New York	Unknown
Dual occupancy room to single occupancy room	Per resident day increase	Minnesota, Michigan	Unknown
Conversion	Low-rate loans	Wisconsin, Iowa	294 in Iowa
	Competitive grants	New York, Iowa, Nebraska	Unknown

Source: Morris, 2007.

States have developed at least six types of financial incentives for nursing homes to secure their participation in these initiatives. These incentives include the following:

- Upward Medicaid rate adjustments on remaining beds when nursing homes either permanently or temporarily close beds.
- One-time extra Medicaid payments when beds close.
- Ending the license fee for beds that temporarily close, reducing facility costs.
- Raising Medicaid reimbursement rates when dual occupancy rooms are converted to single occupancy room.
- Offering competitive grants to help nursing home operators convert existing beds, wings, or facilities to assisted living or a similar less-restrictive environment.
- Low-interest loans or loan guarantees for conversion projects. Grants or loan guarantees often cover capital or one-time costs and operation losses for the first years of operation. Participating nursing homes agree to maintain a set occupancy level for Medicaid beneficiaries for a given number of years.

States engaged in these initiatives faced significant competing political pressure to move slowly on rightsizing and conversion initiatives. To address these pressures, several states formed a task force or a commission to help broker solutions to the need for fewer nursing home beds. For example, New York established a rightsizing commission with diverse stakeholders to address the need for less expensive care in less restrictive settings.

PROVIDE INFORMATION AND SINGLE POINTS OF ENTRY

The fragmentation of the long-term care financing and delivery system may result in a bias toward nursing home placement. While nursing home care consists of a complete package of residential, medical, and social services from one provider and one source of financing, home and community-based services often require putting together a complex package of services from many different providers, who receive payments from a number of different programs, each with their own financial and functional eligibility requirements. In addition, consumers may have to take many steps before becoming eligible for a program or service and, in the process, interact with multiple entities, often “telling their story” and providing the same information multiple times (The Lewin Group, 2006). Sometimes consumers get bounced around within an agency or between different organizations with no systematic follow-up and tracking to determine whether the consumers’ needs were met. Thus, it is often “easier” to enter a nursing home than to stay in the community, especially given the rapidity with which many of these care decisions must be made.

An integrated point of entry or “one stop shop” can address many of these problems (The Lewin Group, 2006). Single points of entry attempt to level the playing field between community and institutional care, allowing people with disabilities to choose services based on what is best for them. These single points of entry provide information to consumers about service and funding options for a wide range of programs, including those funded by the federal and state government, enhancing individual choice and informed decisionmaking. This strategy can also break down barriers to community-based living by offering consumers information about the complete spectrum of long-term care options. Single points of entry also, either directly or through referral, connect people in need of services with agencies that can assess their functional and financial eligibility for various public and private programs, including Medicaid. Given informed decision-making, advocates of single points of entry believe that fewer people would choose nursing home care (Kane, Priester, and Kane, 2007).

To promote this approach, the Administration on Aging and CMS launched the Aging and Disability Resource Center grant initiative with grants to 43 states and territories, including Pennsylvania where the grant is working in Allegheny and Cumberland counties. Aging and Disability Resource Centers also offer resources to health and long-term support professionals and others who provide services to older adults and to persons with disabilities. A major challenge for these grants is taking the lessons learned from often small demonstration projects and implementing statewide systems. For many seniors to be able to make informed decisions for community care,

functional and financial eligibility status under Medicaid and other programs needs to be determined quickly if community living is to be a viable alternative.

ADMINISTER MEDICAID AND STATE-FUNDED HOME AND COMMUNITY-BASED SERVICES MORE EFFICIENTLY

In most states, responsibility for conducting functional assessments and developing care plans is highly decentralized, resulting in wide variation in eligibility determinations and in care plans. This variation creates inequities and inefficiencies. To address this problem, some states are standardizing assessments and more systematically reviewing care plans.

Washington, for example, conducts assessments on laptops and uses an algorithm that produces a care plan (Anderson, Wiener, and O’Keeffe, 2006). The state also uses this information to forecast demand to facilitate development of rates and make projections of future long-term care expenditures. Washington’s assessment software has important features that promote efficiency in the home and community-based services provision. The software provides a means for regular synchronization of all data to ensure accuracy across various software modules to make sure the right information is used at the right time to develop care plans. An enhanced information and referral resource directory can be used to identify all of the social supports needed. Finally, the software incorporates full automation of the algorithms and rules associated with an assessment (2006 conversation with the authors).

ADMINISTER MEDICAID AND STATE-FUNDED HOME AND COMMUNITY-BASED SERVICES MORE EFFICIENTLY

Innovative home and community-based services, including consumer-directed home care and residential care facilities, may provide people with disabilities services that more efficiently meet their needs.

Consumer Direction

Traditional public home care programs rely on public or private agencies to hire and fire home care workers, schedule and direct services, monitor quality of care, discipline workers if necessary, and pay workers and applicable payroll taxes. In the agency-directed model, clients can express preferences for services or workers, but have no formal control over them. This approach to care operates from the assumption that professional expertise and accountability are critical to the provision of good quality care at reasonable cost. At its extreme, a “medical model” is imposed and individuals with disabilities are considered to be “sick,” as opposed to needing compensatory services, such as help with bathing. Consumer-directed home care programs represent the opposite end of the management continuum from agency-directed services. These programs give consumers control over who provides services, when they are provided, and how these services are delivered. Typically, consumer-directed programs allow the consumer to hire, train, supervise, and fire the home care worker. State agencies approve a service plan for consumers and may contract with fiduciary agents to assist consumers with worker contractual arrangements, tax withholding, and payment. In some programs, beneficiaries receive cash payments enabling them to purchase the services they want.

A growing number of states are incorporating consumer direction into their home care programs, including California, Michigan, Oregon, Washington, and Wisconsin. The National Association of State Units on Aging reported that 40 states and territories operated a total of 62 consumer-directed programs that served older people in 2004 (Infield, 2005). CMS promoted consumer-directed services through the Real Choice Systems Change Grants and the Independence Plus Initiative (O’Keeffe, Wiener, and Greene, 2005; O’Keeffe et al., 2007). In addition, the Office of the Assistant Secretary for Planning and Evaluation, CMS, and the Robert Wood Johnson Foundation sponsored “cash and counseling” demonstrations in Arkansas, Florida, and New Jersey where Medicaid beneficiaries of all ages are being given the opportunity to receive a flexible budget rather than service benefits (Doty, Mahoney, and Simon-Rusinowitz, 2007). In addition, several countries, including the United Kingdom, the Netherlands, and Germany, use consumer-directed home care (Wiener, Tilly and Cuellar, 2003).

A limited number of research studies find that satisfaction with consumer-directed services, a major component of quality, is at least comparable to that for agency-directed services and may be higher. In a study of elderly Medicaid personal care beneficiaries in Maryland, Michigan, and Texas, respondents who reported that they had a great deal of choice consistently reported more satisfaction with their services than those without choice (Taylor, Leitman, and Barnett, 1991). Of the three states, however, only Michigan had a full consumer-directed home care program. A small study of younger clients of consumer-directed services in Virginia found that they reported higher satisfaction and greater work productivity than those receiving agency or informal services (Beatty, Richman, Tepper, and DeJong, 1998).

In a study of California's In-Home Supportive Services beneficiaries in the mid-1990s, consumer-directed respondents reported more satisfaction than agency-directed clients with their services and the freedom to select them, a stronger preference for managing services, higher perceived quality of care and higher emotional, social, and physical well-being (Benjamin, Matthias, and Franke, 1998). Respondents who were directing their care also reported greater satisfaction with the providers' ability to assist them than did those consumers using agency-directed services. Other differences in outcomes between the two groups were not significant.

Similarly, in a study of Medicaid beneficiaries receiving consumer-directed and agency-directed home care in Washington in 2003 and 2004, older people, but not younger adults with disabilities, were more satisfied with consumer-directed services (Wiener, Anderson and Khatutsky, 2007). There was no evidence that the quality of care was lower with consumer-directed services.

Finally, in a study of the Cash and Counseling demonstration program in Arkansas, Florida, and New Jersey, Medicaid beneficiaries in the consumer-directed program reported much higher levels of satisfaction and much lower levels of dissatisfaction than beneficiaries receiving agency-directed services (Foster et al., 2003; Schore, Foster, and Phillips, 2007). Beneficiaries in the consumer-directed program also reported that workers were more likely to complete tasks and arrive on time, and were less likely to neglect the client or be rude or disrespectful. This finding was true for both younger adults with physical disabilities and older persons. The Cash and Counseling program was a voluntary demonstration project for people who were eligible for Medicaid personal care or home and community-based services waivers. Demonstration enrollees who were assigned to the treatment group received a monthly allowance that they could use to hire workers (except spouses) and to purchase other services or goods related to their needs, such as assistance devices and home modifications. Persons assigned to the control group received regular agency-directed services.

The cost per hour or per visit of consumer-directed home care is typically much less than for agency-directed home care largely because states and other countries do not pay for agency overhead. In the Netherlands, the individual budgets established for people with disabilities who use consumer-directed home care are reduced by 25 percent to account for this lower overhead (Wiener, Tilly, and Cuellar, 2003). In addition, consumer-directed home care workers typically receive fewer fringe benefits and sometimes lower wages than workers in agencies.

However, unit costs do not guarantee aggregate cost savings. In a rigorous evaluation of the Cash and Counseling demonstration, researchers found that Medicaid costs were generally higher under Cash and Counseling than in the control group, although the difference between the two groups declined over time (Dale and Brown, 2007). The demonstration's higher expenditures were largely due to the increased ability of program demonstration participants to obtain the authorized amounts of paid care for personal care/waiver services. Higher costs for personal care/waiver services were partially offset by savings in other Medicaid services, particularly those related to long-term care. Compared to the Cash and Counseling demonstration group, agency-directed consumers were less likely to receive any services at all and, among those that did obtain services, received a lower proportion of the amount of care authorized. In sum, Cash and Counseling costs were higher because consumer-directed program participants, as compared to agency-directed participants, received the services for which they were authorized because they did not have the workforce shortages and other problems faced by agency-directed participants.

Residential Care Facilities

Most older people with disabilities would prefer to receive services delivered in their own homes (Henry J. Kaiser Family Foundation, 2007). As desirable as this model of care is, it is inherently inefficient in that it requires a worker to travel from one residence to another, rarely seeing more than one consumer at a time. Recognizing that there are certain economies of scale in group residential settings that are lacking in traditional home care, many states and older people are exploring the potential role of residential care, including adult foster care, board and care homes, and assisted living facilities, in part as alternatives to nursing home care (Mollica, Sims-Kastelein, and O’Keeffe, 2007). Pennsylvania, which has a large number of personal care homes, passed legislation in 2007 authorizing the licensing of assisted living facilities and application to the federal government for a Medicaid home and community-based services waiver to include an assisted living benefit.

Policymakers and older people hope that these facilities will be able to provide services in a more home-like environment that provides greater personal autonomy and more personal choice than nursing homes. These settings may be particularly useful for persons who do not need a large amount of hands-on care, but do need a lot of supervision, such as persons in the early or middle stages of Alzheimer’s disease or with other cognitive impairments.

Although residential care has operated for years without much attention by policymakers, there are a large number of facilities and units/beds. As of 2007, state licensing agencies reported 38,373 licensed residential care facilities with 974,585 units/beds (Mollica, Sims-Kastelein, and O’Keeffe, 2007). By contrast, in June 2008 there were an estimated 15,739 nursing homes with 1,670,419 beds (American Health Care Association, 2008).

In addition to providing more choices for people with disabilities, state officials also hope that these residential care facilities can be lower-cost alternatives to nursing home care. Indeed, some of the states that have made the most progress in balancing their long-term care systems, such as Oregon, Washington, and Wisconsin, rely heavily on residential care as part of their home and community-based services system (Kane et al., 2008; Wiener, Tilly and Alecxih, 2002). In general, assisted living facilities cost less than nursing homes, but they are still expensive. In a survey of private pay costs of long-term care, Genworth Financial (2008) reported that the average private pay cost of a year in a nursing home was \$76,285 and \$36,096 in an assisted living facility.

Most residential care facility residents pay privately. In addition to their personal income, their care is often supplemented by financial assets and contributions from other family members. Probably the most common public payment source for low-income facility residents is the federal Supplemental Security Income (SSI) program. States may provide an additional amount above the monthly SSI payment to cover additional room, board, and some service costs (Mollica, Sims-Kastelein, and O’Keeffe 2007). However, SSI levels, even when supplemented with optional state payments, may be inadequate to cover room, board, and service costs for residents with moderate to high service needs (O’Keeffe and Wiener, 2004).

Medicaid is a potentially important source of payment for residential care facilities. In 2007, 42 states covered services in residential care facilities under Medicaid, with 29 states doing so under home and community-based services waivers, 7 states under the personal care option, and 6 under both options (Mollica, Sims-Kastelein, and O’Keeffe, 2007). While services may be covered through the personal care option or through home and community-based services waivers, room and board in residential care facilities is not reimbursable by Medicaid as part of home and community-based services waivers.

Despite the larger number states with waivers, the number of Medicaid beneficiaries receiving long-term care services in group residential settings outside of nursing homes or intermediate care facilities for people with mental retardation is small, only about 115,000 beneficiaries in 2007, down slightly from 2004 (Mollica, Sims-Kastelein, and O’Keeffe, 2007). Although exact figures are not readily available, about half of these Medicaid beneficiaries are older people and younger adults with physical disabilities (Kitchener et al., 2006). Nationwide,

Medicaid waiver expenditures for residential care facility services for older people and younger persons with physical disabilities totaled only \$537 million in 2002.

In assessing whether residential care facilities, such as assisted living facilities and adult foster care, increase or reduce state costs, several factors must be taken into account. First, annual costs to Medicaid of nursing home care are about twice the cost of residential care provided through home and community-based waivers. During 2002, average Medicaid waiver residential care facility expenditures per beneficiary were \$9,153, compared with \$22,326 for nursing home care (CMS, 2008; Kitchener et al., 2006).

This is not, however, strictly an apples-to-apples comparison because it does not adjust for differences in services provided or the disability of residents. Moreover, Medicaid nursing home payments include room and board, while payments for residential care do not. These figures also do not take into account possible differences in the use of acute care services by people in nursing homes and residential care facilities. There is some evidence that persons with disabilities in the community have higher acute care expenses than nursing home residents, although most of these expenses are incurred by Medicare rather than Medicaid (Komisar, Hunt-Cool and Feder, 1997-98).

Second, the costs of residential care facilities and nursing homes reflect, at least to some extent, the functional and medical characteristics of the residents. While there is some overlap in resident characteristics between nursing homes and residential care facilities, on average nursing home residents are more disabled. In a 2006 survey of assisted living facilities, the average resident had 2.0 deficiencies in ADLs (AAHSA et al., 2006); in contrast, the average nursing home resident had 4.0 deficiencies in ADLs (American Health Care Association, 2008). Similarly, the National Study of Assisted Living for the Frail Elderly found that most assisted living residents are less impaired than typical nursing home residents, although the study also found that a third of assisted living facility residents had cognitive impairment and a quarter had three or more ADL problems (Hawes, Rose and Phillips, 1999). In Ohio, a comparison of participants in the Medicaid assisted living waiver and nursing home residents found that 75 percent of Medicaid nursing home residents had problems with four or more ADLs, compared with 49 percent of assisted living waiver participants (Brown and Applebaum, 2007).

Third, as with other home and community-based services, a critical issue in terms of whether costs increase or decrease is whether residential care facilities draw additional persons into the publicly financed service system who previously would have gone without these services in the absence of residential care. Little is known about whether, on net, residential care facilities reduce nursing home use or whether they have no impact. As noted above, at least some of the states that have had success rebalancing their long-term care systems and have substantially reduced nursing home use rates also depend heavily on residential care facilities to provide a substantial portion of their home and community-based services. For example, between 1995 and 2005, the nursing home use rate per 1,000 older people in Wisconsin and Washington declined by 29 percent and 37 percent, respectively.

Conclusions

Almost all states, the federal government, and many other countries want to change the balance of the long-term care delivery system by increasing the importance of home and community-based services. States have made substantial progress in implementing this policy over the last 10 years as the percentage of long-term care services spent on home and community-based services has risen substantially; nonetheless, for older people and younger persons with physical disabilities, nursing home care still claims a substantial majority of Medicaid funding. A key issue in accomplishing that goal is how to finance these new services. States are pursuing two broad strategies to finance the expansion of home and community-based services: (1) simply adding more money to public programs and private insurance for noninstitutional services, and (2) minimizing the cost of expanding home and community-based services, largely by improving efficiency and increasing the likelihood of substitution for nursing home care.

The first strategy for balancing the long-term care system is simply to spend more public and private money on home and community-based services. Medicaid dominates state-level public funding for home and

community-based services, in large part because of the availability of the federal financial match. States can provide personal care and a few other optional services through the regular Medicaid program; Pennsylvania has not taken advantage of this option. Most policy initiatives, however, have focused on expanding home and community-based services waivers, which give states more fiscal control. Medicaid home and community-based services allow coverage of a broad array of services and people with more income and assets than are typically allowed. States must limit eligibility to people who need nursing home level of care and must keep average costs under the average cost of serving a person in a nursing home. In addition, most states have at least one program that provides home and community-based services funded entirely with state dollars; Pennsylvania has one of the largest of these programs. These state-funded programs are largely used to provide services to people above the Medicaid financial eligibility threshold or who do not meet the functional requirements and to fill the gaps in services that are not covered by Medicaid. States have also sought to increase funding for home and community-based services by promoting private long-term care insurance, but the high costs of the policies means that insurance continues to play a very small role in financing long-term care.

The second strategy is to minimize the cost of expanding home and community-based services by making services more efficient and by increasing the likelihood that they will substitute for nursing home care, thus limiting new expenditures. In the current fiscal environment where additional funding for long-term care is likely to be scarce, many states are focusing on this strategy. The research evidence that changing the delivery system will produce substantial Medicaid savings is not strong, but it is a premise strongly held by many state officials and consumer advocates. Moreover, although agreeing that no one should be institutionalized unless absolutely necessary, the nursing home industry in most states resists the notion that nursing home use can be substantially reduced by expanding home and community-based services.

State initiatives to reduce the incremental cost of home and community-based services span six different strategies. First, states have improved program linkages between home and community-based services by reorganizing their administrative and budgeting functions. They have done this by consolidating responsibility and decisionmaking for long-term care into single departments and divisions of departments and developed global budgets that make it easier to reallocate funds from institutional to home and community-based services.

Second, largely as a result of the federal requirements of Medicaid home and community-based services waivers, states are targeting home and community-based services to populations with relatively severe disabilities. Few states, however, go beyond functional and medical criteria to take into account other determinants of institutionalization, such as the availability of informal care. Money follows the person initiatives attempt to maximize targeting of people who would be institutionalized without home and community-based services by focusing on people already in nursing homes.

Third, states are structuring financial incentives to increase the use of home and community-based services and decrease nursing home use. By making a single capitated payment that includes both home and community-based services and nursing home care, managed care organizations may have a financial incentive to shift resources to lower-cost noninstitutional care. Establishing these managed care organizations, especially those integrating acute and long-term care services, is difficult, and has not been successfully implemented in many states. States are also providing direct financial incentives to nursing homes to reduce the number of their beds and to convert them to other uses, such as assisted living facilities.

Fourth, states are providing information to consumers and establishing single points of entry to the long-term care system. The current fragmentation of the long-term care financing and delivery system is bewildering to consumers and makes assembling a comprehensive package of home and community-based services difficult, making nursing home care, in some cases, the unnecessary default option. Aging and Disability Resource Centers, a jointly funded initiative by the Administration on Aging and CMS, address these issues by functioning as “one-stop shops” for information and for access to a wide range of financing and service options. The assumption is that if

consumers know that staying in the community is feasible and affordable they will choose that option over nursing home care.

Fifth, states are reexamining their assessment, care planning, and operational processes to determine where efficiencies are possible as a way of both reducing administrative costs and making sure that the level of services provided are what is needed but not more. Use of computerized assessment systems and care planning algorithms are key components of this approach.

Finally, states are providing a range of innovative services that may be lower cost while meeting the needs of people with disabilities. Consumer-directed home care enables program participants to hire, fire, schedule and train their own workers, whose payment rates do not include agency overhead. Although per unit costs may be lower, increased use of authorized services by people using consumer-directed services may offset these savings. Residential care facilities, especially assisted living facilities, have boomed over the last decade, although their use by Medicaid remains limited. These facilities attempt to capture the economies of scale of nursing homes but with more consumer choice and less of a medical orientation.

The large projected increase in the elderly population over the next 40 years, especially among the population aged 85 and older, almost guarantees that the demand for long-term care will rise dramatically in the future. This increase in demand provides us with the opportunity to substantially restructure the long-term care system of the future. Home and community-based services can play a substantially larger role if the federal and state governments put policies in place to achieve this goal. One of the key issues will be how to finance home and community-based services.

Authors

Joshua M. Wiener, PhD is a senior fellow and program director of Aging, Disability, and Long-Term Care at the research organization RTI International in Washington, D.C. He is the author or editor of 8 books and over 100 articles on health care for older people, people with disabilities, long-term care, Medicaid, health reform, health care rationing, and maternal and child health. He is currently involved in studies of Medicaid home and community-based services, the long-term care workforce, quality assurance for long-term care, and projection and simulation models for long-term care. Dr. Wiener is co-director of the U.S. Administration on Aging-funded Alzheimer's Disease Demonstration Grants to States National Resource Center. Before coming to RTI, Dr. Wiener did policy analysis and research for the Urban Institute, the Brookings Institution, the Health Care Financing Administration, the Massachusetts Department of Public Health, the Congressional Budget Office, the New York State Moreland Act Commission on Nursing Homes and Residential Facilities, and the New York City Department of Health.

Wayne L. Anderson Ph.D., is a senior research economist with RTI International in Research Triangle Park, North Carolina. His research focuses on disability and the long-term care system, including financing, budgeting, and organizational and workforce issues. He has played leading roles in federally funded research projects, including studies to estimate total health care expenditures attributable to disability nationally and by state, analyze systems-level changes in state long-term care systems, and understand the institutional and community-based direct care workforce.

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.

The authors gratefully acknowledge useful comments on an earlier draft of this paper from Drs. Howard Degenholtz and Judith Lave of the University of Pittsburgh. The views expressed in this paper are those of the authors and do not necessarily represent the views of the University of Pittsburgh, the Jewish Healthcare Foundation, or RTI International.

References

- AARP. (2003). *Beyond 50: A Report to the Nation on Independent Living and Disability*. Washington, DC: AARP.
- Alexih, L.M.B. (2006). *Nursing home use by "oldest old" sharply declines*. Fairfax, VA: The Lewin Group. Available at <http://www.lewin.com/content/publications/NursingHomeUseTrendsPaperRev.pdf>.
- Alexih, L.M.B., Olearczyk, B.A., Neill, C., & Zeruld, S. (2003). *Wisconsin Family Care Final Evaluation Report*. Falls Church, VA: The Lewin Group. Available at <http://www.legis.state.wi.us/lab/PastReportsByDate.htm>.
- Alliance for Health Reform. (2007). *Long-term care partnerships: An update*. Washington, DC. Available at http://www.allhealth.org/publications/long-term_care/long_term_care_partnerships_53.pdf.
- American Association of Homes and Services for the Aging (AAHSA), American Senior Housing Association, Assisted Living Federation of America, National Center for Assisted Living, and the National Investment Center for the Seniors Housing & Care Industry. (2006). *2006 overview of assisted living*. Washington, DC.
- American Health Care Association. (2007). *Trend in Certified Nursing Facilities, Beds, and Residents, CMS Nursing Facility OSCAR Standard Health Survey Data, December 2007*. Washington, DC. Available at http://www.ahcancal.org/research_data/trends_statistics/Documents/trends_nursing_facilities_characteristics_Dec2007.pdf.
- American Health Care Association. (2008). *Trends in nursing facility characteristics*. Washington, DC: American Health Care Association. Available at http://www.ahcancal.org/research_data/trends_statistics/Documents/trends_nursing_facilities_characteristics_Jun2008.pdf.
- Anderson, W.L., Wiener, J.M., and O'Keeffe, J. (2006). *Money Follows the Person initiatives of the Systems Change grantees*. Research Triangle Park, NC: RTI International. Available at: <http://www.cms.hhs.gov/RealChoice/downloads/MFP.pdf>.
- Armour-Garb, A. (2004). *Point of entry systems for long-term care: State case studies*. New York: New York City Department on Aging. Available at www.adrc-tae.org/tiki-download_file.php?fileId=2679.
- Ashok, J.B., Pandav, R., Changyu, S., Dodge H.H., & Ganguli M. (2004). Predictors of nursing facility admission: A 12-year epidemiological study in the United States. *Journal of the American Geriatrics Society*, 52(3), 434-439. <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1532-5415.2004.52118.x?journalCode=jgs>.
- Beatty, P.W., Richaman, G.W., Tepper, S., and DeJong, G. (1998). Personal assistance for persons with physical disabilities: Consumer direction and satisfaction with services. *Archives of Physical and Medical Rehabilitation*, 79: 674-677.
- Benjamin, A.E., Matthias, R.E., and Franke, T.M. (1998). *Consumer-directed and agency models for providing supportive services at home*. Los Angeles: University of California, Los Angeles, School of Public Policy.
- Brown, J.S., & Appelbaum, R. (2007). *Evaluation of Ohio's assisted living Medicaid waiver program: Report on program costs*. Miami, OH: Scripps Gerontology Center, Miami University. Available at <http://www.scripps.muohio.edu/research/publications/documents/ReportonProgramCosts.pdf>.
- Burwell, B., Sredl, K., & Eiken, S. (2003). *Medicaid long-term care expenditures in FY 2002*. Cambridge, MA: Medstat.
- Burwell, B., Sredl, K., & Eiken, S. (2008). *Medicaid expenditures for long-term care in fiscal year 2007*. Cambridge, MA: Thomson Healthcare. Available at http://www.hcbs.org/moreInfo.php/nb/doc/2374/Medicaid_Long_Term_Care_Expenditures_FY_2007.

- Campbell, J.C., & Ikegami, N. (2000). Long-term care insurance comes to Japan. *Health Affairs*. 19(3), 26-39.
- Coronel, S. (2004). *Long-term care insurance in 2002*. Washington, DC: America's Health Insurance Plans. Available at http://www.ahipresearch.org/pdfs/18_LTC2002.pdf.
- Crowley, J. (2006). *Issue paper: Medicaid long-term services reforms in the Deficit Reduction Act*. Kaiser Commission on Medicaid and the Uninsured. Available at <http://www.kff.org/medicaid/upload/7486.pdf>.
- Cuellar, A.E., & Wiener, J.M. (2000). Can social insurance for long-term care work? The case of Germany. *Health Affairs*, 19(3), 8–25.
- Dale, S.B., & Brown, R.S. (2007). How does cash and counseling affect costs? *Health Services Research*. 42(1: Part II), 488-509.
- Disability Policy Collaboration. (2006). *The Deficit Reduction Act of 2005, P.L. 109-171*. Available at http://www.ucp.org/uploads/Deficit_Reduction_Act_of_2005_March_06.doc.
- Doty, P., Mahoney, K., & Simon-Rusinowitz, L. (2007). Designing the cash and counseling demonstration and evaluation. *Health Services Research*, 42(1 Part II), 378–396.
- Feder, J., Komisar, H.L., & Friedland, R.B. (2007). *Long-term care financing: Policy options for the future*. Washington, DC: Georgetown University. Available at <http://ltc.georgetown.edu/forum/ltcfinalpaper061107.pdf>.
- Foster, L., Brown, R., Phillips, B., Schore, J., and Carlson, B. (2003). Improving the quality of Medicaid personal assistance through consumer direction.” *Health Affairs Web Exclusive*. March 26, 2003. Available at: <http://content.healthaffairs.org/cgi/content/full/hlthaff.w3.162v1/DC1>.
- Fox-Grage, W., Coleman, B., & Milne, D. (2006). *Pulling together: Administrative and budget consolidations of state long-term care services*. Washington, DC: AARP. Available at http://assets.aarp.org/rgcenter/il/2006_05_state_ltc.pdf.
- Genworth Financial. (2008). *Genworth Financial 2008 cost of care survey: Home care providers, adult day health facilities, assisted living facilities, and nursing homes*. Richmond, VA: Genworth Financial. Available at http://www.genworth.com/content/genworth/www_genworth_com/web/us/en/products_we_offer/long_term_care_insurance/long_term_care_overview/what_is_the_cost_of_long_term_care.html.
- Grabowski, D.C. (2006). The cost-effectiveness of noninstitutional long-term care services: Review and synthesis of the most recent evidence. *Medical Care Research & Review*, 63(1), 3-28.
- Harrington, C., Carrillo, H., Wellin, V., Norwood, F., & Miller, N. (2001). Access of target groups to home and community based services. *Home Health and Community Services Quarterly*, 20(2), 61-80.
- Hawes, C., Rose M., and Phillips C.D. (1999). *A National study of assisted living for the frail elderly: Results of a national survey of facilities*. Washington, DC: U.S. Department of Health and Human Services. Available at: <http://aspe.hhs.gov/daltcp/reports/facres.htm>.
- Henry J. Kaiser Family Foundation. (2007). Update on the public's views of nursing homes and long-term care services. Washington, DC. Available at <http://www.kff.org/kaiserpolls/upload/7719.pdf>.
- Henry J. Kaiser Family Foundation. (2008). *Long-term care tax incentives offered by states, 2008*. Washington, DC. Available at <http://www.statehealthfacts.org/comparetable.jsp?ind=381&cat=7>.
- Ikegami, N., and Campbell, J.C. (2000). Long-term care insurance comes to Japan. *Health Affairs*, 19(3): 26-39. Available at:

<http://content.healthaffairs.org/cgi/reprint/19/3/26?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=japan&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>.

- Infield, D.L. (2005). *States' experiences implementing consumer-directed home and community services: Results of the 2004 survey of state administrators, opinion survey & telephone interviews*. Washington, DC: National Association of State Units on Aging.
- Johnson, R.W., Toomey, D., & Wiener, J.M. (2007). *Meeting the long-term care needs of the baby boomers: How changing families will affect paid helpers and institutions*. Washington, DC: The Urban Institute. Available at http://www.urban.org/UploadedPDF/311451_Meeting_Care.pdf.
- Johnson, R.W., & Wiener, J.M. (2006). *A profile of older Americans and their caregivers*. Washington, DC: The Urban Institute. Available at http://www.urban.org/UploadedPDF/311284_older_americans.pdf.
- Kane, R.A., Kane, R.L., Kitchener, M., Priester, M., & Harrington, C. (2006). *State long-term care systems: Organizing for rebalancing*. Minneapolis, MN: University of Minnesota. Available at http://www.hpm.umn.edu/lcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_2_State_Organizational_Structure_for_Rebalancing.pdf.
- Kane, R.A., Kane, R.L., Priester, R., & Homyak, P. (2008). *Research on state management practices for the rebalancing of state long-term care systems: Final report*. Minneapolis, MN: University of Minnesota. Available at http://www.hpm.umn.edu/lcresourcecenter/research/rebalancing/attachments/final_report.pdf.
- Kane, R., Priester, R., & Kane, R. (2007). *State long-term support systems to promote informed consumer decisions: Information provision, decision tools, and options counseling*. Minneapolis, MN: University of Minnesota. Available at http://www.hpm.umn.edu/lcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_4_State_Strategies_to_Promote_Consumer_Decisions.pdf.
- Kaye, H.S., LaPlante, M.P., & Harrington, C. (2009). Do noninstitutional long-term care services reduce Medicaid spending? *Health Affairs*, 28(1), 262-272.
- Kemper, P. (1988). The evaluation of the national long term care demonstration. Overview of the findings. *Health Services Research*, 23(1), 161-174.
- Kemper, P., Applebaum, R., & Harrigan, M. (1987). Community care demonstrations: What have we learned? *Health Care Financing Review*, 8(4), 87-100.
- Khatutsky, G., Anderson, W.L., & Wiener, J.M. (2006). Personal care satisfaction among aged and physically disabled Medicaid beneficiaries. *Health Care Financing Review*, 28(1), 69-86.
- Kitchener, M., Hernandez, M., Ng, T., & Harrington, C. (2006). Residential care provision in Medicaid home- and community-based waivers: A national study of program trends. *Gerontologist*, 46(2), 165-172.
- Kitchener, M., Ng, T., Carrillo, H., Miller, N., & Harrington, C. (2007a). Developing personal care programs: National trends and interstate variation, 1992-2002. *Inquiry*, 44, 69-87.
- Kitchener, M., Ng, T., & Harrington, C. (2007). State Medicaid home care policies: Inside the black box. *Home Health Care Services Quarterly*, 26(3), 23-38.
- Kitchener, M., Wong, A., Willmott, M., & Harrington, C. (2007b). *Home and community-based services: State-only funded programs*. UCSF National Center for Personal Assistance Services. Available at http://www.pascenter.org/state_funded/index.php.

- Komisar, H.L., Hunt-McCool, J., and Feder, J. (1997-98) Medicare spending for elderly beneficiaries who need long-term care," *Inquiry*, Winter: 302-310.
- LaPlante, M.P., Kang, T., Kaye, H.S., Harrington C. (2004). Unmet need for personal assistance services: estimating the shortfall in hours of help and adverse consequences. *Journal of Gerontology B Psychological Sciences Social Sciences*, 59(2): S98-S108.
- LeBlanc, A.J., Tonner, M., & Harrington, C. (2001). State Medicaid programs offering personal care services. *Health Care Financing Review*, 22(4), 155–173.
- Leutz, W.N., & Capitman, J. (2005). Met needs, unmet needs, and satisfaction among social HMO members. *Journal of Aging and Social Policy*, 19(1), 1–19.
- Lewin Group. (2006). *The Aging and Disability Resource Center (ADRC) demonstration grant initiative*. Fairfax, VA: Available at <http://www.adrc-tae.org/documents/InterimReport.doc>.
- Long-Term Care Community Coalition. (2005). *Single point of entry for long-term care and Olmstead: An introduction and national perspective for policy makers, consumers and advocacy organizations*. New York. Available at <http://www.ltccc.org/news/documents/POEOlmsteadReportFINAL.doc>.
- Long-Term Care Partnership Program. (2009). *Long-term care state partnership tracking map*. Available at <http://www.dehpg.net/LTCPPartnership/map.aspx>.
- 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 health and function in the U.S. elderly population. *Proceedings of the National Academy of Sciences, U.S.A.*, 103(48), 18374-18379.
- Mattimore TJ, et al. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatrics Society*, 45: 818-824.
- McCall, N. (1996). *The Arizona health care cost containment system: Thirteen years of managed care in Medicaid*. Menlo Park, CA: Henry J. Kaiser Family Foundation.
- Miller, E., & Weissert, W. (2000). Predicting elderly people's risk of nursing home placement, hospitalization, functional impairment and mortality: a comprehensive review and analysis. *Medical Care Research and Review*, 57(3), 259-297.
- Mollica, R., Sims-Kastelein, K., & O'Keeffe, J. (2007). *Residential care and assisted living compendium: 2007*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <http://aspe.hhs.gov/daltcp/reports/2007/07alcom.htm>.
- Morris, M. (2007). *Reducing nursing home utilization and expenditures and expanding community-based options*. New Brunswick, NJ: Community Living Exchange of Rutgers Center for State Health Policy and the National Academy for State Health Policy.
- Muramatsu, N., Yin, H., Campbell, R.T., Hoyem, R.L., Jacob, M.A., & Ross, C.O. (2007). Risk of nursing home admission among older Americans: Does states' spending on home- and community-based services matter? *Journal of Gerontology: Social Sciences*, 62B(3), S169–S178.
- National PACE Association. (2008). *What is PACE?* Alexandria, VA: National PACE Association. Available at <http://www.npaonline.org/website/article.asp?id=63>.
- O'Keeffe, J., O'Keeffe, C., Wiener, J.M., & Siebenaler, K. (2007). *Increasing options for self-directed services initiatives of the 2003 Independence Plus Grantees*. Research Triangle Park, NC: RTI International. Available at <http://www.hcbs.org/files/130/6482/IPpaper.pdf>.

- O’Keeffe, J., & Wiener, J. (2004). Public funding for long-term care services for older people in residential care settings. *Journal of Housing for the Elderly*, 18(3)/4, 51–80.
- O’Keeffe, J., Wiener, J.M., & Greene, A.M. (2005). *Consumer direction initiatives of the FY 2001 and 2002 grantees: Progress and challenges*. Research Triangle Park, NC: RTI International. Available at http://www.hcbs.org/moreInfo.php/source/151/doc/1601/Consumer_Direction_Initiatives_of_the_FY_2001_and.
- Organisation for Economic Co-Operation and Development. (2005). *Long-term care for older people*. Paris: OECD.
- Rogers, S., & Komisar, H. (2003). *Who needs long-term care?* Washington, DC: Georgetown University Long-Term Care Financing Project. Available at <http://ltc.georgetown.edu/pdfs/whois.pdf>.
- Rosenbaum, S. and Teitelbaum, J. (2004). *Olmstead at Five: Assessing the Impact*. Washington, DC: Henry J. Kaiser Family Foundation. Available at: <http://www.kff.org/medicaid/upload/Olmstead-at-Five-Assessing-the-Impact.pdf>.
- Schore, J., Foster, L., and Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research*, 42(pt.2): 446-466.
- Shostak, D.I., & London, P.A. (2008). State Medicaid expenditures for long-term care: 2008-2027. Strategic Affairs Forecasting. Available at <http://www.ahip.org/content/default.aspx?docid=24597>.
- Steinmetz E. 2006. Americans with disabilities: 2002. *Current Population Reports*, U.S. Census Bureau. [Online]. Available: <http://www.sipp.census.gov/sipp/p70s/p70-107.pdf>.
- Summer, L., & Ihara, E. (2004). *State-funded home and community-based service programs for older people*. AARP Public Policy Institute. Available at http://www.aarp.org/research/housing-mobility/homecare/statefunded_home_and_communitybased_service_progra.html.
- Taylor H., Leitman, R., and Barnett, S. (1991). The importance of choice in Medicaid home care programs: Maryland, Michigan and Texas.” Survey conducted for the Commonwealth Fund, New York: Louis Harris and Associates.
- Tumlinson, A, Aguiar, C., & Watts, M.O’M. (2009). *Closing the long-term care funding gap: The challenge of long-term care insurance*. Washington, DC: Kaiser Family Foundation. Available at <http://www.kff.org/insurance/upload/Closing-the-Long-Term-Care-Funding-Gap-The-Challenge-of-Private-Long-Term-Care-Insurance-Report.pdf>.
- U.S. Census Bureau. (1995). Resident population of states (by 5-year age groups and Sex): 1980-1990. Release Date: August. Available at <http://www.census.gov/popest/archives/1980s/s5yr8090.txt>.
- U.S. Census Bureau. (2006). *Age of householder—households, by total money income in 2004, type of household and Hispanic origin of householder*. Available at http://pubdb3.census.gov/macro/032005/hhinc/new02_001.htm.
- U.S. Census Bureau. (2008). Table 1. Annual estimates of the population by sex and five-year age groups for the United States: April 1, 2000 to July 1, 2007 (NC-EST2007-01). Release Date: May 1, 2008. Available at <http://www.census.gov/popest/national/asrh/NC-EST2007/NC-EST2007-01.xls>.
- U.S. Centers for Medicare & Medicaid Services (CMS). (2008). Table 13.15. Medicaid payments per person served (beneficiary), aged by type of service: Fiscal years 1975–2005. *Medicare and Medicaid Data Compendium*. Baltimore, MD. Available at <http://www.cms.hhs.gov/MedicareMedicaidStatSupp/downloads/2008Table13.15.pdf>.

- U.S. Congressional Budget Office. (2004). *Financing long-term care for the elderly*. Washington, DC: U.S. Congressional Budget Office. Available at <http://www.cbo.gov/ftpdocs/54xx/doc5400/04-26-LongTermCare.pdf>.
- U.S. Congressional Research Service. (2006). *Side-by-side comparison of Medicare, Medicaid, and SCHIP provisions in the Deficit Reduction Act of 2005*. Congressional Research Service, Library of Congress. Available at <http://digital.library.unt.edu/govdocs/crs/permalink/meta-crs-9230:1>.
- U.S. Government Accountability Office (2005). *Long-term care partnership program*. GAO-05-2021R. Washington, DC: Author. Available at <http://www.gao.gov/new.items/d051021r.pdf>.
- Weissert, W., Lesnick, T., Musliner, M., et al. (1997). Cost savings from home and community-based services: Arizona's capitated Medicaid long-term care program. *Journal of Health Politics, Policy and Law*, 22(6), 1329–1357.
- Wiener, J. M., Anderson, W. L., & Khatutsky, G. (2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontologist*, 47(6), 763–774.
- Wiener, J. M., Brown, D., Gage, B., et al. (2004). *Home and community-based services: A synthesis of the literature*. Report to the Administration on Aging. Washington, DC: RTI International.
- Wiener, J.M., & Cuellar, A.E. (1999). Public and private responsibilities: Home and community-based services in the United Kingdom and Germany. *Journal of Aging and Health*, 11(3), 417–444.
- Wiener, J.M., Illston, L.H., & Hanley, R.J. (1994). *Sharing the burden: Strategies for public and private long-term care insurance*. Washington, DC: The Brookings Institution.
- Wiener, J.M., Stevenson, D.G., and Goldenson, S.M. (1999). Controlling the supply of long-term care providers at the state level. *Journal of Aging and Social Policy*, 10(4), 51–72.
- Wiener, J. M., Stevenson, D. G., and Kasten, J. (2000). *State Cost Containment Initiatives for Long-Term Care for Older People*. Washington, DC: U.S. Congressional Research Service.
- Wiener, J.M., Tilly, J., & Alecxih, L.M.B. (2002). Home and community-based services for older persons and younger adults with disabilities in seven states. *Health Care Financing Review*, 23(3), 89–114.
- Wiener, J.M., Tilly, J., and Cuellar, A.E. (2003). *Consumer-directed home care in the Netherlands, Germany and England*. Washington, DC: AARP. Available at <http://www.aarp.org/research/>.
- Yael, H., and Cooper, J.K. (2006). Depressive symptoms in older people predict nursing home admission. *Journal of the American Geriatrics Society* 54(4), 593–597.

pmpc
Pennsylvania
Medicaid
Policy Center

University of Pittsburgh
A616 Crabtree Hall
130 DeSoto Street
Pittsburgh, Pennsylvania 15261

phone (412) 624-3104
fax (412) 624-3146
www.PAMedicaid.pitt.edu