Expanding Home and Community-Based Services for the Elderly

ISSUE BRIEF No. 3

Nothing written here is to be construed as necessarily reflecting the views of The Century Foundation or as an attempt to aid or hinder the passage of any bill before Congress.

THE IDEA

With the need for long-term care expected to grow sharply in the near future, studies show that the majority of seniors who will require such care prefer to receive it in their home or community if possible. States should address these needs and preferences by developing and expanding home and community-based services as an alternative to nursing homes.

THE PROBLEM

Manuel Cortez, a 220-pound retired shipfitter and widower who lived in Auburn, always had a smile on his face and a penchant for exploring. “He’d go off for five hours to see a mountain,” said Diane Cevolani, his daughter. “I always thought Dad might die on the road.” Instead, he spent his last months dying of lung cancer, at age 72. His slow death took him from middle-class status to welfare applicant. “You had to fill out this form that states this person is indigent,” said Cevolani of San Rafael, whose father died Dec. 4, the day after she applied for Medi-Cal, California’s Medicaid program, to pay for his care. “It gave me a knot in my stomach.”

When Cortez became ill, Cevolani’s sister and brother-in-law began caring for him in their Auburn home. Cevolani went up on weekends. They hired nurses’ aides to take up the slack. “We went through $12,000 in the blink of an eye,” Cevolani said. With costs and stress escalating, the family put him in an Auburn nursing home. It was hard. “My father had his full faculties,” Cevolani said. “He was not happy about going to a home. He’d start crying. All he worried about was the money. He’d say, ‘Diane, give me my checkbook. I want to get out of here.’

~ Adapted from The San Francisco Examiner, April 4, 1995

Two decades ago, people in need of long-term care – those who are the least able to care for themselves because of disabilities or impairments resulting from a chronic illness, mental disability, or physical disability – were dependent on services that were primarily medical in nature and provided largely in nursing homes. Since then, there has been an expansion of less restrictive alternatives to nursing homes and a substantial increase in the number of medical and social support services from which the elderly can choose. There were two reasons for this trend toward expanding home and community-based services. (See box for a definition and description of these services.) First, states wanted to move away from expensive nursing homes and help control their rapidly increasing health care costs. Second, this expansion coincided with the preference many people with chronic conditions and disabilities expressed for remaining in a home-like environment.
Despite this trend, however, elderly Americans in need of intensive long-term care are still mostly dependent on nursing homes. This persistent institutional bias is reflected in the following observations:

- The majority of long-term care spending is still directed to nursing homes;
- Most Medicaid expenditures for home and community-based alternatives are not aimed at the elderly;
- Efforts to move towards a more balanced long-term care system are confined to a limited number of states.

These conditions continue to undermine the aim of building a long-term care system that achieves a higher level of consumer satisfaction and cost-effectiveness. In order to create a long-term care system for the elderly that will help satisfy the needs of the future, states need to move toward a more “balanced” system, building on the examples of states like Oregon and Washington.²

The need for long-term care will grow:

The population that needs long-term care services is very diverse in terms of age and scope and degree of disabling condition.³ This paper focuses on the elderly, since the growth in this population is expected to have an enormous impact on the long-term care system.

An estimated 60 percent of all people who require long-term care are elderly.⁴ People aged 65 and over currently constitute 12.7 percent of the total population, but this number will grow to 20 percent in 2030. By then people aged 85 and over, the group that is most likely to require long-term care, are estimated to count 8.9 million, twice the current number. By 2040 this population will have more than tripled (See Figure 1).⁵

Figure 1: Population Projections For Age Groups 65+ and 85+

![Population Projections For Age Groups 65+ and 85+](chart)

This aging of the baby boom generation, 76 million people born between 1946 and 1964, combined with increased longevity, will lead to an increase in the number and proportion of elderly people in the society, putting great pressure on the long-term care system. Even if disability rates continue to decline, as they have done in recent years, the total number of elderly people requiring long-term care is expected to grow rapidly. The General Accounting Office estimates that the “number of disabled elderly who will need care ranges between 2 and 4 times the current number.”

In 1994, 57 percent of the 3.9 million elderly with long-term care needs who were living in the community depended exclusively on unpaid support, often provided by their spouse, family, or friends. This pool of informal caregivers is expected to shrink in the years to come. Families will become smaller and geographically more widespread. Women, traditionally the designated informal caregivers, are entering the work force in increasing numbers. Although seniors will be better off financially than before, their long-term care expenses are also likely to be higher. Expenditures for long-term care for the elderly are expected to grow by 2.6 percent annually, adjusted for inflation, between 2000 and 2040.

These demographic and economic changes, combined with the preference for less restrictive care, call for a revamping of the current long-term care system.

### What are Home and Community-based Services?

Home and community-based services are an array of services provided outside of nursing homes that help people who need assistance with their daily functioning. These range from personal care services that assist people with bathing or dressing to large-scale residential long-term care options such as assisted living. These settings and services are licensed under widely different names from state to state but are all considered home and community-based services.

<table>
<thead>
<tr>
<th>Name of Service</th>
<th>Type of Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-home care:</td>
<td>Assistance with housekeeping chores, such as cleaning, grocery shopping, and cooking</td>
</tr>
<tr>
<td>Personal care support:</td>
<td>Assistance with tasks such as bathing, toileting, feeding, and dressing.</td>
</tr>
<tr>
<td>Respite care:</td>
<td>Short-term supervision, meant to provide relief for informal caregivers.</td>
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<tr>
<td>Adult day care programs:</td>
<td>Daytime care aimed at providing relief for informal caregivers.</td>
</tr>
<tr>
<td>Adult foster homes:</td>
<td>Small number of people living together who receive routine care and personal services tailored to individual need.</td>
</tr>
<tr>
<td>Adaptive equipment:</td>
<td>Modifications to a home or vehicle, for example.</td>
</tr>
<tr>
<td>Assisted living facilities:</td>
<td>Residential units meeting specific structural requirements (such as a private kitchen and bathroom), where housekeeping and personal care may be included in the contract.</td>
</tr>
</tbody>
</table>
The majority of long-term care spending is still directed to nursing homes:

Approximately 72 percent of the $98 billion spent in 2000 on long-term care for the elderly was directed towards institutional care, a slight increase over the 71 percent in 1995. Most of this comes from Medicaid (44 percent) and out-of-pocket payments (40 percent) (See Figure 2).10

Medicaid contains multiple features that encourage the institutionalization of long-term care users. For example, anyone eligible for nursing home placement under Medicaid must be placed if a bed is available. The provision for home and community services does not enjoy the same entitlement status; it is subject to the budget constraints of individual states. States, in fact, must maintain a statewide nursing home network that meets certain standards simply to qualify for federal Medicaid funds. In a number of states it is easier to be admitted to nursing homes than to qualify for home and community-based services, largely through rules about assisting the "medically needy" and the treatment of spousal income that apply in the former case but not in the latter.11

What is Medicaid?

Medicaid, a jointly funded federal-state health financing program for low-income Americans who also meet other conditions of eligibility, is the largest public payer for long-term care and is expected to remain the principal sponsor in the years to come.12 It was enacted in 1965 at the same time as Medicare, the federal program for older and disabled Americans. In order to meet Medicaid’s eligibility criteria, which permit a very low level of income and assets, many people have to “spend down” their resources. This impoverishment occurs at an increased speed once people move to a nursing home – on average, nursing home care currently costs $55,000 annually.13

Most Medicaid expenditures for home and community-based alternatives are not directed to the elderly:

States have tried to diminish this institutional bias through provisions of Medicaid law. There has been a steady increase in states’ use of options for obtaining federal Medicaid dollars to pay for long-term care services in home and community-based settings. This has led to new programs such as home health services, personal care state plans, and home and community-based waiver services.14

Since Congress authorized the Medicaid waiver program in 1981, states have been able to ask the Health Care Financing Administration to permit them to offer services not normally covered by Medicaid.15 Designed as an experimental project, this waiver program has a dual character. On the one hand, it allows states to better address the needs of long-term care users by expanding the array of services. On the other, because states are authorized to target their support to a specific subpopulation or to a limited area in the state, waivers may be used to control access to these new services. Since these features allow states to more accurately predict spending, they have increasingly chosen the waiver program to expand their long-term care systems.16
While the three programs together account for the vast majority of Medicaid spending on home and community-based services, waivers have shown a much higher average annual growth rate than the other two programs. In 2000, they accounted for two-thirds of Medicaid spending on home and community-based services – up from almost one-third a decade ago.

Between 1990 and 2000, the average annual growth of Medicaid expenditures on waivers exceeded 25 percent. However, only 19 percent of the $9 billion spent on Medicaid waivers in 1998 went to those programs aimed at providing support for the elderly. The largest part went to younger people, especially those with mental retardation or developmental disabilities, who received 76 percent of total spending. This latter group more than doubled its average number of recipients between 1992 and 1997. Over that same period, the average number of recipients per 100 individuals ages 85 and over grew at a much slower rate – from 6.6 to 9.8. Moreover, a recent survey conducted in all 50 states concluded that “the financial eligibility criteria many states impose on their waiver program [for the elderly] contribute to a continuing institutional bias in the program.”

**Figure 2: Long-Term Care Expenditures for the Elderly by Source of Payment**

<table>
<thead>
<tr>
<th>Source of Payment</th>
<th>Medicaid</th>
<th>Medicare</th>
<th>Out-of-Pocket</th>
<th>Other Public Payers</th>
<th>Private Insurance</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>in Billions of Dollars</strong></td>
<td>$4.9</td>
<td>$11.2</td>
<td>$28.2</td>
<td>$2.8</td>
<td>$70.7</td>
<td>$27.3</td>
</tr>
</tbody>
</table>

**Note:** Other public payers are three federal programs: the Social Services Block Grant, the Older Americans Act, and the Supplemental Security Income (SSI) program. These programs pay for less than $1 million for institutional care (data omitted in chart). Long-term care private insurance pays $0.3 million for institutional care and $0.2 million for home and community-based care.

Efforts to move towards a more balanced long-term care system are confined to a limited number of states:

States have tremendous flexibility in how they arrange their long-term care services. As a result, there are dramatic differences in expenditures between them. Total annual Medicaid long-term care spending per capita in 2000 ranged from $680.03 in New York to $73.02 in Nevada.\(^{22}\) Nationally, 27 percent of all Medicaid long-term care spending is directed towards home and community-based services.\(^{23}\) However, more than half of the national growth in Medicaid’s home and community-based expenditures from 1999 to 2000 occurred in nine states.\(^ {24}\) Further indication of the variation across states is the broad range of expenditures per recipient in 1997 on waivers aimed at the elderly, which was from $1,153 to $14,287.\(^ {25}\)

Not only do states vary in their commitment to long-term care in general, and home and community-based services in particular, but they also differ in the expected demand for long-term care. States that have been investing limited amounts in their long-term care system are the ones that are most likely to see the greatest increase in demand due to the aging of their population.\(^ {26}\)

**SOURCE OF THE PLAN**

Oregon and Washington are positive examples whose initiatives other states should emulate:

Oregon and Washington are examples of states that have made a relatively successful effort to expand their Medicaid home and community-based care programs to better serve residents with long-term care needs. Oregon and Washington spend 62 and 45 percent respectively of their long-term care Medicaid budgets per capita on home and community-based care programs, compared to the national average of 29 percent.\(^ {27}\)

Both states have used Medicaid waivers to expand their services and have controlled costs by limiting the number and use of nursing home beds.\(^ {28}\) Oregon and Washington both use programs that actively seek to relocate nursing home residents back to their homes.\(^ {29}\) Oregon has the lowest nursing home occupancy in the country and, in 1998, had a bed growth rate of –1.96 licensed beds per 1000 population aged 65 and over, compared to the national average of –0.12.\(^ {30}\) Between 1993 and 2000, Washington reduced its number of Medicaid nursing home residents from 17,448 to 13,789, despite an increase in the number of elderly in the state.\(^ {31}\)

More than three-quarters of Oregon’s Medicaid recipients receive care in home and community-based settings. The state offers a range of long-term care services: these include in-home care with a client-employed provider, adult foster care, relative adult foster care (i.e., care in which a relative who provides care is paid for the service), and assisted living. Besides a person’s own home and a nursing home, seniors can choose from a number of residential care facilities. In 1998, Oregon had more than twice the number of residential care facility beds per 1000 population age 65 and over than the national average.\(^ {32}\) In Oregon, a case manager establishes a person’s care plan with help from that individual and their family members and subsequently monitors the care that person receives, even when they receive it in their own residence.\(^ {33}\)

In Washington, almost twice as many people receive home and community-based services as receive Medicaid-funded nursing home care.\(^ {34}\) Services include – but are not limited to – assistance with personal care and household tasks in the home, adult day care, adult family
homes, and assisted living. Case management is also a critical component of the service system in Washington. Case managers assist with the Medicaid applications if necessary and also assess a person’s needs from which they develop a plan of care. Their tasks include monitoring a person’s care, but if people remain in their own residence, the responsibility is transferred to a local agency.

Another important feature of these programs is full integration of all long-term care services for the elderly under one state agency. These are the Senior and Disabled Services Division (SDSD) in Oregon and the Aging and Adult Services Administration (AASA) in Washington. These agencies are responsible for financing, regulation, quality assurance, and policy. At the local level Area Agencies of Aging (AAAs) in cooperation with SDSD and AASA provide a single point of entry for the elderly who seek government-sponsored care for the multifaceted long-term care system. These single-points of entry are designed for the elderly to obtain the specific services that they need because the caseworker can authorize services from different programs. That seniors are able to go to one agency for all their long-term care needs has made the long-term care system far less confusing for them than it is in most other states.

HOW THE PLAN WOULD WORK

Key elements:

A number of key elements have been essential to the transformation of the long-term care systems in Oregon and Washington. To be sure, conditions unique to each state have contributed to their success, such as the political climate, state budgets, and demographics. However, states will need to emulate three critical features of Oregon and Washington’s experience in order to expand successfully their provision of long-term care services:

- Dedication by the state to developing home and community-based care;
- Mobilization of elderly in advocacy groups;
- Coordination of organizational structures of long-term care.

State’s dedication:

The first key element is for the state’s policymakers to be committed to the development of less restrictive long-term care. An indication of a state’s commitment to home and community-based services can be inferred from the proportion of total Medicaid long-term care spending per capita that is directed towards home and community-based programs (home health services, personal care state plans, and waiver services) (See Figure 3). In 2000, twenty-seven states were below the national average of 29 percent, and fourteen states spent less than 20 percent of their long-term care expenditures on these programs.35

A 1995 study by the University of Minnesota calculated states’ commitment to home and community-based services for the elderly by comparing overall home and community-based expenditures with those aimed specifically at the elderly. Twenty-four states scored low to very low, fifteen states scored average, and twelve states were labeled as having a high to very high commitment to providing less restrictive care.36 This indicates that most states have been lagging in their efforts to provide less restrictive care.
Figure 3: Nursing Home and Home and Community-Based Care Expenditures Per Capita as Percentage of Total Medicaid Long-Term Care Expenditures in 2000

Note: Arizona, which is unique in having a fully capitated managed long-term care system, is not included.

Source: Calculated from HCFA-64 Reports compiled by the Medstat Group. Total home and community-based care (personal care, home health, and HCBS waivers) and nursing home care (nursing home services) as percentage of total Medicaid long-term care expenditures per capita, FY 2000.

Oregon and Washington both have shown a strong commitment to long-term care policies that promote independence and development of an array of home and community-based services for the elderly. Oregon, for example, describes nursing homes as placement of the last resort for the elderly and states “quality of life is related to participation in the community.” Washington, likewise, aims at the goal of “help[ing seniors] maintain … privacy, dignity, independence, and freedom of choice.” This commitment by state officials is critical in overcoming barriers such as a lack of funding, the power of the nursing home lobby, and uncertainty about whether expanding services will contain costs.

In 1999, the Supreme Court decision in Olmstead v. L.C., 119 S.Ct. 2176 ruled that individuals with disabilities should live in the most integrated setting appropriate to their needs. HCFA, in a letter to state Medicaid directors, encouraged states to develop and implement “comprehensive, effectively working plans” that would ensure compliance with that ruling. HCFA also pointed out that programs should not be limited only to individuals with mental disabilities. Responding to a question by a state Medicaid director, HCFA clarified that the intended recipients included the elderly.

A study that analyzed the Olmstead decision and its implications for long-term care for the elderly observed that HCFA’s position leaves states with considerable latitude in how they
choose to respond to this ruling. However, this study expects that states will use Medicaid to develop home and community-based care for the elderly as a way to comply with the Olmstead decision. Its authors state that “[the] Olmstead [decision] gives both the federal government and consumers the power to more closely examine state efforts to develop community services for persons with disabilities for whom an institutional placement would be inappropriate.”

The active engagement of state officials – either voluntarily or in response to civic or judicial pressure – is essential to overcoming the barriers that currently thwart the transformation of state long-term care systems. Their support of legislation and solicitation of federal support will help create an environment in which the movement towards a more balanced system can take place.

Advocacy groups:

Second, the political mobilization of the elderly can promote the effort to transform the long-term care system, acting as a counterbalance to the well-organized and politically effective nursing home industry. In Oregon and Washington, lobbying by senior advocacy groups has had a strong influence on the long-term care policies that were adopted. Extensive lobbying by seniors in Oregon in the early 1980s resulted in the consolidation of funding for long-term care services and the creation of a new state agency responsible for medical assistance for seniors – initially called the Oregon Senior Services Division, which later became the Senior and Disabled Services Division.

Many people support the development of a less restrictive long-term care system and may be willing to mobilize. When people were asked about their preferences should they need long-term care for more than a year, 64 percent preferred to receive care in their own home, 15 percent wanted to move into housing with supportive services (such as assisted living), and only 3 percent wanted to move to a nursing home (See Figure 4). The older the group, the stronger the preference to remain in their current residence for as long as possible – 83 percent of the people ages fifty-five to sixty-four, 92 percent of the people ages sixty-five to seventy-four, and 95 percent of the people ages seventy-five and over. Mobilizing these seniors by promoting formation or expansion of consumer advocacy groups will make a contribution towards shaping the services that are provided.

Advocacy groups for seniors such as the AARP should cooperate with other groups that have similar interests – such as advocates for persons with Alzheimer’s disease and advocates for younger people with disabilities. Instead of competing for funding or services, different advocacy groups should acknowledge their shared interests.

Coordination of organizational structures:

The third key element to success is coordinating the organizational structures of long-term care. The current long-term care landscape is fragmented on many levels. Funding sources, providers, functional and financial eligibility criteria, services provided, care settings, accountability, and administration differ across and within states.

Fragmented funding, and especially Medicaid’s part in it – which offers states considerable freedom in how they direct federal dollars – dictates the way long-term care is organized and delivered. In the absence of a national long-term care program, states have been building on existing structures – using any feasible program at hand as a source of funding. However, having multiple departments at the state and local level that share responsibility has complicated the coordination of services and programs.
Since it is unlikely that a new national long-term care program will be created in the near future, each state should centralize and establish greater uniformity in its long-term care system. Better coordination will lead to increased efficiency in the funding and delivery of services. It will enable state and local administrators to concentrate on their specific tasks, while communication between these two levels will be easier because officials will deal with a single agency in common. Better coordination will also mean a more transparent long-term care system for seniors and their families. Finding the care that they need in the setting that they prefer will be much easier.

One example of positive change in this direction can be found in New Jersey. As a consequence of complaints by seniors and their family members about New Jersey’s senior services system being too fragmented, confusing, and frustrating, the NJ EASE (New Jersey Easy Access, Single Entry) was formed. Begun in 1996 and expected to be implemented statewide by the end of 2001, this initiative establishes a clearly defined entry point through which services such as information, referral, care planning and care management for long-term care options can be assessed – thereby improving access to services and promoting informed personal choice.

**Figure 4: People's Preference for Care Setting in the Event of Serious Illness**

![Pie chart showing preferences](chart.png)

**Note:** People were asked to choose their preferences for care settings among these options in the event they became seriously ill and needed substantial assistance for a year or longer. This study included a national cross-section of 1,490 adults, with an additional oversample of persons with a chronic illness and adults who provide informal caregiving services, for a total of 663 chronically ill and 320 caregivers (N=1,663).

**Source:** Survey of the general public, adults with chronic conditions and caregivers; *Chronic Illness and Caregiving*, conducted for the Robert Wood Johnson Foundation/John Hopkins University Partnership for solutions, conducted by Harris Interactive Inc., March 17, 2000 through November 22, 2000.
Would Adopting Home and Community Services Lower Long-Term Care Costs?

Uncertainty about future spending holds back many states from implementing new long-term care initiatives or from relaxing the limits placed on existing programs. Managers of Medicaid and other state-based health programs worry that expanding home and community-based services will lead to an overall increase in health care costs. Many people who have disabilities and might qualify for nursing home care do not seek formal long-term care services because they strongly prefer to remain in their homes. States are apprehensive that such new applicants for long-term care services will “come out of the woodwork” if a broader spectrum of services that better match their preferences is offered. Should utilization of home and community services increase, it might more than offset any savings associated with a decrease in nursing home use.

Oregon and Washington have been credited with controlling costs while expanding their home and community-based services. As one knowledgeable observer recently testified to the Senate Finance Committee, “States like Oregon and Washington have demonstrated that [residential alternatives to nursing facilities] can improve quality of life, while controlling costs.” Would their experience hold for other states? There is no definitive answer. Studies that investigated the cost effectiveness in Oregon and Washington concluded that providing home and community-based services helped contain long-term care costs by providing an alternative to nursing homes (e.g., substitution of nursing home care for home and community-based services and putting restrictions on these new services).

However, these studies are regarded suggestive rather than conclusive – partly due to the assumptions that were made and the difficulty of measuring cost effectiveness. The fragmentation of the long-term care system makes it very hard to establish if policy decisions truly result either in cost containment or in cost shifting between different programs.

THE COST

It would be advisable to increase federal sources of financing in order to allow states to expand and diversify their long-term care services while maintaining their fiscal health – especially for those states with limited budgets. The aim would be to create a long-term care infrastructure in advance of the baby boom’s retirement. Our proposal would spend $10 billion annually over a five-year period, drawing upon federal general revenues.

Since Medicaid is the major sponsor of long-term care, and especially considering the important role its waiver programs play in expanding home and community-based services, state budgets are a determining factor in enabling the transformation towards less restrictive care. As the General Accounting Office points out, “States generally must maintain balanced budgets without deficits, and their revenues often decline in periods of low or negative economic growth.” The combination of projected increases in Medicaid expenditures and a decline in revenues for many states could very well result in a decrease in state expenditures on long-term care.
Part of this additional federal funding should be directed towards states that already have made substantial efforts to expand their home and community-based options but have had to limit the scope of their programs due to the uncertainty of steady sources of financing. Additional funding would minimize the need for restrictive program features such as targeting a subpopulation and offering only specific services. It would further allow for new programs to be developed and tested over longer periods of time.

The largest share of this additional federal funding should be directed towards states that have, or are expected to have, a high long-term care demand but have been lagging in their efforts to balance their long-term care system. As Robert Kane and colleagues note:

“Generally, the higher the demand on state-supported long-term care services, the harder it is to change the long-term care system. This is especially true if that change entails adding home and community-based services. […] The investment in home and community-based services is much more likely to happen in states where the demand for state-supported services is low or very low.”

They further point out that states with the highest demand for state-supported long-term care services had almost all below-average per-capita tax revenues, which in turn is highly correlated with the amount spent on home and community-based services. Additional federal funding could entice states that have had serious worries concerning cost containment to take action and concurrently would serve as an encouragement for states that have the will to transform their long-term care system but do not have the means to do so. As a report released by the federal Department of Health and Human Services in 2001 states: “Alabama state officials would like to expand home and community-based services, but they are very constrained in their ability to do so by the lack of state funding.”

States should keep in mind that there are other considerations beside the issue of cost. As shown, seniors prefer to receive care in the least restrictive setting and expect that remaining in the community will result in their having a better quality of life. Nursing homes are likely to be most suitable and cost-effective for patients who need high levels of care. Home and community-based services, which may be purchased in smaller “increments” than a nursing home bed, are likely to better suited for those who need less extensive and more intermittent care. In sum, providing seniors with a choice of settings and services improves their well-being while raising the value of states’ spending on long-term care.

Written by Eelco Slagter, Leif Wellington Haase, and Andrea Magyera, researchers at The Century Foundation.

All of the Issue Briefs in this series, along with a catalog of The Century Foundation’s publications are available at [http://www.tcf.org](http://www.tcf.org). For more information please contact Tina Doody at 212-452-7750 or doody@tcf.org.
Notes

3 Stone, R., “Long-Term Care: Coming of Age in the Twenty-First Century,” _Life in an Older America_ 1999.
4 Spector, W.D., Fleishman, J.A., Pezzin, L.E., and Spillman, B.C., _The Characteristics of Long-Term Care Users_, Prepared for the Committee on Improving Quality in Long-Term Care, Institute for Medicine, 1998. Estimates are based on the National Health Interview Survey (NHIS) Disability Supplement, 1994 (for community residents) and the 1996 Medical Expenditure Panel Survey (for nursing home residents). Estimates of the number of persons who need assistance as a result of impairment vary depending upon the number and types of limitations and other factors used for measurement.
9 Congressional Budget Office, _CBO Memorandum: Projections of Expenditures for Long-Term Care Services for the Elderly_, March 1999.
11 Kane, R.A., op. cit., pp.77-80.
13 General Accounting Office, _Baby Boom Generation Increases Challenge of Financing Needed Services_, p1, Statement of William J. Scanlon, Director, Health Care Issues, March 2001. Eligibility for nursing home placement may be determined by an estimate that a person will exhaust his or her resources in the near future.
14 The waivers were authorized under Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981 (PL 97-35). The waivers were called 1915 (c) waivers, named after the section of the Social Security Act that authorized them. Besides the most widely used 1915 (c) waiver there are other waiver programs. For example, Arizona uses exclusively 1115 (c) waivers. Since the mid 1970s, states have had the option to offer personal care services under the Medicaid state plan (mainly used in New York, California, Arkansas, and Texas). Since 1970, home health services have been mandatory for persons entitled to nursing facility care.
15 Services can include those viewed as not strictly medical, and more liberal financial eligibility criteria can be used than in regular Medicaid program requirements. Services are restricted to people who meet the state’s nursing home level-of-care criteria; they may be targeted at a specific group of people and they do not have to be provided statewide. The budget neutrality test and the cost effectiveness test are two ways to predict the costs of new home and community-based waiver programs. Budget neutrality involves comparing the total long-term care costs with and without home and community-based services, while a program is labeled cost effective if spending per beneficiary for home and community-based services does not exceed per beneficiary spending on nursing home care. Acknowledging that budget neutrality is extremely difficult to achieve, the federal law requires a state that its waiver program is only cost effective. Despite this explicit federal requirement, states’ long-term care proposals are infused with concerns for both cost effectiveness and budget neutrality.
19 HCFA-64 Report, FY 2000, compiled by the Medstat Group.
21 Kassner, E., and Shirey, L., Medicaid Financial Eligibility for Older People: State Variations in Access To Home and Community-Based Waiver and Nursing Home Services, April 2000.
22 HCFA-64 Report, FY 2000, compiled by the Medstat Group. The range excludes Arizona, which is unique in having a capitated long-term care system.
23 Calculated from HCFA-64 Reports compiled by the Medstat Group. Total home and community-based care (personal care, home health, and HCBS waivers) as percentage of total Medicaid long-term care expenditures per capita, FY 2000.
24 Calculated from HCFA-64 Reports, FY1999 and FY2000. Available at http://www.hcfa.gov/medicaid/m64.htm.
26 Merlis, M., Financing Long-Term Care in the Twenty-First Century: The Public and Private Roles, Institute for Health Policy Solutions, September 1999.
27 Calculated from HCFA-64 Reports compiled by the Medstat Group. Total state home and community-based care (personal care, home health, and HCBS waivers) per capita as percentage of state Medicaid long-term care expenditures per capita, FY 2000. The range excludes Arizona, which is unique in having a capitated long-term care system.
35 Calculated from HCFA-64 Reports compiled by the Medstat Group. Total state home and community-based care (personal care, home health, and HCBS waivers) per capita as percentage of state Medicaid long-term care expenditures per capita, FY 2000. The range excludes Arizona, which is unique in having a capitated long-term care system.
38 Oregon: Choices, Senior and Disabled Division, 2000. Available at http://www.sdsd.hr.state.or.us/pubs/choices.pdf
40 Two Georgia women whose disabilities include mental retardation and mental illness brought the Olmstead case. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA (Americans with Disabilities Act) to live in the most integrated setting appropriate.
41 January 14, 2000 letter by HCFA to state Medicaid directors stated: “The recent Court decision in Olmstead v. L.C., 119S.Ct. 2176 (1999), provides an important legal framework for our mutual efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs.”
July 25, 2000 letter by HCFA to state Medicaid directors stated: “No matter what specific impairment or group of people is at issue—including elderly people and children—each must meet the same threshold definition of disability in order to be covered by the ADA.” further: “With respect to elderly people, age alone is not equated with disability.”


States have a Medicaid obligation that parallels the ADA to ensure that individuals are not being inappropriately placed in institutions, and in modifying their public programs to develop appropriate community-based care, states can be expected to turn to Medicaid, which offers a broad array of options for covering individuals with disabilities.


The legislation (Senate Bill 955) brought into a single administrative unit both federally and state-financed programs.


Testimony of Steven Lutzky, Chief, Office on Disabilities and Aging, Medical Assistance Administration, District of Colombia Department of Health before the Senate Finance Committee, “State Efforts to Redesign Their Long-Term Care Delivery Systems,” March 27, 2001.


Lutzky, S., op. cit., p. 32

Doty, P., *Cost Effectiveness of Home and Community-Based Long-term Care Services*, USHHS/ASPE Office of Disability, Aging and Long-Term Care Policy, June 2000.


Kane, R.A., op. cit., pp. 17-27, quality of life in long-term care is described as a combination of different categories that include: maximize independence and autonomy, enhance social well-being, and permit people to live in the least restrictive setting feasible.