United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging, U.S. Senate

For Release on Delivery
Expected at 1:00 p.m.
Monday, September 24, 2001

LONG-TERM CARE

Implications of Supreme Court's *Olmstead* Decision Are Still Unfolding

Statement of Kathryn G. Allen
Director, Health Care—Medicaid
and Private Health Insurance Issues

G A O
Accountability * Integrity * Reliability

GAO-01-1167T

Mr. Chairman and Members of the Committee:

I am pleased to be here today as you address challenges in providing for long-term care, in view of the Supreme Court's 1999 decision, known as *Olmstead*, that addressed issues pertaining to the setting in which a person with disabilities receives care.[1] Long-term care includes many types of services that a person with a physical or mental disability may need, and encompasses a wide array of care settings. Such care can be provided in institutional settings such as nursing homes or state psychiatric facilities, or in community settings such as assisted living facilities, adult foster homes, and people's own homes. About 80 percent of the estimated 5.2 million elderly individuals who require assistance with daily activities[2] live at home or in community-based settings, while about 20 percent live in nursing homes or in other institutions. Many people with disabilities who live outside of institutions rely on home and community-based services such as home health care or nursing services, assistance with meals or medication management, and personal care services. Many people with disabilities are elderly adults, but children and adults of all ages have diverse types of disabilities that may require long-term care services.

In *Olmstead*, the Supreme Court decided that states may be violating title II of the Americans With Disabilities Act of 1990 (ADA)[3] if they provide care to people with disabilities in institutional settings when they could be appropriately served in a home or community-based setting. While the *Olmstead* decision involved two women with developmental disabilities and mental illness who were residents of a psychiatric hospital, it has been interpreted to extend beyond these specific circumstances. This includes applicability to people with physical as well as mental disabilities, to those in nursing homes and other institutional settings in addition to psychiatric hospitals, and to those who live in the community and are at risk of institutionalization. As a result, the decision has generated considerable discussion about its implications for the provision of long-term care services—not only for people with disabilities who currently need services, but also for the growing numbers of aging baby boomers who

[1] *Olmstead v. L.C.,* 527 U.S. 581 (1999).

[2] Individuals needing long-term care may have difficulty performing some activities of daily living (ADL) without assistance, such as bathing, dressing, toileting, eating, and moving from one location to another; or instrumental activities of daily living (IADL) such as preparing food, doing housekeeping, and handling finances; or both.

[3] See 42 U.S.C. §§12131-12165.

will need care in the coming decades. In responding to these current and future long-term care service needs, much attention has been focused on Medicaid, the joint federal-state health financing program for certain low-income individuals, including the elderly and persons with disabilities. Flexibility built into the Medicaid program allows states to make many of their own decisions, within broad federal guidelines, about whom and what long-term care services to cover, and in what settings.

As part of your ongoing series of hearings on long-term care, you asked us to address the implications of the *Olmstead* decision in this larger context. My remarks today, which are based on our current and previous work[4] and on the research of others, will focus on (1) an overview of the demand for and financing of long-term care, in view of the *Olmstead* decision and the growing numbers of baby boomers, and (2) implications of the decision for state-administered long-term care programs.

In summary, the extent to which the *Olmstead* decision will dictate major shifts in long-term care services from institutional to home and community-based settings—and for whom—is uncertain. What is more certain, however, is that responses to the decision will take place in the larger context of preparing for the tidal wave of aging baby boomers who will increasingly tax the current capacity of public and private resources. This aging generation, with the associated expected increase in the numbers of people with disabilities, could increase the number of disabled elderly people who will need care to between 2 and 4 times the current number. While many public programs support people with disabilities, Medicaid is the dominant public program supporting long-term care institutional and home and community-based services, accounting for about 44 percent of the $134 billion spent for these services nationwide in 1999. Historically, Medicaid has financed long-term care primarily in nursing homes or other institutions. While Medicaid spending for home and community-based services is growing, these are largely optional benefits that states may or may not choose to offer, and states vary widely in the degree to which they cover them as part of their Medicaid programs. Consequently, the ability of Medicaid-eligible people with disabilities to access care in home and community-based settings also varies widely from state to state and even from community to community. Private resources—which include out-of-pocket spending and private health and long-term-care insurance—make up the second largest source of long-term

[4]A list of related GAO products is at the end of this statement.

care financing, comprising about 40 percent of total spending. This public and private spending, however, does not quantify the total costs of long-term care. Families play a major role in supplying services. For example, an estimated 60 percent of disabled elderly individuals living in communities rely exclusively on their families and other unpaid sources for their care.

Implications of the *Olmstead* decision—in terms of the scope and nature of states' obligation to provide home and community-based long-term care services—are still unfolding. While the Supreme Court ruled that, under certain circumstances, providing care in institutional settings may violate the ADA, it also recognized that there are limits to what states can do, given available resources and the obligation to provide a range of services for people with disabilities. The ADA does not require states to "fundamentally alter" their existing programs. The decision thus left many open questions for states and lower courts to resolve. To date, most states' responses to *Olmstead* have focused on preparing plans that lay out goals and actions for expanding home and community services for people with disabilities. The Supreme Court had indicated that such plans were a way for states to demonstrate they were making reasonable progress in changing their long-term care programs. Because most of these plans are works in progress, it is too soon to tell how and when they will be implemented. State programs also may be influenced over time as dozens of lawsuits and hundreds of formal complaints seeking access to appropriate services are resolved.

Background

The plaintiffs in the *Olmstead* case were two women with developmental disabilities and mental illness who claimed that Georgia was violating title II of the ADA, which prohibits discrimination against people with disabilities in the provision of public services. Both women were being treated as inpatients in a state psychiatric hospital. The women and their treating physicians agreed that a community-based setting would be appropriate for their needs. The Supreme Court held that it was discriminatory for the plaintiffs to remain institutionalized when a qualified state professional had approved community placement, the women were not opposed to such a placement, and the state could

reasonably accommodate the placement, taking into account its resources and the needs of other state residents with mental disabilities.[5]

The *Olmstead* decision is an interpretation of public entities' obligations under title II of the ADA. As one of several federal civil rights statutes, the ADA provides broad nondiscrimination protection for individuals with disabilities in employment, public services, public accommodations, transportation, and telecommunications. Specifically, title II of the ADA applies to public services furnished by governmental agencies and provides in part that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[6]

Two ADA implementing regulations were key in the Supreme Court's ruling in *Olmstead*. The first requires that public entities make "reasonable modifications" when necessary to avoid discrimination on the basis of disability, unless the entity can demonstrate that the modification would "fundamentally alter the nature of the service, program or activity."[7] The second requires public entities to provide services in "the most integrated setting appropriate to the needs of qualified individuals with disabilities."[8] That setting could be in the community, such as a person's home, or in an institution, depending on the needs of the individual. For example, professionals might agree that a nursing home is the most integrated setting appropriate for an institutionalized person's needs. In *Olmstead*, physicians at the state hospital had determined that services in a community-based setting were appropriate for the plaintiffs. The Supreme Court recognized, however, that the appropriate setting for services is

[5]527 U.S. 581, 607 (1999). The Supreme Court remanded the case to the United States District Court for the Northern District of Georgia for further consideration of whether changes would "fundamentally alter" the nature of the services, programs, or activities of the state of Georgia. On July 11, 2000, the parties settled. Under the settlement agreement, the state agreed to provide both plaintiffs with community-based residential placements; individual service plans; and, in the event of institutionalization, a return to community-based treatment within 30 days of a determination that a return to residential or community-based treatment is appropriate.

[6]The ADA defines a public entity as including (1) a state or local government or (2) a department, agency, special purpose district, or other instrumentality of a state, states, or local government. 42 U.S.C. §12131(1).

[7]28 C.F.R. §35.130(b)(7).

[8]28 C.F.R. §35.130(d).

determined on a case-by-case basis and that the state must continue to provide a range of services for people with different types of disabilities.

The ADA has a broad scope in that it applies to individuals of all disabilities and ages. The definition of disability under the ADA is a physical or mental impairment that is serious enough to limit a major life activity, such as caring for oneself, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, or learning.[9] The breadth of this definition thus covers people with very diverse disabilities and needs for assistance. For some individuals with disabilities, assistance from another person is necessary—direct, "hands-on" assistance or supervision to ensure that everyday activities are performed in a safe, consistent, and appropriate manner. For others, special equipment or training may enable them to continue to function independently. Disability may be present from an early age, as is the case for individuals with mental retardation or developmental disabilities; occur as the result of a disease or traumatic injury; or manifest itself as a part of a natural aging process. Moreover, the assistance needed depends on the type of disability. For example, individuals with physical disabilities often require significant help with daily activities of self-care. In contrast, individuals with Alzheimer's disease or chronic mental illness may be able to perform everyday tasks and may need supervision rather than hands-on assistance. To be a "qualified" individual with a disability under title II of the ADA, the person must meet the eligibility requirements for receipt of services from a public entity or for participation in a public program, activity, or service—such as the income and asset limitations established for eligibility in the Medicaid program.[10]

[9]Specifically, the ADA defines "disability" as (1) a physical or mental impairment that substantially limits one or more of an individual's major life activities, (2) a record of such an impairment, or (3) being regarded as having such an impairment. 42 U.S.C. §12102(2).

[10]States impose specific standards regarding who is sufficiently disabled to qualify for publicly funded long-term care. Only a subset of the population considered to be disabled within the meaning of the ADA may be affected by state long-term care programs targeted to people with extensive service needs.

Breadth of Population Affected by *Olmstead* Is Uncertain but Likely to Grow, With Medicaid the Dominant Payer

The breadth of the disabled population to whom *Olmstead* may eventually apply is uncertain. Much is unknown about the widely varying population of people with disabilities, the settings in which they are receiving services, and the extent to which their conditions would put them at risk of institutionalization. Demographic data show, however, that the response to *Olmstead* will take place in the context of significant increases in the number of people with disabilities. As the baby boom generation grows older, they are more likely to be affected by disabling conditions. Of the many public programs that support people with disabilities, the federal-state Medicaid program plays the most dominant role for supporting long-term care needs. Services through this program have been provided primarily in institutional long-term care settings, but a growing proportion of Medicaid long-term care expenses in the past decade has been for home and community-based services. At present, however, there are wide differences between states in the degree to which home and community-based services are provided. States also face varying challenges in supporting community living beyond what can be provided through long-term care programs, such as ensuring adequate supports for housing and transportation, and maintaining adequate programs to ensure quality care is provided in community settings.

Comprehensive Information on Those Institutionalized or at Risk Is Lacking

The *Olmstead* decision has been widely interpreted to apply to people with varying types of disabilities who are either in institutions or at risk of institutionalization. One reason for the uncertainty about how many may be affected is that, as the decision recognized, the appropriateness of a person's being placed in an institution or receiving home or community-based services would depend in part on the person's wishes and the recommendations of his or her treatment professionals. Another reason is that information on the number of people with disabilities who are at risk of institutionalization is difficult to establish.

- Number of institutionalized individuals. On the basis of information from different sources, we estimate that the total number of people with disabilities who are being served in different types of institutional settings is at least 1.8 million. This figure includes about 1.6 million people in nursing facilities,[11] 106,000 in institutions for the mentally retarded or

[11]We earlier reported that approximately 1.6 million elderly and disabled residents were in nursing facilities in 1999. *Nursing Homes: Complaint Investigation Processes Often Inadequate to Protect Residents* (GAO/HEHS-99-80, Mar. 22, 1999), p. 1.

developmentally disabled,[12] and 57,000 in state and county facilities for the mentally ill.[13]

- Number at risk of institutionalization. The number of people who are living in the community but at risk of institutionalization is difficult to establish. In an earlier study we estimated that, nationwide, 2.3 million adults of all ages lived in home or community-based settings and required considerable help from another person to perform two or more self-care activities.[14] More difficult to estimate is the number of disabled children at risk of institutionalization.[15]

Changing Demographics Will Drive Increased Demand for Long-Term Care

The demographics associated with the increasing number of aging baby boomers will likely drive the increased demand for services in a wide range of long-term care settings. Although a chronic physical or mental disability may occur at any age, the older an individual becomes, the more likely a person will develop disabling conditions. For example, less than 4 percent of children under 15 years old have a severe disability, compared with 58 percent of those 80 years and older. The baby boom generation—those born between 1946 and 1964—will contribute significantly to the growth in the number of elderly individuals with disabilities who need long-term care and to the amount of resources required to pay for it. The oldest baby boomers, now in their fifties, will turn 65 in 2011. In 2000, about 13 percent of our nation's population was composed of individuals

[12]David L. Braddock, unpublished data for 2000 from the State of the States Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities and the Department of Psychiatry, University of Colorado. In surveys of state programs for people with developmental disabilities, Braddock identified nearly 35,000 people with developmental disabilities living in nursing facilities in addition to the 106,000 in state and private Intermediate Care Facilities for persons with Mental Retardation (ICF/MR) with seven or more beds.

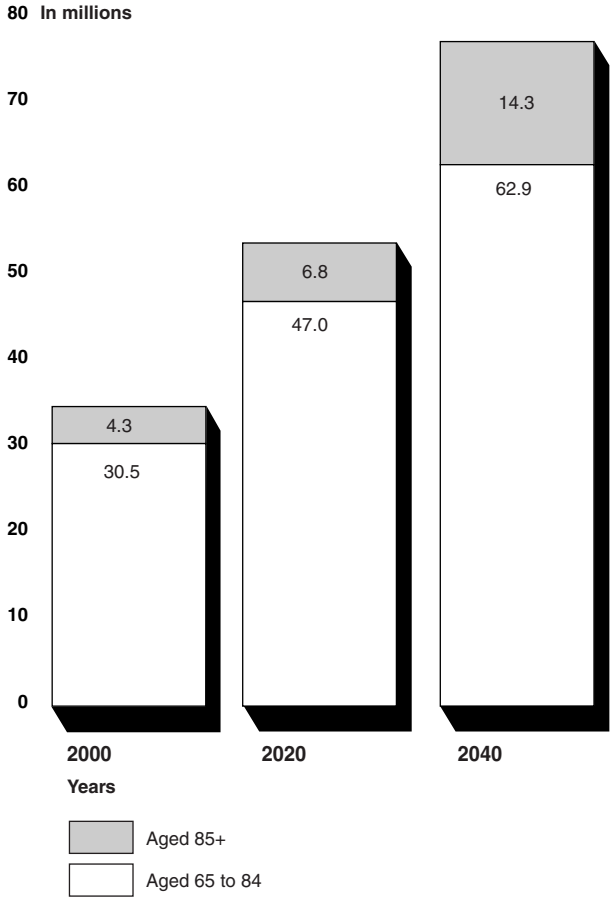
[13]*Additions and Resident Patients at End of Year, State and County Mental Hospitals by Age and Diagnosis by State, United States 1998* (Rockville, Md.: SAMHSA, Center for Mental Health Services, 2000). See also David L. Braddock, *Public Financial Support for Disability at the Close of the 20th Century*, Coleman Institute for Cognitive Disabilities and Department of Psychiatry (Denver, Colo.: University of Colorado, Aug. 1, 2001).

[14]Since there is no consensus on what constitutes a severe disability, we estimated, using National Health Interview Survey data, the number of adults who had either a lot of difficulty with or was unable to perform either three or more ADLs or two ADLs and four IADLs. See *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

[15]See *Children With Disabilities: Medicaid Can Offer Important Benefits and Services* (GAO/T-HEHS-00-152, July 12, 2000).

aged 65 or older. By 2020, that percentage will increase by nearly one-third to about 17 percent—one in six Americans—and will represent nearly 20 million more seniors than there are today. By 2040, the number of seniors aged 85 and older will more than triple to 14 million (see fig. 1). However, because older people are healthier now than in the past, no consensus exists on the extent to which the growing elderly population will increase the number of disabled elderly people needing long-term care. Projections of the number of disabled elderly individuals who will need care range between 2 and 4 times the current number.

Figure 1: Estimated Number of Elderly Individuals in 2000, 2020, and 2040



Source: Bureau of the Census, "Projections of the Total Resident Population by 5-Year Age Groups and Sex With Special Age Categories: Middle Series," selected years, 2000 to 2040 (Washington, D.C.: Jan. 2000).

The changing demographics will also likely affect the demand for paid long-term care services. An estimated 60 percent of the disabled elderly living in communities now rely exclusively on their families and other unpaid sources for their care. Because of factors such as the greater geographic dispersion of families and the large and growing percentage of women who work outside the home, many baby boomers may have no option but to rely on paid long-term care providers. A smaller proportion of this generation in the future may have a spouse or adult children to provide unpaid care and therefore may have to rely on more formal or public services.

Medicaid Plays a Dominant Role in Financing Long-Term Care

Medicaid is by far the largest public program supporting long-term care.[16] States administer this joint federal-state health financing program for low-income people within broad federal requirements and with oversight from the Centers for Medicare and Medicaid Services (CMS),[17] the agency that administers the program at the federal level.[18] In 2000, Medicaid long-term care expenditures represented over one-third of the total $194 billion spent by Medicaid for all medical services. Although at least 70 different federal programs provide assistance to individuals with disabilities at substantial cost, Medicaid is the most significant source of federal funds

[16]People with disabilities generally become eligible for Medicaid through one of two routes. First, individuals become eligible if they meet a state's income and resource criteria for institutional care and are determined to require services equivalent to a nursing home level of care. This is how the elderly most often become eligible for Medicaid. The second route is through eligibility for the Social Security Administration's Supplemental Security Income (SSI) program. SSI is the federally-administered means-tested income assistance program that provides a financial safety net for disabled, blind, or aged individuals who have low incomes and limited resources. As of October 2000, 40 states provided Medicaid to all individuals who were receiving SSI payments. In the remaining states, a disabled individual's Medicaid eligibility was not automatic since these states have elected to continue using the SSI standards that were in effect on January 1, 1972, and are more restrictive than current SSI eligibility criteria.

[17]Formerly the Health Care Financing Administration (HCFA), until June 2001. We continue to refer to HCFA where agency actions were taken under its former name.

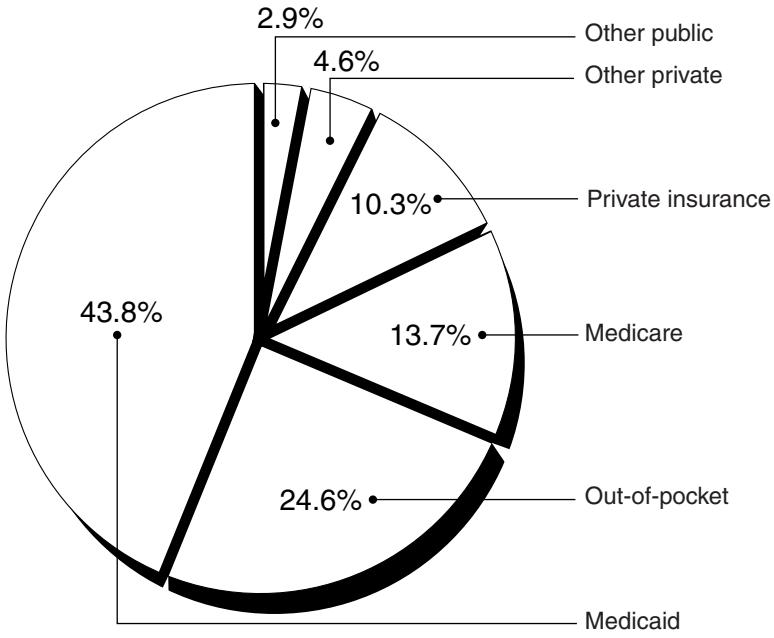
[18]Medicaid costs are shared by the federal government and states, and each state program's federal and state funding shares are determined through a statutory matching formula. The federal share of states' medical assistance payments ranges from 50 to 83 percent, depending on a state's per capita income in relationship to the national average. On average, the federal share of Medicaid expenditures is 57 percent.

for providing long-term care.[19] Earlier this year, we reported that Medicaid paid nearly 44 percent of the $134 billion spent nationwide for long-term care in 1999, including postacute and chronic care in nursing homes and home and community-based care. Individuals needing care, and their families, paid for almost 25 percent of these expenditures out-of-pocket. Medicare and other public programs covered almost 17 percent, and private insurance and other private sources (including long-term care insurance as well as services paid by traditional health insurance) accounted for the remaining 15 percent. (See fig. 2.) These amounts, however, do not include the many hidden costs of long-term care. For example, they do not include wages lost when an unpaid family caregiver takes time off from work to provide assistance.[20]

[19]Federal programs supporting people with disabilities can be categorized generally into two groups. The first group is programs with disability as a central eligibility criterion, composed of 30 programs largely providing cash benefits, with estimated expenditures totaling $110 billion in fiscal year 1999. The second group uses disability as one of many potential criteria for program participation and consists of 40 programs, including Medicaid, for which age, income, or both also serve as bases for eligibility. See *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

[20]See *Long-Term Care: Baby Boom Generation Increases Challenge of Financing Needed Services* (GAO-01-563T, Mar. 27, 2001).

Figure 2: Percentage of Expenditures for Long-Term Care, by Source of Payment, 1999



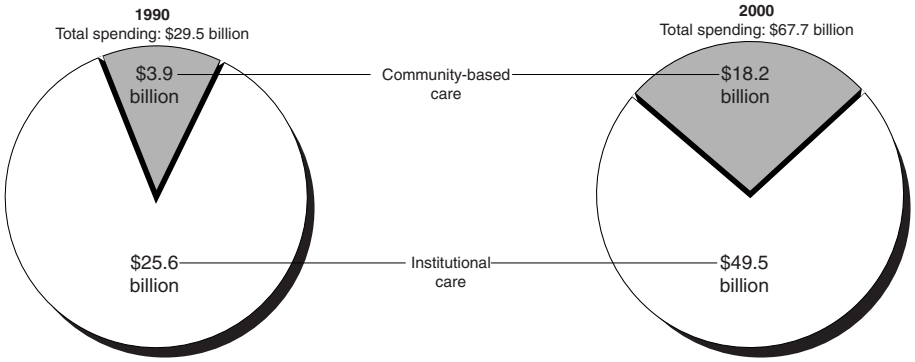
Note: Includes Medicaid expenditures for home and community-based services, which are considered as part of "other personal health care" in HCFA's national health care accounts.

Source: HHS, HCFA, Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, 2001.

Medicaid Funding for Home and Community-Based Services Is Increasing

Historically, Medicaid long-term care expenditures have financed services delivered in nursing homes or other institutions, but the proportion of spending directed to home and community-based care has increased steadily over the past decade, as shown in figure 3. Federal and state Medicaid spending on home and community-based services was about $18 billion (27 percent) of the $68 billion spent on long-term care in fiscal year 2000.

Figure 3: Trends in Medicaid Long-Term Care Spending for Institutional and Home and Community-Based Care, 1990-2000



Source: The MEDSTAT Group, from HCFA 64 Data.

Much of the Medicaid coverage of home and community-based services is at each state's discretion. One type of coverage, however, is not optional: states are required to cover home health services for medically necessary care (see table 1). A second type of services, called personal care, is optional. The primary means by which states provide home and community-based services is through another optional approach: home and community-based services (HCBS) waivers, which are set forth at section 1915(c) of the Social Security Act.[21] States apply to the federal government for these waivers, which, if approved, allow states to limit the availability of services geographically, target specific populations or conditions, control the number of individuals served, and cap overall expenditures.[22] To receive such a waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus other state

[21]These waivers are codified at 42 U.S.C. §1396n(c).

[22]Provisions of the Medicaid statute that may be waived include (1) "statewideness," which requires that the services be available throughout the state (a waiver allows services to be provided only in particular geographic locations); (2) comparability, which requires that all services be available to all eligible individuals (a waiver allows states to limit services to a specific number of individuals on the basis of certain criteria determined by the state, such as disease, condition, and age); and (3) the community income and resource rules for the medically needy (a waiver allows states to use institutional eligibility rules—which are more generous than community rules—for individuals residing in the community). For more information on these and other types of home and community services, see *Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services* (GAO/HEHS-99-101, May 14, 1999).

Medicaid services) is no more than what would have been spent on institutional care (plus any other Medicaid services provided to institutionalized individuals). States often operate several different waivers serving different population groups, and they have often limited the size and scope of the waivers to help target their Medicaid resources and control spending.

Table 1: Expenditures for Home and Community-Based Services Covered by Medicaid, by Type, Fiscal Year 2000

Dollars in billions			
Type of service	**Required or optional**	**Description**	**Medicaid expenditures**
Home Health Care	Required	Home health care includes medically necessary nursing, home health aides, medical supplies, medical equipment and appliances suitable for use in the home.	$2.3
Personal Care Services	Optional	Personal care services include a range of assistance to enable people to accomplish tasks they would normally do for themselves if they did not have a disability. Types of assistance that may be provided may include light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management.	$3.8
Home and Community-Based Services (HCBS) Waivers	Optional	HCBS provided under what is called the 1915(c) waiver program includes a broad range of services such as case management, homemaker, home health aide, personal care, adult day health, respite care, and, for individuals with chronic mental illness, outpatient clinic services.	$12.0

Source: HCFA.

While expenditures for these services have generally grown over time, states' use of HCBS waivers to provide services in community settings has grown at the highest rate. Expenditures for services provided under HCBS waivers grew at an average annual rate of 28 percent between 1988 and 2000—twice as much as Medicaid's expenditures for home health services and three times as much as for personal care services.

Expenditures under the HCBS waivers vary widely with the type of disability covered. The average cost across all programs in 1999 was about $15,331 per recipient. For persons with developmental disabilities, the average cost was twice the average ($30,421); for programs serving the aged and aged disabled, the average cost was much lower ($5,849). This variation results from several factors, but primarily from differences in the type and amount of program services supplied versus services from other sources such as family members. The average costs for providing waiver and other home and community-based services is much lower than average costs for institutionalizing a person. However, the costs of these community-based services do not include significant other costs that must be covered when a person lives in his or her home or in a community-based setting, such as costs for housing, meals, and transportation, as well as the additional costs and burden for family and other informal caregivers.

Provision of Home and Community-Based Services Varies Widely by State

The proportion of Medicaid long-term care spending devoted to home and community-based services varies widely among states. Some states have taken advantage of Medicaid HCBS waivers to develop extensive home and community-based services, while other states have traditionally relied more heavily on institutional and nursing facility services. This variation is reflected in differences in the extent of states' total Medicaid long-term care spending devoted to home and community-based care (defined to include the waivers, home health, and personal care services). For example, in 1999, 9 states devoted 40 percent or more of Medicaid long-term care expenditures to community-based care, whereas 11 states and the District of Columbia devoted less than 20 percent. (See fig. 4.)

Figure 4: Proportion of Medicaid Long-Term Care Spending for Home and Community-Based Care, by State, 1999

Source: Based on data from the National Conference of State Legislatures.

States also vary in the amount of home and community-based services they offer specifically through HCBS waivers. According to data compiled by researchers, an estimated 688,000 disabled persons were being served under 212 HCBS waivers in 49 states (excluding Arizona) and the District of Columbia in 1999.[23] (See app. I.) These waivers covered several different types of disabled populations and settings. All but two states operated at least one waiver covering services for people with mental retardation or developmental disabilities, and all but the District of Columbia operated at

[23]Charlene Harrington and Martin Kitchener, *Medicaid 1915(c) Home and Community Based Waivers: Program Data, 1992-1999*, prepared for The Kaiser Commission on Medicaid and the Uninsured (San Francisco, Calif.: University of California, San Francisco, Aug. 2001).

least one waiver for the aged disabled. Overall, states had 73 waivers covering services for people with mental retardation or developmental disabilities serving nearly 260,000 participants, 65 waivers covering services for almost 382,000 aged or aged disabled participants, and 27 waivers serving about 25,000 physically disabled individuals.[24] Nationwide, the number of people served by waivers varies substantially across states. Oregon, for example, served more than 8 times as many people per capita in its large waiver for the aged and disabled, compared with several other states that had waivers for the same target population.

In most states, the demand for HCBS waiver services has exceeded what is available and has resulted in waiting lists.[25] Waiting list data, however, are incomplete and inconsistent. States are not required to keep waiting lists, and not all do so. Among states that keep waiting lists, criteria for inclusion on the lists vary. In one 1998-99 telephone survey of 50 states and the District of Columbia, Medicaid officials in 42 states reported waiting lists for one or more of their waivers, although they often lacked exact numbers. Officials in only eight states reported that they considered their waiver capacity and funding to be adequate and that they did not have waiting lists for persons eligible for services under those waivers.[26]

States Face Challenges in Supporting Community Living

The states face a number of challenges in providing services to support people with disabilities living in the community, and these challenges extend beyond what can be provided by the Medicaid program alone. The additional costs to the states of supporting people with disabilities in the community are a concern. For example, Medicaid does not pay for housing or meals for individuals who are receiving long-term care services in their own homes or in a community setting, such as an adult foster home. Consequently, a number of state agencies may need to coordinate the delivery and funding of such costly supports as housing and

[24]The remaining waivers served almost 22,000 individuals with AIDS, traumatic brain injuries, and children with severe medical disabilities.

[25]Waiting lists can result when states are providing services for the full number of participants or "slots" authorized by the waiver agreement with CMS. States may apply to CMS to amend their waivers to expand the number of authorized slots. However, waivers also allow states to cap overall expenditures, which my contribute to waiting lists.

[26]Charlene Harrington and others, "Met and Unmet Need for Medicaid Home and Community Based Services in the States," University of California, San Francisco, March 2001. This unpublished report has been accepted for publication in a forthcoming issue of the *Journal of Applied Gerontology*.

transportation. States may also find their efforts to move people out of institutions complicated by the scarcity of caregivers—both paid personal attendants and unpaid family members and friends—who are needed to provide the home and community services.

Finally, there are concerns about the difficulty of establishing adequate programs to ensure that quality care is being provided in the different types of noninstitutional service settings throughout the community. We have reported on quality-of-care and consumer protection issues in assisted living facilities, an increasingly popular long-term care option in the community. States have the primary responsibility for the oversight of care furnished in assisted living facilities, and they generally approach this responsibility through state licensing requirements and routine compliance inspections. However, the licensing standards, as well as the frequency and content of the periodic inspections, are not uniform across the states. In our sample of more that 750 assisted living facilities in four states, the states cited more than 25 percent of the facilities for five or more quality-of-care or consumer protection problems during 1996 and 1997. Frequently identified problems included facilities providing inadequate or insufficient care to residents; having insufficient, unqualified, and untrained staff; and failing to provide residents appropriate medications or storing medications improperly. State officials attributed most of the common problems identified in assisted living facilities to insufficient staffing and inadequate training, exacerbated by high staff turnover and low pay for caregiver staff.[27]

Full Implications of *Olmstead* for State Programs Not Yet Known

The Supreme Court's *Olmstead* decision left open questions about the extent to which states could be required to restructure their current long-term care programs for people with disabilities to ensure that care is provided in the most integrated setting appropriate for each person's circumstances. Interpretation of the *Olmstead* decision is an ongoing process. While the Supreme Court held in *Olmstead* that institutionalization of people with disabilities is discrimination under the ADA under certain circumstances, it also recognized that there are limits to what states can do, given available resources and the obligation to provide a range of services for people with disabilities. Most states are

[27] *Assisted Living: Quality-of-Care and Consumer Protection Issues* (GAO/T-HEHS-99-111, Apr. 26, 1999). See also *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States* (GAO/HEHS-99-27, Apr. 26, 1999).

responding to the decision by developing plans for how they will serve people with disabilities in less restrictive settings. These plans are works in progress, however, and it is too soon to tell how and when they may be implemented. State responses will also be shaped over time by the resolution of the many pending lawsuits and formal complaints that have been filed against them and others.

The Supreme Court Recognized Limitations to State Obligations

The Supreme Court held that states may be required to serve people with disabilities in community settings when such placements can be reasonably accommodated. However, it recognized that states' obligations to provide services are not boundless.[28] Specifically, the Court emphasized that while the ADA's implementing regulations require reasonable modifications by the state to avoid discrimination against the disabled, those regulations also allow a state to resist requested modifications if they would entail a "fundamental alteration" of the state's existing services and programs.

The Court provided some guidance for determining whether accommodations sought by plaintiffs constitute a reasonable modification or a fundamental alteration of an existing program, which would not be required under the ADA. The Court directed that such a determination should include consideration of the resources of the state, the cost of providing community-based care to the plaintiffs, the range of services the state provides to others with disabilities, and the state's obligation to provide those services equitably.[29] The Court suggested that if a state were to "demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated, the reasonable modification standard would be met."[30]

Most States Are Preparing *Olmstead* Plans

The single most concrete state response to the *Olmstead* decision has been to develop plans that demonstrate how the states propose to serve people with disabilities in less restrictive settings, as suggested by the

[28] 527 U.S. 581, 603 (1999).

[29] 527 U.S. 581, 597 (1999).

[30] 527 U.S. 581, 605-606 (1999).

Supreme Court. HCFA provided early guidance and technical assistance to states in these efforts. But most of these state plans are still works in progress, and it is too soon to tell how and when they will be implemented.

To help states with their *Olmstead* planning activities, between January and July 2000 , HCFA issued general guidance to the states in developing "comprehensive, effectively working plans" to ensure that individuals with disabilities receive services in the most integrated setting appropriate.[31] To encourage states to design and implement improvements in their community-based long-term care services, HCFA also announced a set of competitive grant initiatives, funded at nearly $70 million, to be awarded by October 1, 2001. (See app. II for details about these competitive grants.) In addition, HCFA made $50,000 starter grants available to each of the states and territories, with no financial match required, to assist their initial planning efforts. As of July 2001, 49 states (every state except Arizona) had applied for and received these starter grants, which must be used to obtain consumer input and improve services.[32]

As of September 2001, an estimated 40 states and the District of Columbia had task forces or commissions that were addressing *Olmstead* issues. According to the National Conference of State Legislatures (NCSL), which is tracking the states' efforts, the goal for most of these states was to complete initial plans by the end of this year or early 2002. Ten states were not developing *Olmstead* plans, for a variety of reasons. NCSL reported that some of the states that were not planning already have relatively extensive home and community care programs and may believe that such planning is not necessary. As the result of a 1999 lawsuit settlement, for example, Oregon had developed a 6-year plan to eliminate the waiting list

[31]The guidance for developing *Olmstead* plans included the following recommendations: involving individuals with disabilities and their representatives in the planning process, addressing the need to identify individuals who are eligible for community services, assessing the appropriateness and capacity (including waiting lists) of available community-based services, offering individuals with disabilities choices among services, and taking steps to ensure quality assurance in community services. HHS' Office for Civil Rights (OCR) also provides technical assistance to the states on planning issues. For example, states may choose to submit their draft *Olmstead* plans to OCR for review and assistance. According to officials, OCR does not approve or disapprove the plans, but the office assesses the extent to which the plans address the concerns raised in complaints.

[32]CMS also funds a contractor to maintain the *Olmstead* National Technical Assistance Center. The contractor operates a Web site to facilitate communication between states and consumers and provides research and summaries on HCBS programs and initiatives.

of more than 5,000 people for its waiver program serving people with developmental disabilities. Moreover, Oregon was the only state to dedicate more than half of its 1999 Medicaid long-term care spending to home and community-based services. Vermont also is not working on an *Olmstead* plan because it has implemented a range of activities over the years that are related to downsizing institutions and moving toward home and community-based care.[33]

On the basis of a preliminary review of about 14 draft *Olmstead* plans, NCSL reported that the contents are quite variable. A few plans are relatively extensive and well documented, including determinations of need, inventories of available services, funding needs, and roadmaps for what needs to be done. According to NCSL, other plans consist primarily of lists of recommendations to the governor or state legislature, without specifying how the recommendations are to be implemented, by which agencies, or in what time frame.

It is too early to tell how or when the states will implement the steps they propose in their *Olmstead* plans. On the basis of the information collected by NCSL, it appears that few states have passed legislation relating to *Olmstead*—for example, appropriating funding to expand community residential options or authorizing program changes. As of July 2001, NCSL was able to identify 15 *Olmstead*-related bills that were considered in eight states during 2001, of which 4 were enacted. One bill simply provided for development of the state plan, while others appropriated funding, required a new home and community-based attendant services program, or proposed long-term care reforms. Increased state legislative activity is expected in 2002, as more *Olmstead* plans are completed.

Resolution of Pending Lawsuits and Complaints Will Help Establish *Olmstead*'s Reach

State responses to *Olmstead* also will be influenced by the resolution of the numerous lawsuits and formal complaints that have been filed and are still pending. *Olmstead*-related lawsuits, now being considered in almost half the states, often seek specific Medicaid services to meet the needs of people with disabilities. Lawsuits on behalf of people with disabilities seeking Medicaid and other services in community-based settings often are initiated by advocacy organizations. According to the National

[33]According to NCSL, states not developing *Olmstead* plans were Michigan, Minnesota, Nebraska, New York, Oregon, Rhode Island, South Dakota, Tennessee, Vermont, and Virginia.

Association of Protection and Advocacy Systems (NAPAS), Protection and Advocacy Organizations report that about 30 relevant cases concerning access to publicly funded health services whose resolution may relate to *Olmstead* are still active.[34] Plaintiffs in the cases include residents of state psychiatric facilities, developmental disabilities centers, and nursing homes, as well as people living in the community who are at risk of institutionalization. Their complaints raise such issues as prompt access to community-based services, the limitations of Medicaid waiver programs, and the need for assessments to determine the most integrated setting appropriate to each individual.

It is difficult to predict the overall outcome of these active cases since each involves highly individual circumstances, including the nature of the plaintiffs' concerns and each state's unique Medicaid program structure and funding. According to a NAPAS representative, two recent cases in Hawaii and Louisiana illustrate some of the issues raised by *Olmstead*-related lawsuits and how they were resolved through voluntary settlements.

- The Hawaii case[35] shows how one federal court addressed the state's obligation to move people off its waiting lists at a reasonable pace, applying the *Olmstead* decision to people with disabilities who were not institutionalized. The plaintiffs claimed that Hawaii was operating its waiver program for people with mental retardation and developmental disabilities in a manner that violated the ADA and Medicaid law. The plaintiffs were living at home while on a waiting list for community-based waiver services—the majority of the plaintiffs had been on the waiting list for over 90 days and some for over 2 years. They could have obtained services if they had been willing to live in institutions, but they wished to stay in the community. The court found that *Olmstead* applied to the case even though the plaintiffs were not institutionalized. Hawaii argued that the plaintiffs were on the waiting list because of a lack of funds and that providing services for more people would cause the state to exceed funding limits set up in its waiver program. [36] The court rejected the state's

[34]Protection and Advocacy Organizations are part of a national protection and advocacy system established by federal statutes to provide legal representation and advocacy services for people with disabilities in every state. These organizations operate through federal grants.

[35]*Makin v. Hawaii*, 114 F. Supp. 2d 1017 (D.HI, 1999).

[36]Hawaii had 976 federally approved "slots" for its HCBS waiver program for people with mental retardation in 1998. In 1999, 801 people were on the waiting list.

argument and held that funding shortages did not meet the definition of a "fundamental alteration." The court also found that Hawaii did not provide evidence of a comprehensive plan to keep the waiting list moving at a reasonable pace, suggested by the *Olmstead* opinion. In July 2000, the parties settled the case by agreeing that Hawaii would fund 700 additional community placements over 3 years and move people from the waiting list at a reasonable pace.

- The Louisiana case[37] was filed in 2000 on behalf of people living in nursing homes, or at imminent risk of nursing home admission, who were waiting for services offered through three Medicaid HCBS waivers that provided personal attendant care, adult day health care, and other services to elderly and disabled adults. The plaintiffs claimed that the state was failing to provide services in the most integrated setting as required by the ADA. They also claimed that the state was not following Medicaid statutory requirements to provide services with reasonable promptness and to allow choice among available services.[38] As part of a settlement of this case, Louisiana agreed to make all reasonable efforts to expand its capacity to provide home and community-based services and to reduce waiting lists in accordance with specific goals. For example, the state will increase the number of waiver slots by a minimum of 650 slots by 2002, with additional increases planned through 2005. The state also agreed to apply to CMS to add a personal care service option to its Medicaid plan, thereby making personal care services available to all eligible Medicaid recipients who are in nursing homes, at imminent risk of nursing home admission, or recently discharged. In addition, the state agreed to determine the status of persons currently on waiting lists for waiver services and to take steps to inform Medicaid beneficiaries and health professionals about the full range of available service options.

Olmstead issues are also being addressed through a formal complaint resolution process operated by the Office for Civil Rights (OCR) within HHS. As part of its responsibility for enforcing the ADA, OCR receives and helps resolve formal complaints related to the ADA. When OCR receives

[37] *Barthelemy v. Louisiana Department of Health and Human Services*, Civil Action No. 00-1083 (E.D.LA).

[38] The Medicaid statute requires that states furnish assistance "with reasonable promptness to all eligible individuals." 42 U.S.C. §1396a(8). States with home and community-based care waiver programs must provide assurances to HHS that individuals who are determined to be likely to require institutional care be informed of the feasible alternatives and provision of services "at the choice of such individuals." 42 U.S.C. § 1392n(c)(2)(C). See also 42 U.S.C. §1396n(d)(2)(C).

Olmstead-related complaints from individuals and parties, it works through its regional offices to resolve them by involving the complainants and the affected state agencies. If a complaint cannot be resolved at the state and regional OCR level, OCR's central office may get involved. Finally, if these steps are not successful, the complaint is referred to the Department of Justice. As of August 2001, no *Olmstead*-related cases had been referred to the Department of Justice.

From 1999 through August 2001, OCR received 423 ADA-related complaints.[39] These complaints generally involved a concern that people did not receive services in the most integrated setting. OCR reported that, as of August 2001, 154 complaints had been settled and 269 remained pending. These complaints had been filed in 36 states and the District of Columbia, with more than half filed in seven states. A recent analysis of 334 *Olmstead*-related complaints indicated that 228 complaints (68 percent) were related to people residing in institutions.[40]

The ongoing resolution of *Olmstead*-related lawsuits and complaints will help establish precedent for the types of Medicaid program modifications states may have to make to their long-term care programs. Meanwhile, it is difficult to generalize about the potential impact of the many ongoing cases because each case will be decided on its own facts. The extent of what federal courts will require states to do to comply with the ADA as interpreted in *Olmstead* will become more clear over time as additional cases are resolved.

Concluding Observations

In the wake of the *Olmstead* decision, states may face growing pressures to expand services for the elderly and other people with disabilities in a variety of settings that allow for a range of choices. Despite the numerous activities under way at the state and federal levels to respond to this decision, the full implications of the *Olmstead* decision are far from settled. Ongoing complaints and legal challenges continue to prompt states to make incremental changes at the same time that they continue to frame states' legal obligations for providing services to the disabled. States face

[39]OCR officials indicated that they were in the process of updating their database with respect to *Olmstead*-related complaints and that the data should be considered preliminary.

[40]Presentation of Sara Rosenbaum, J.D., and Alexandra Stewart, J.D., School of Public Health and Health Services, The George Washington University, at the National Academy for State Health Policy Annual Conference, August 12, 2001, Charlotte, N.C.

challenges in determining who and how many people meet the criteria of needing and seeking services and also in balancing the resource and service needs of eligible individuals with the availability of state funds.

This balancing of needs and resources will be an even greater issue in the coming years as the baby boom generation ages and adds to the demand for long-term care services. While Medicaid has a prominent role in supporting the long-term care services provided today, other financing sources also play an important role in our current system. These include private resources—including out-of-pocket spending, private insurance, and family support—as well as many other public programs. Finding ways to develop and finance additional service capacity that meets needs, allows choice, and ensures quality care will be a challenge for this generation, their families, and federal, state, and local governments.

Mr. Chairman, this concludes my prepared statement. I will be happy to answer any questions you or the other Committee members may have.

Contacts and Staff Acknowledgments

For more information regarding this testimony, please contact me at (202) 512-7114 or Katherine Iritani at (206) 287-4820. Bruce D. Greenstein, Behn Miller, Suzanne C. Rubins, Ellen M. Smith, and Stan Stenersen also made key contributions to this statement.

Appendix I: Medicaid Home and Community-Based Services Waivers, by State, 1999

State	Number of waivers	Number of persons served, by waiver type: Mentally retarded/ developmentally disabled	Aged/disabled	Physically disabled	Other[a]	Total persons served	State expenditures (in millions)
AK	4	589	712	345	0	1,646	$38.3
AL	3	3,994	5,826	335	0	10,155	129.1
AR	3	1,104	8,158	298	0	9,560	46.8
CA	5	34,212	8,551	120	4,015	46,898	482.9
CO	10	6,517	11,481	0	1,929	19,927	209.6
CT	4	4,328	8,978	198	0	13,504	364.0
DC	1	29	0	0	0	29	51.5
DE	3	490	734	0	365	1,589	34.4
FL	8	13,316	16,805	0	6,337	36,458	287.1
GA	4	2,683	14,018	0	293	16,994	119.2
HI	4	948	923	0	66	1,937	34.2
IA	5	4,984	3,994	0	70	9,048	86.6
ID	3	549	1,000	0	0	1,549	17.5
IL	5	6,961	17,396	12,387	1,483	38,227	290.8
IN	4	1,866	2,338	0	131	4,335	84.5
KS	6	5,325	6,701	3,822	894	16,742	239.9
KY	3	1,060	13,339	52	0	14,451	97.3
LA	4	2,885	759	113	0	3,757	78.0
MA	2	11,076	5,132	0	0	16,208	427.7
MD	3	10,021	132	0	205	10,358	156.7
ME	4	1,624	1,395	697	0	3,716	119.5
MI	3	8,748	6,328	0	0	15,076	253.2
MN	5	7,413	7,838	3,625	367	19,243	429.5
MO	5	7,779	20,821	11	80	28,691	232.0
MS	3	348	2,540	127	0	3,015	14.9
MT	2	980	1,514	0	0	2,494	41.7
NC	4	5,016	11,159	0	273	16,448	316.3
ND	3	1,845	347	0	14	2,206	41.1
NE	4	2,394	2,357	0	21	4,772	88.3
NH	3	2,535	1,367	0	90	3,992	117.4
NJ	9	7,027	4,587	290	611	12,515	292.3
NM	4	1,752	1,404	0	212	3,368	119.2
NV	4	867	1,235	131	0	2,233	15.1
NY	7	36,179	19,732	0	964	56,875	1,784.9
OH	4	5,897	26,135	0	0	32,032	316.8
OK	3	2,687	9,042	0	0	11,729	172.9
OR	2	3,583	26,410	0	0	29,993	298.9
PA	8	10,553	2,463	1,948	70	15,034	516.2
RI	4	2,833	2,304	58	0	5,195	109.7
SC	5	4,242	14,361	32	1,390	20,025	151.7
SD	4	1,764	791	52	0	2,607	48.8
TN	3	4,063	511	0	0	4,574	118.4

State	Number of waivers	Number of persons served, by waiver type: Mentally retarded/ developmentally disabled	Aged/disabled	Physically disabled	Other[a]	Total persons served	State expenditures (in millions)
TX	6	6,227	27,978	100	895	35,200	506.0
UT	5	0	3,422	21	97	3,540	66.0
VA	6	3,650	11,835	235	523	16,243	211.2
VT	5	1,553	1,014	0	208	2,775	67.7
WA	4	5,071	25,718	0	35	30,824	332.2
WI	4	8,884	13,900	0	205	22,989	387.9
WV	2	0	5,284	0	0	5,284	110.3
WY	3	1,110	982	0	0	2,092	45.4
Total	**212**	**259,561**	**381,751**	**24,997**	**21,843**	**688,152**	**$10,550.0**

[a]"Other" includes waivers that serve the conditions other populations, such as children with special health care needs, persons with AIDS, individuals with mental health needs, and individuals with traumatic brain injuries and head injuries.

Source: Charlene Harrington and Martin Kitchener, Medicaid 1915(c) Home and Community Based Waivers: Program Data, 1992–1999, prepared for The Kaiser Commission on Medicaid and the Uninsured (San Francisco, Calif.: University of California, San Francisco, Aug. 2001).

Appendix II: HCFA's "Systems Change for Community Living" Grant Initiative

In January 2001, HCFA announced a set of grant initiatives called "Systems Change for Community Living." These grants are intended to encourage states to design and implement improvements in community long-term support services. Total funding for these grants is $70 million for fiscal year 2001. States will have 36 months to expend the funds. States and other organizations, in partnership with their disabled and elderly communities, were invited to submit proposals for one or more of these four distinct grant programs (see table 2). Agency officials reported receiving 161 separate applications for these grants for more than $240 million. The agency expects all grant awards to be made by October 1, 2001.

Table 2: Overview of "Systems Change for Community Living" Grants

Name of grant	Description of grant	Total grant funding available	Maximum award	Estimated number of awards
Nursing Facility Transitions	To help states transition eligible individuals from nursing facilities to the community.	$10 million to $14 million	$1.2 million	16 to 26
Community-Integrated Personal Assistance Services and Supports	To improve personal assistance services that are consumer-directed or offer maximum individual control.	$5 million to $8 million	$1.2 million	9 to 12
Real Choice Systems Change	To help design and implement effective and lasting improvements in community support systems to enable children and adults of any age who have a disability or long-term illness to live and participate in their communities.	$41 million to $43 million	$3.5 million	30 to 40
National Technical Assistance Exchange for Community Living	To provide technical assistance, training, and information to states, consumers, families, and other agencies and organizations.	$4 million to $5 million	$4.0 million to $5.0 million	1

Source: Coordinated Invitation to Apply for "Systems Change Grants for Community Living," (Washington, D.C.: HHS, HCFA, May 17, 2001).

Related GAO Products

Long-Term Care: Baby Boom Generation Increases Challenge of Financing Needed Services (GAO-01-563T, Mar. 27, 2001).

Mental Health: Community-Based Care Increases for People With Serious Mental Illness (GAO-01-224, Dec. 19, 2000).

Long-Term Care Insurance: Better Information Critical to Prospective Purchasers (GAO/T-HEHS-00-196, Sept. 13, 2000).

Children With Disabilities: Medicaid Can Offer Important Benefits and Services (GAO/T-HEHS-00-152, July 12, 2000).

Adults With Severe Disabilities: Federal and State Approaches for Personal Care and Other Services (GAO/HEHS-99-101, May 14, 1999).

Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States (GAO/HEHS-99-27, Apr. 26, 1999).

Nursing Homes: Complaint Investigation Processes Often Inadequate to Protect Residents (GAO/HEHS-99-80, Mar. 22, 1999).

Long-Term Care: Baby Boom Generation Presents Financing Challenges (GAO/T-HEHS-98-107, Mar. 9, 1998).

Medicaid: Waiver Program for Developmentally Disabled Is Promising but Poses Some Risks (GAO/HEHS-96-120, July 22, 1996).

Long-Term Care: Current Issues and Future Directions (GAO/HEHS-95-109, Apr. 13, 1995).

Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (Aug. 11, 1994).

Health Care Reform: Supplemental and Long-Term Care Insurance (GAO/T-HRD-94-58, Nov. 9, 1993).

(290083)