



**Long-Term Care: What Direction for Public Policy?
Testimony Before the House Committee on Energy
and Commerce**

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Statement of Carol O'Shaughnessy
Specialist in Social Legislation
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Good morning, Mr. Chairman and Members of the Committee. My name is Carol O'Shaughnessy. I am a Specialist in Social Legislation at the Congressional Research Service. I am pleased to present testimony this morning. My testimony summarizes key characteristics about people who receive long-term care services, services they receive, and the role of public programs in financing these services.

Summary

Long-term care support refers to a range of health and social services needed by persons who lack the capacity for self-care due to physical, cognitive, or mental illnesses that result in functional impairment and dependence on others for an extended period of time. Long-term care services include care in nursing homes and other institutions, as well as in home and community settings. The need for long-term care is measured by a person's inability to carry out basic human functions, or activities of daily living (ADLs), such as bathing, dressing, eating, toileting, transferring from a bed to a chair, and getting around inside the home.² It is also measured in terms of people needing supervision with performing ADLs when they have cognitive impairments, such as dementia. The extent of care needed varies depending upon a person's degree of impairment.

- *The need for long-term care affects persons of all ages* — children who are born with disabling conditions, such as mental retardation, or cerebral palsy; working age adults with inherited or acquired disabling conditions; and the elderly who have chronic conditions or illnesses. While the likelihood of needing long-term care assistance occurs more frequently in older ages, advances in medical care are enabling persons of all ages with disabilities to live longer. Of all persons receiving assistance with at least one ADL and who reside at home or in nursing homes, about 56% are persons over age 65, and 44% are under age 65.

¹ This testimony includes key contributions from Bob Lyke, Specialist in Social Legislation, Diane Justice, Specialist in Gerontology, Laura Shrestha, Specialist in Demography, Specialist in Social Legislation, and Julie Stone and Karen Tritz, Analysts in Social Legislation. Technical support was provided by Barbara Sanders and Charles Dibble, CRS.

² Other measures include a person's need for assistance with meal preparation, and light housework, known as instrumental activities of daily living (IADLs).

- *In 2003, total public and private spending on long-term care was \$182 billion. Despite this significant spending, the nation lacks a comprehensive policy on long-term care.* While multiple public programs provide assistance, no one program is designed to support the full range of long-term care services and supports.
- *Of total public and private spending, \$123 billion, or 68% is from public sources. Yet, most care received by people with disabilities is provided by unpaid, informal sources — family and friends.* The aging of society will exacerbate demand on family caregivers. Assisting families to prepare for potentially catastrophic costs of long-term care is viewed by many as an important component of family financial security.
- *Coverage of institutional care, largely under Medicaid, has defined federal long-term care policy for decades.* However, a 1999 Supreme Court decision — *Olmstead v. L.C.* — has sharpened federal and state policy attention on home and community-based services. The Court held that, under certain circumstances, institutionalization of persons who could live in community settings, violates the Americans with Disabilities Act (ADA).
- *Despite enormous federal research and demonstration activities designed to inform federal long-term care policy over the last several decades, Congress has not reached consensus on what road to take.* The complexity of financing and delivering long-term care to diverse groups of persons with disabilities in a variety of settings through multiple federal programs has been a challenge to federal and state governments.
- *The last time Congress made a systemic change in federal long-term care policy was in 1981 when it created the Medicaid Section 1915(c) home and community-based services waiver program for persons who would otherwise require care in institutions.* The last time Congress comprehensively reviewed policy options for long-term care reform was in 1990 under the U.S. Bipartisan Commission on Comprehensive Health Care (known as the Pepper Commission). Other changes have included changes in Medicaid eligibility rules for long-term care services when in 1988, Congress provided financial protections for spouses of persons needing nursing home care and other Medicaid services, and again in 1993 when Congress tightened rules on transfer of assets. In 2000, Congress recognized the needs of caregivers by authorizing a caregiver support program under the Older Americans Act.
- *At the center of the debate on long-term care financing is the Medicaid program.* Medicaid, by default, has become the nation's primary source of public financing for people who need long-term care support. One-third of total Medicaid spending in FY2003 was devoted to long-term care — \$84 billion with about 65% for institutional care and 33% for home and community-based services. From 1990 through 2003, Medicaid long-term care expenditures grew at an annual average rate of 8% per year. Over the last 15 years, Medicaid long-term care spending has experienced a change in composition with a greater proportion of spending devoted to home and community-based services and a lower proportion for institutional care for persons with mental retardation and developmental disabilities.

- *A number of themes of reform have been advanced over the last several decades.* The principal debate in financing long-term care has focused on the respective roles of the public and private sectors. Because of the diverse socio-economic and disability characteristics of the population in need, one approach to financing reform may not fit all people. Defining the public and private sector roles in financing long-term care for these diverse groups may need to account for their varying needs and financial abilities.

A broad spectrum of proposals have been advanced over the years to change the way long-term care services are financed, ranging from social insurance programs to private sector approaches. While some policymakers are concerned about the cost of new social insurance programs, others are concerned about the affordability of certain private sector solutions, such as long-term care insurance, by moderate and low income persons.

Other subsidiary issues in the reform debate have included proposals to address the costs and quality of care; create more incentives for home and community-based care; assist family caregivers; and encourage individuals and families to plan for the potentially catastrophic costs of care. CRS is currently preparing a report summarizing a broad range of options that Congress might consider in revising the nation's long-term care system.

Long-Term Care: Consumers, Providers, and Spending

The Long-Term Care Population

Long-term care support refers to a range of health and social services needed by persons who lack the capacity for self-care due to physical, cognitive, or mental illnesses that result in functional impairment and dependence on others for an extended period of time. Long-term care services include care in nursing homes and other institutions, as well as in home and community settings. The need for long-term care is measured by a person's inability to carry out basic human functions, or *activities of daily living (ADLs)*, such as bathing, dressing, eating, toileting, transferring from a bed to a chair, and getting around inside the home. Other measures include a person's need for assistance to live independently in the community, such as shopping, meal preparation, and light housework, known as *instrumental activities of daily living (IADLs)*. It is also measured in terms of people needing supervision with performing ADLs or IADLs when they have cognitive impairments, such as dementia. The amount of care needed varies depending upon a person's degree of impairment.

The need for long-term care affects persons with disabilities of all ages — children who are born with disabling conditions, such as mental retardation, or cerebral palsy, and remain disabled the rest of their lives; working age adults with inherited or acquired disabling conditions; and finally, persons aged 65 and older who have chronic conditions or illnesses. While the likelihood of needing long-term care assistance occurs more frequently in older ages, advances in medical care are enabling persons of all ages with disabilities to live longer.

Estimates of the number of persons of all ages who receive long-term care, need assistance with one or more ADLs, and reside at home or in facilities, range from 6.2 million to 8.0 million persons.³ Estimates would be higher if persons who receive assistance with IADLs only are included.⁴ Of all persons receiving assistance with at least one ADL and who reside at home or in nursing homes, about 56% are persons over age 65, and 44% are under age 65.⁵

The vast majority of adults, regardless of age — over 80% — receive care in home and community settings, *not* in nursing homes or other institutions. About 1.8 million adults — less than 20% of all adults receiving assistance — reside in institutions. Only the very old — persons aged 95 and older — have about an equal chance of being cared for in an institution or in the community (**Table 1**).

³ This range is drawn from a variety of sources: the National Nursing Home Survey (1999); the Survey of Income and Program Participation (1997); the National Long-Term Care Survey (1999); the National Health Interview Survey (2002); and the National Medical Expenditure Survey (1996).

⁴ Estimates of the number of persons who receive long-term care vary depending upon the numbers and types of ADL and IADL limitations, whether the person receives human assistance, standby help from another person, and other factors used for measurement.

⁵ CRS estimates based on data from the National Health Interview Survey (NHIS) 2002, and the National Nursing Home Survey (NNHS), 1999.

Table 1. Persons Aged 65 and Older Receiving Long-Term Care Services, 1999
(population in thousands)

Age range	Persons aged 65 or older	Percent receiving long-term care ^a	% Receiving long-term care in the community ^b	% Receiving long-term care in institutions ^c
Total, persons age 65 or older	34,459	5,479 15.9%	3,824 11.1%	1,654 4.8%
Age				
65-69	9,443	5.7%	5.0%	0.7%
70-74	8,785	8.8%	7.2%	1.7%
75-79	7,305	13.6%	10.1%	3.5%
80-84	4,797	24.8%	17.3%	7.4%
85-89	2,601	39.8%	24.8%	15.0%
90-94	1,133	59.8%	33.7%	26.1%
95 years and older	0,396	72.1%	35.7%	36.4%

Source: Unpublished tabulations of the 1999 National Long-Term Care Survey by Brenda C. Spillman. The Urban Institute, 2003.

- Receipt of long-term care is defined as receiving human assistance or standby help with at least one of six ADLs or being unable to perform at least one of eight IADLs without help.
- This does not include about 1.3 million persons with disabilities who use special equipment to manage their disabilities, but do not receive human assistance.
- This includes about 1.5 million persons in nursing homes and slightly more than 150,000 persons in other care facilities.

People residing in institutions have more limitations than people residing at home. However, people receiving long-term care services at home are also highly impaired. Of the 1.6 million people residing in nursing homes with at least one ADL, about 91% were severely impaired with three or more limitations in ADLs (1999). Of 4.2 million persons receiving assistance at home, about 53% had limitations in three or more ADLs (2002). (**Figures 1 and 2 below.**)

Figure 1. LTC Recipients, Age 65 and Older, at Home, by Level of Need

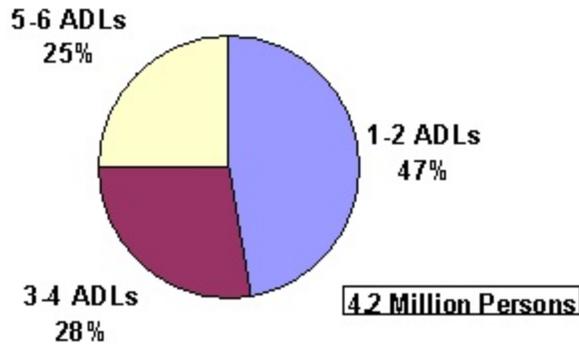
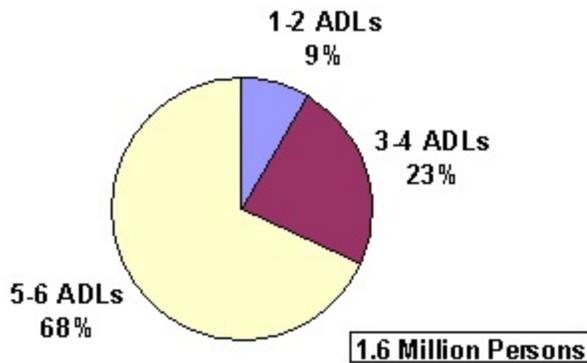


Figure 2. LTC Recipients Age 65 and Older, in Nursing Homes, by Level of Need



Source: CRS computations based on data in B.C. Spillman, *Changes in Elderly Disability Rates and the Implications for Health Care Utilization and Cost*, prepared for Office of Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Feb. 2003. Original source of data: National Long Term Care Survey (1999).

Notes: Includes long term care recipients (5.8 million) with at least one ADL limitation. These individuals may be using equipment or receiving either active or standby help with their ADLs. The population size in these charts differs from estimates presented in Table 1 for two reasons: (1) Table 1 includes persons with IADL limitations and these figures do not; and (2) long term care recipients who use equipment to manage their ADL limitations are included in these figures but not in Table 1.

Providers of Long-Term Care

The primary source of long-term care assistance is informal caregivers — families and friends of people with disabilities who provide assistance without compensation. Two-thirds of the functionally impaired elderly receiving care for impairments with ADLs or IADLs, and about 71% of such persons age 18-64, rely *exclusively* on informal, unpaid assistance (**Table 2**).

Table 2. Type of Care Received by Persons Aged 18 and Over Living in the Community

Persons receiving long-term care assistance in the community	Persons age 65 and older	Persons age 18-64
Total	3.7 million	3.4 million
Percent receiving care from unpaid providers only	66%	71%
Percent receiving paid care only	9%	6%
Percent receiving unpaid and paid care	26%	6%
Unknown	Not applicable	18%

Source: For persons aged 65 and older. National Long-Term Care Survey, 1999; estimates prepared by Brenda Spillman of the Urban Institute cited in *Older Americans 2004, Key Indicators of Well-Being*, Federal Interagency Forum on Aging Related Statistics, 2004. For persons 18-64, 1994 National Health Interview Survey, Disability Supplement. William Spector, et al., *Characteristics of Long-Term Care Users*, Prepared for the Institute of Medicine, 1998. Note: These estimates include persons with limitations in IADLs.

Estimates of the number of caregivers can range from 10-13 million people caring for people with moderate or severe disabilities, and can be many millions more, depending upon the characteristics of the population served and the amount and intensity of care provided. Research has shown that while adults of all ages provide long-term care assistance, people in middle to late middle age are most likely to be caregivers. While women are most likely to be caregivers, both men and women provide care. In addition, caregivers often have competing demands — about one-half are employed and one-third have minor children in the home.⁶

The aging of society will exacerbate demands on family caregivers for people with disabilities of all ages, not only for the elderly. Family caregivers are also vital for people with developmental disabilities. About 60% of the 4.6 million people with mental retardation or developmental disabilities receive care from family caregivers; of these people, more than one in six were living with caregivers over the age of 60. Many people with developmental disabilities are living longer with medical advances and supportive care. Some observers have pointed to a likelihood that people with developmental disabilities could live into their own retirement and outlive their family caregivers.⁷

⁶ Administration on Aging, *National Family Caregiver Resource Guide*, Prepared by The Lewin Group, Inc., Washington, D.C., Aug. 2002.

⁷ David Braddock, Richard Hemp and Mary Rizzolo, *State of the States in Developmental Disabilities: 2004. Mental Retardation*, vol. 42, no. 5, pp. 356-370 and Mary C. Rizzolo, et al., *The State of the State in* (continued...)

In addition to the enormous amount of informal care provided by families and friends, the long-term care services system includes thousands of formal care providers. They range from institutional providers, including nursing homes and residential care facilities for people with mental retardation and developmental disabilities, to a variety of agencies and programs that provide a wide array of home and community-based services. These services include home health care, personal care, homemaker and chore assistance, adult day care services, home-delivered meals, transportation, and many others. In addition, assisted living facilities, adult foster care homes and other group homes provide both room and board as well as personal care and other assistance to people who have lost the capacity to live independently in their own homes.

Utilization and supply of the various formal care providers is of concern to policymakers because these factors affect both cost and quality of care. The supply of nursing home beds varies widely among states as do the numbers and types of home and community-based providers. The average number of nursing home beds in the U.S. is 49 beds per 1,000 people aged 65 and older; but the number of beds per state ranges from 73 beds per 1,000 elderly people in Louisiana to 21 beds in Nevada. Similarly, the range in supply of personal and home care aides varies widely, from 45 aides per 1,000 elderly people in Texas to three aides per 1,000 elderly people in Mississippi, with a national average of 14 aides per 1,000 elderly people.⁸

Researchers predict that the increased numbers of people reaching age 65 as well as their increasing longevity will affect future demand for formal providers. One study predicts that 44% of those people who turned age 65 in 2000, will enter a nursing home during their remaining lifetimes. Almost one-third will have nursing home stays of three months or longer, and almost one-fourth will have stays of one year or longer. This same study predicts that the number of people age 65 years old who will have any nursing home use will more than double from 2000 to 2020 (from 891,000 to 1.8 million people) (**Table 3**). Policymakers may want to assess the utilization and supply issues affecting nursing facilities to determine whether other care modalities, such as greater supply of home care, assisted living and other residential care settings, may substitute for nursing home care for some people.

⁷ (...continued)

Developmental Disabilities, 2004. In the 1970s, the mean age of death for people with mental retardation was 56 years; in 1993, it was 66 years.

⁸ Mary Jo Gibson et al., AARP, *Across the States, Profiles of Long-Term Care, 2004*.

Table 3. Probability of Nursing Home Use at Age 65 for Various Years

Category of nursing home use	Persons turning age 65 in 2000		Persons turning age 65 in 2010		Persons turning age 65 in 2020	
	Number (thousands)	%	Number (thousands)	%	Number (thousands)	%
Category of use	2,013		2,625		3,922	
Any use	891	44	1,185	45	1,807	46
Three months or longer	651	32	873	33	1,344	34
One year or longer	469	23	632	24	977	25
Five years or longer	169	8	232	9	363	9
Timing of use						
Use in last year of life	793	39	1,057	40	1,618	41
Use only prior to last year of life	98	5	127	5	190	5

Source: Brenda C. Spillway and James Lubitz, "New Estimates of Lifetime Nursing Home Use: Have Patterns Changed?," *Medical Care*, vol. 40, no. 10, 2002.

Cost of Care. The cost of long-term care is related to the type, intensity, and duration of services needed by individuals, as well as the availability of informal assistance from family and friends. At one end of the spectrum, costs for 24-hour care in nursing homes can range from \$60,000-\$70,000 per year,⁹ and even higher in institutions for persons with developmental disabilities where costs can exceed \$100,000 per person. At the other end, the cost of providing home-delivered meals to a frail older person living at home may be quite modest.

Researchers and policymakers have long debated whether expanded access to home and community-based care for the nation's long-term care population is less costly than institutional care. This question is very complex and many factors must be considered, including how best to target home and community-based services and serve only those who would have entered a nursing home without the availability of expanded home care; what is the most effective mix of services to divert persons from institutional care; and how to assist informal caregivers who often make a difference in keeping their family members from entering an institution.

Long-Term Care Spending

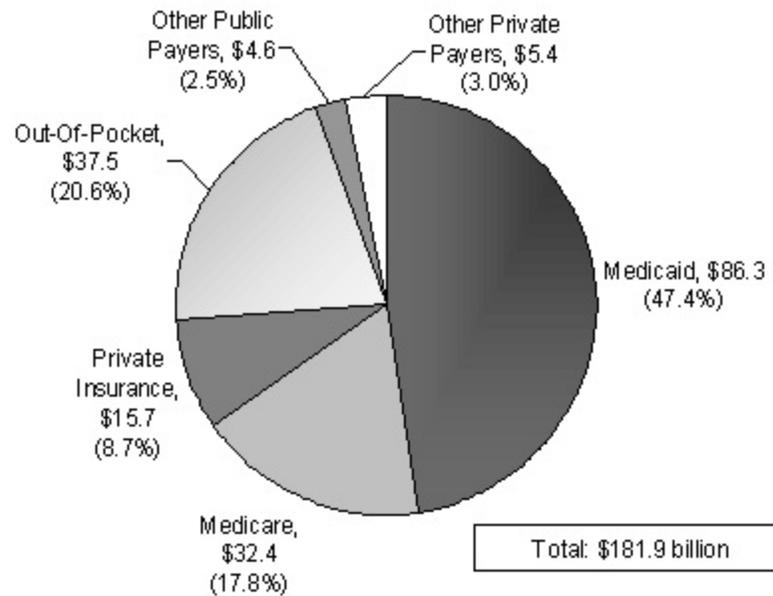
A variety of public and private sources finance long-term care. Many federal programs assist persons needing long-term care services, either directly or indirectly through a range of health and social services, through cash assistance, and through tax benefits. While Medicaid is the primary source of public financing for long-term care, other programs, including Medicare, and social service programs, such as the Older Americans Act, provide assistance to persons who need long-term supports. No one program, however, is designed to support the full range of long-term care services

⁹ *The MetLife Market Survey of Nursing Home and Home Care Costs*, Sept. 2004. The average yearly rate for a private room in a nursing home was \$70,080 and for a semi-private room was \$61,685.

needed by people with disabilities of all ages. Eligibility requirements, benefits, and reimbursement policies differ among major programs.

Of the \$1.44 trillion spent on all U.S. personal health care services in 2003, \$181.9 billion, or about 12.6%, was spent on long-term care (**Figure 3**). This amount includes spending on services in institutions (nursing homes and intermediate care facilities for individuals with mental retardation (ICFs/MR)), and a wide range of home and community-based services, such as home health care services, personal care services, and adult day care, among others. **Figure 3** (below) does not take into account the economic value of care provided to individuals with long-term care needs by uncompensated informal care providers.

Figure 4. Long-Term Care Expenditures, by Payer, CY2003
(expenditures in billions)



Source: CRS analysis of National Health Expenditure Data, Centers for Medicare and Medicaid Services (CMS). Also includes unpublished data from CMS, National Health Statistics Group on Medicaid and Medicare expenditures for hospital-based nursing home and home health providers and data for the Medicaid 1915(c) home and community-based waivers. Does not include spending for hospital-based nursing home and home health for other payers.

Most public long-term care spending comes from the Medicaid program (a means-tested program jointly funded by federal and state governments). In CY2003, Medicaid spending accounted for 47.4% of all long-term care spending, or \$86.3 billion. After Medicaid, private out-of-pocket spending is the next highest source of financing for long-term care, accounting for 20.6% of all long-term care spending, or \$37.5 billion. Medicare plays a somewhat smaller role accounting for 17.8%, or \$32.4 billion, of the total. Private insurance accounts for about 8.7% of spending, or \$15.7 billion.

Medicaid's Role in Long-Term Care

At the center of the debate on long-term care financing is the Medicaid program. Medicaid, by default, has become the nation's primary source of public financing for persons who need long-term care support. Medicaid coverage of long-term care is intended to serve as a safety net for persons who cannot afford the cost of institutional care or home and community-based services. People turn to Medicaid when they have no more than \$2,000 in countable assets (excluding the person's home and certain other exempted assets). Generally, if they are not eligible for cash assistance under the Supplemental Security Income (SSI) program, they must apply most of their income to the cost of their care.

Financing of institutional care has dominated Medicaid long-term care spending for decades. However, in recent years, state Medicaid programs have played an increasingly larger role in financing home and community-based services.

Nursing Homes. In 1965, with the enactment of Medicaid, Congress created an entitlement to skilled nursing facility care. The Social Security Amendments of 1965 that created Medicaid required states to cover skilled nursing facility services and gave nursing home care the same level of priority as hospital and physician and other services.

These early legislative developments were the basis for the beginnings of the modern day nursing home industry. Significant growth in the number of nursing homes occurred during the 1960s—from 1960 to 1970 the number of homes more than doubled, from 9,582 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than one million.¹⁰ (In 2004, there were about 16,000 nursing homes with 1.6 million beds.¹¹)

Intermediate Care Facilities for Persons with Mental Retardation. The early history of services to persons with mental retardation and developmental disabilities is characterized by the development of large state-financed institutions some of which were established during the latter part of the 19th century and continuing through the first part of the 20th century. In 1967, the number of residents in institutions peaked to almost 200,000 nationwide in 165 state-operated facilities.¹²

The Social Security Amendments of 1965, which created the Medicaid program, required states to provide skilled nursing facility services under their state Medicaid plans, and gave nursing home care the same level of priority as hospital and physician services.

"Section 1902 (a) A State plan for medical assistance must provide for inclusion of some institutional and some noninstitutional care and services, and, effective July 1, 1967, provide (A) for inclusion of at least ... (1) inpatient hospital services ...; (2) outpatient hospital services; (3) other laboratory and X-ray services; (4) skilled nursing home services (other than services in an institution for tuberculosis or mental diseases) for individuals 21 years of age or older; (5) physicians' services" PL. 89-97, July 30, 1965.

¹⁰ U.S. Congress, Senate Special Committee on Aging, *Developments in Aging, 1970*, S.Rept. 92-46, Feb. 16, 1970, Washington, D.C. Cited from the *American Nursing Home Association Fact Book, 1969-1970*.

¹¹ Centers for Medicare and Medicaid Services (CMS), OSCAR, cited by American Health Care Association. [<http://www.acha.org/research>]. Data are for Dec. 2004.

¹² David Braddock, et al., *The State of the States in Developmental Disabilities*, University of Illinois at Chicago, American Association of Mental Retardation, Washington, 1998.

In 1971, federal financing for intermediate care facilities for the mentally retarded (ICFs/MR) was authorized under the Medicaid program; states that were able to meet the federal requirements governing care for persons with mental retardation in ICFs/MR shifted their state-financed facilities to the Medicaid program. Although care in ICFs/MR facilities is not a required service under state Medicaid plans, all states cover this care. Today, although some states are still faced with the legacy of large institutions, a major change has occurred toward care for persons with developmental disabilities in smaller, community-based residences as well as home-based services financed by Medicaid.

Home and Community-Based Services. Medicaid supports a range of home and community-based long-term care services, including home health care, personal care services, and a range of supportive services under the Medicaid Section 1915(c) waiver program. The latter program has become the centerpiece of home and community-based services policies for certain persons with disabilities, especially persons with mental retardation and developmental disabilities, in most states. About 840,000 persons were served under this program in 2001. Under Section 1915(c) waivers, the most frequently provided services are personal care assistance and other home care services, habilitation,¹³ adult day care, case management, and respite services for caregivers.

Section 1915(c) allows the Secretary of the Department of Health and Human Services (DHHS) to waive certain statutory requirements to assist states in financing care at home and in other community-based settings for persons who, without these services, would be in an institution. States may waive the following Medicaid requirements: (1) statewide — states may cover services in only a portion of the state, rather than in all geographic jurisdictions; and (2) comparability of services — states may cover state-selected groups of persons, rather than all persons otherwise eligible. In addition to waiving these requirements, states may use more liberal income requirements than would ordinarily apply to persons living in the community.

Federal law requires that persons eligible for home and community-based waiver services meet the level of care requirements (as defined by each state) provided in a hospital, nursing facility or ICF/ME. Level of care requirements describe the level and/or severity of functional limitations that individuals must have in order to be admitted to an institutional setting.

In implementing home and community-based waiver programs, States are constrained by a *budget neutrality test* in defining services they wish to cover. The law requires that the Secretary may not approve a waiver unless the average per capita expenditures for individuals provided waiver services do not exceed the average per capita expenditures that would have been paid if individuals had received Medicaid-supported institutional care. The Section 1915(c) waiver program has been particularly attractive to states because they have been able to control costs by limiting the number of waiver recipients and employing a variety of cost-management techniques, including fixed budgets, care management, and cost caps.

¹³ Habilitation refers to services to assist individuals in developing skills necessary to reside successfully in home and community-based settings. It includes such activities as prevocational, educational, and supported employment.

Medicaid Long-Term Care Spending

Medicaid is the dominant payer of long-term care services in this country paying for nearly one-half of all long-term care expenditures. Of *total* Medicaid spending — \$269 billion in FY2003 — more than one-third was spent on long-term care.

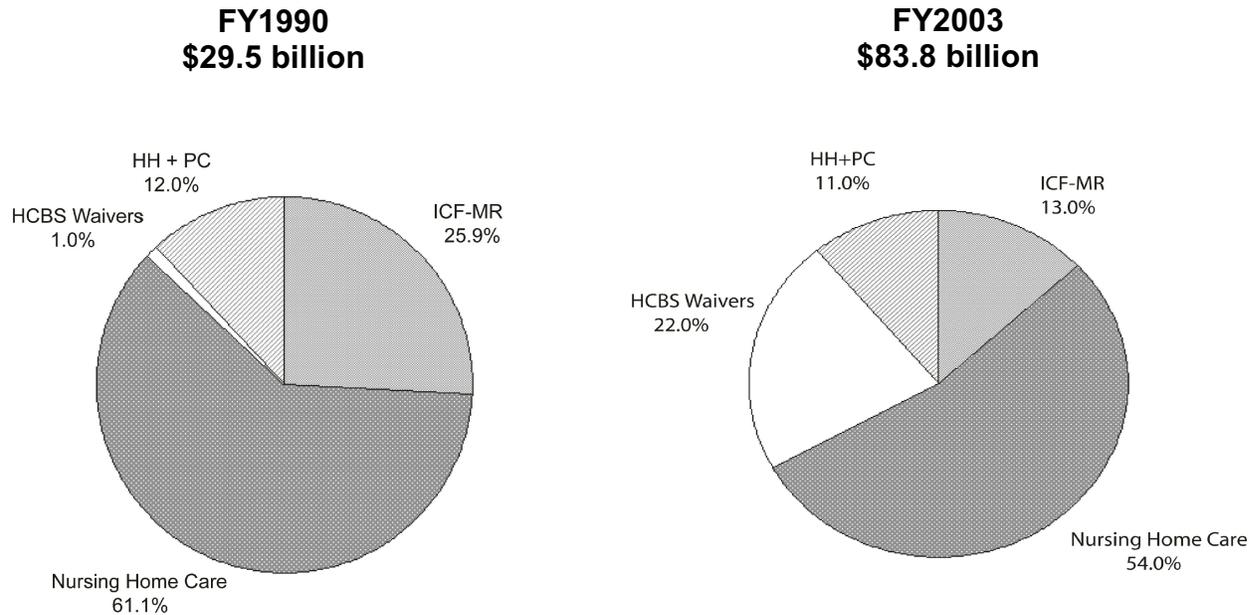
Of total Medicaid long-term care spending — \$83.8 billion in FY2003:

- 67% was spent on institutional care (nursing homes and ICFs/MR); and
- 33% was spent on home and community-based services (home health, personal care and home and community-based waiver services).

From 1990 through 2003,¹⁴ Medicaid long-term care expenditures grew at an annual average rate of 8% per year. Institutional spending grew at an annual average rate of growth of 6%. States' efforts to focus on home and community-based services has resulted in a higher rate of growth for these services, growing at an average of 17% per year. Expenditures for the Section 1915(c) waiver program in particular grew at an average annual rate of 25%, and reached almost \$18 billion in FY2003. This increase has been a result of states' effort to contain the rate of growth in their nursing home expenditures and to provide expanded access to home and community-based services to persons with disabilities in order to respond to their preferences for this modality of care.

For many years, spending for institutional care has dominated Medicaid long-term care spending. However, over the last 15 years, Medicaid spending for long-term care has experienced a change in composition. In FY1990, 87% of long-term care spending was devoted to institutional care, declining to 67% by FY2003. In FY1990, about 13% of Medicaid long-term care spending was for home and community-based care, increasing to about 33% by FY2003, primarily as a result of increased spending under the Section 1915(c) waiver program. (**Figure 4**). This waiver program has been a significant source of support to care for persons with mental retardation and developmental disabilities. In FY2003, about three-quarters of waiver spending was for this population; the balance was spent on diverse groups of persons with disabilities, including the elderly and persons with physical disabilities. Despite the growth in home and community-based waiver services, many of these home and community-based waiver programs have been unable to meet the demand for services and maintain waiting lists.

¹⁴ Growth rates shown have been calculated on a calendar year basis.

Figure 4. The Changing Face of Medicaid Long-Term Care Spending

Source: Congressional Research Service (CRS) analysis of data and estimated expenditures from CMS-Form 64. HH+PC refer to home health and personal care services.

Long-Term Care: Themes of Reform

Despite enormous spending on long-term care services, the nation lacks a comprehensive policy on financing of long-term care. Options to change the way long-term care is financed and delivered have been considered by Congress for over 35 years. The complexity of financing and delivering these services to diverse groups of persons with disabilities in a variety of care settings through multiple federal programs has been a challenge to federal and state governments.

Even after significant federal policy review on ways to improve the long-term care financing and delivery over the last two decades, Congress has not reached consensus of what road to take. The last time Congress made a systemic change in federal long-term care policy was in 1981 when it created the Medicaid Section 1915(c) home and community-based waiver program for persons with disabilities. In 1996, Congress clarified the tax treatment of long-term care insurance and allowed taxpayers who itemize a limited deduction for premiums. Other changes have included changes in Medicaid eligibility rules for long-term care services when in 1988, Congress provided financial protections for spouses of persons needing nursing home care and other Medicaid services, and again in 1993 when Congress tightened rules on transfer of assets. In 2000, Congress recognized the needs of caregivers by authorizing a caregiver support program under the Older Americans Act. That same year, Congress established a voluntary long-term care insurance program for federal employees, retirees, and family members. The last time that Congress comprehensively reviewed policy options for long-term care reform was in 1990 under the U.S. Bipartisan Commission on Comprehensive Health Care (known as the Pepper Commission).

Literally dozens of proposals have been considered and debated. For the past two decades, the principal debate in financing long-term care reform has focused on the respective roles of the public and private sectors. Proposals that have been debated are arrayed on a spectrum. On one end, are proposals for new social insurance programs that would expand or replace current programs, perhaps relying on payments from individuals through cost-sharing, premiums and deductibles, rather than means-testing and spend-down requirements under Medicaid. At the other, are proposals that rely on private sector financing, such as long-term care insurance, with the rationale that the nation cannot afford the additional tax burden of another entitlement program.

Other subsidiary issues in the reform debate have included proposals to address the costs and quality of care; create more incentives for home and community-based care; assist family caregivers; and encourage individuals and families to plan for the potentially catastrophic costs of care.

The following presents broad themes of proposals that have been advanced.

Insurance Options. Many believe that the need for long-term care is an insurable event where risk of needing services is not effectively spread across the population through pooled risk. Proposals for expanding insurance for long-term care, either on a mandatory or voluntary basis, have been considered in the past. For example, the Pepper Commission took the stand that long-term care should be treated as an insurance event whose risk can be spread through both public and private coverage.¹⁵ In 2001, Citizens for Long-Term Care, a coalition of over 60 national organizations representing major national associations of long-term care providers, insurers, and advocacy groups also came to this conclusion.¹⁶

Some people believe that a social insurance approach is necessary to assure universal coverage (at least for a defined target population) since many persons with disabilities will not be able to afford private coverage. Such a program would have to be designed to assure affordability for both the public sector as well as individual participants. Others believe that costs of a new or expanded social insurance program would be prohibitive. Some proposals have suggested government-sponsored voluntary insurance programs. Such approaches could be designed to attract persons in middle ages or younger who want to plan for future long-term care costs, but may not attract sufficient numbers of persons to create an insurance pool. Also, voluntary programs may have to be designed to encourage participation by persons at the lowest economic scale.

Options to create incentives for individuals to purchase private long-term care insurance have been proposed frequently. The number of policies sold has increased in recent years with over 9 million policies sold from the inception of the market through the end of 2002.¹⁷ The market grew at an average of 18% each year from 1987 to 2002.¹⁸ For some people, insurance is a viable option and can assist them in paying for catastrophic long-term care expenses. However, policies can be expensive for purchase by low and moderate income persons.

¹⁵ U.S. Bipartisan Commission on Comprehensive Health Care, The Pepper Commission, *A Call to Action*. Final Report, 1990, Washington, D.C., p. 119.

¹⁶ Citizens for Long Term Care, *Defining Common Ground, Long Term Care Financing Reform in 2001*, Feb. 2001, Washington. D.C., p. 3.

¹⁷ This number does not include the number of policies dropped, canceled, or lapsed.

¹⁸ American Health Insurance Plans, *Long-Term Care Insurance in 2002*, June 2004., Washington, D.C.

Another possible means of providing access through an insurance approach might be to extend Medicaid coverage for people who have higher income or more assets than current Medicaid tests allow, and then requiring them to pay premiums and cost-sharing (as is the case in certain Medicaid state optional programs, such as for working disabled under the Ticket To Work program). Depending upon how it is structured, such an approach could assist persons with catastrophic costs according to their ability to pay. However, policymakers may be more concerned about containing, rather than expanding, long-term care benefits.

Shared Public and Private Options. Some observers argue that the complexity of long-term care financing for diverse groups of individuals with disabilities — children and working age persons with disabilities, as well as the elderly, with differing types and severity of impairments — necessitates a multi-pronged strategy of financing and delivery reform. Because of the diverse socio-economic and disability characteristics of the population in need, one approach to financing reform may not fit all people. Defining the public and private sector roles in financing long-term care for these groups would need to account for their varying needs and financial abilities.

Approaches might combine some aspects of incentives for private financing as well as public financing. Strategies that would promote both private insurance for those who could afford premiums, as well those that would preserve safety net programs for those who cannot afford catastrophic expenses or private financing solutions, might be sought.

Policymakers will have to evaluate the proposals in light of a number of dimensions. This would include their potential budgetary impact, including their potential to increase total costs, to decrease an otherwise expected rate of increase in costs in one sector of care (for example, by substituting less costly per beneficiary services for more costly services), or across multiple programs, or within an individual program. Other dimensions might include the proposals' potential effect on aspects of service delivery goals, such as assisting persons to reside in community settings rather than in institutions, and assisting informal caregivers to continue their support for family members.

Rebalancing Institutional and Home and Community-Based Services Options.

Over the last three decades, a constellation of proposals have been made to level the playing field so that home and community-based services receive the same priority as institutional services under Medicaid. A factor sharpening recent federal and state policy attention on home and community-based care are legal actions that have taken place in states as a result of the 1999 Supreme Court decision, *Olmstead v. L.C.* (528 U.S. 581). In this decision, the Court stipulated that, under certain circumstances, institutionalization of persons who could live in community settings, and desire to do so, violates the Americans with Disabilities Act (ADA) (see box).

Many people refer to Medicaid as having an “institutional bias” since nursing home care is an entitlement for persons who can meet eligibility

Olmstead v. L.C. In its decision, the Supreme Court stipulated that, under certain circumstances, institutionalization of persons who could live in community settings, and desire to do so, violates the Americans with Disabilities Act (ADA). In the case, physicians had determined that two patients living in a state psychiatric hospital in Georgia were able to live in community settings. When the state refused to transfer them to a less restrictive setting, the patients brought suit under the ADA. The Court ruled that the state had violated Title II of ADA which prohibits “unjustified isolation” and that it was discriminatory to force someone to remain in an institutional setting when (1) treatment professionals determine that a community setting is appropriate; (2) the individuals do not oppose the placement; and (3) the placement can be reasonably accommodated, taking into consideration the resources of the state and needs of other persons with disabilities.

tests, but the Section 1915(c) waiver program, the primary source of financing home and community-based services, is not. Numerous proposals have been made to reformulate the Section 1915(c) home and community-based services waiver program (e.g., by eliminating its “wavier” nature and changing certain eligibility features) and to expand personal care services. Some believe that such approaches would give this type of care the same priority as institutional care. Others are concerned that if such programs were expanded without controls on numbers of persons to be served, costs would increase.

Such approaches would have to be evaluated in terms of total cost. Nevertheless, some state administrators have maintained that it is possible to control the rate of increase in long-term care costs that would have occurred by instituting systemic reform that includes (1) controlling access to institutional care and limiting its supply; (2) expanding home and community-based care for those who otherwise need institutional care; (3) and balancing consumer choice with appropriate cost controls.

Policy Questions

The answers to a number of policy questions will influence the future direction of federal policy:

- Given expected demographic changes as a result of population aging, and expected escalating public spending for long-term care, what should be the respective roles for the public and private sector?
- Should any revised public long-term care strategy be universally available to a specific group of people, or should it be targeted on the basis of income and/or disability? If it is available on the basis of income, how should income and assets should be considered?
- What is the best way to provide individuals with incentives to save personal funds for long-term care and/or purchase insurance to protect themselves from high out of pocket expenses for long-term care?
- How can individuals and families be encouraged to plan for long-term care expenses as part of planning for a secure retirement?
- Can federal policies be changed to better best assist family members and other informal caregivers who already provide most long-term care support?
- Can federal policies be changed to address access issues for services for those who do not have family caregivers?
- To what extent do public programs need to be balanced to support increased home and community-based services? How can we assure that all modalities of care meet quality measures?

As it considers these questions, Congress might continue making incremental policy changes like those of the past two decades. On the other hand, many believe that incremental changes may not be sufficient to prepare for future needs and that larger scale reform may be necessary.