

An hourglass-shaped graphic with a globe in the top bulb and another globe in the bottom bulb. The hourglass is light blue and has a dark blue top cap. The globe in the top bulb is dark blue, and the globe in the bottom bulb is light blue. The text is centered within the hourglass.

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*Long-Term Care Chart Book: Persons Served, Payers and
Spending*

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Abstract. This report provides the latest spending data, taken from the Long-Term Care Chart Book: Persons Served, Payers, and Spending.

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Long-Term Care Chart Book: Persons Served, Payors and Spending

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Summary

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness or frailty. The need for long-term care is projected to grow substantially in the future as a result of the increasing elderly population. In 2001, spending for long-term care services for persons of all ages represented 12.2% of all personal health care spending (\$151.2 billion of \$1.24 trillion). Congress may address a number of issues related to long-term care over the next several years, including issues related to assistance to caregivers, possible expansion of home and community-based care, and financing of services.

To provide background on long-term care, in May 2000 the Congressional Research Service (CRS), in collaboration with The Urban Institute, prepared the *Long-Term Care Chart Book: Persons Served, Payors, and Spending*. The Chart Book presents selected background information on persons receiving long-term care assistance, providers of care, and financing sources using the latest data available as of May 2000. While some of the data are not the most recent, the trends are long-term and the information is helpful in understanding the dimensions of the problem. (This report presents the latest spending data.) Congressional requesters may now access the *Long-Term Care Chart Book* at [<http://www.congress.gov/crsp/lsd/00.122.doc.pdf>]. The Chart Book was funded in part through a grant from the Retirement Research Foundation.

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness or frailty. Experts predict that in the coming decades long-term care services will be in greater demand due to increased numbers of older persons, especially those in the oldest age categories. However, the need for long-term care assistance affects persons of all ages, not just older persons. Advances in medical care are enabling persons of all ages with disabilities to live longer.

Congress may be increasingly called upon to address many unresolved issues related to long-term care. These issues may include (1) whether to offer more assistance to families and other unpaid caregivers, who provide the bulk of long-term care assistance

to persons with disabilities; (2) whether to expand home and community-based services (which most people with disabilities prefer over institutional care); and (3) how to combine public and private sources of financing for long-term care in ways that are effective and equitable.

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The following presents a brief overview of key points addressed by the Chart Book.

How is Long-Term Care Measured?

The need for long-term care is measured by assessing a person's need for assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs).

- **ADLs** are activities necessary to carry out basic human functions, and include the following: bathing, dressing, eating, getting around inside the home, toileting, and transferring from a bed to a chair.
- **IADLs** are tasks necessary for independent community living, and include the following: shopping, light housework, telephoning, money management, and meal preparation. IADLs are sometimes used to measure a person's need for assistance as a result of mental or cognitive disabilities.

How Many Persons Receive Long-Term Care Assistance?

About nine million persons over age 18 receive long-term care assistance, either in community settings or in nursing homes. Over 80% of adults who receive long-term care assistance reside in the community, not in institutions. In addition, about 459,000 children living in the community have difficulty performing some ADLs.

The likelihood of receiving long-term care assistance increases dramatically with age. However, while use of nursing home care occurs more frequently as a person ages, most people receive long-term care assistance in community settings rather than in nursing homes, even those 85 and older.

Who Provides Long-Term Care Services?

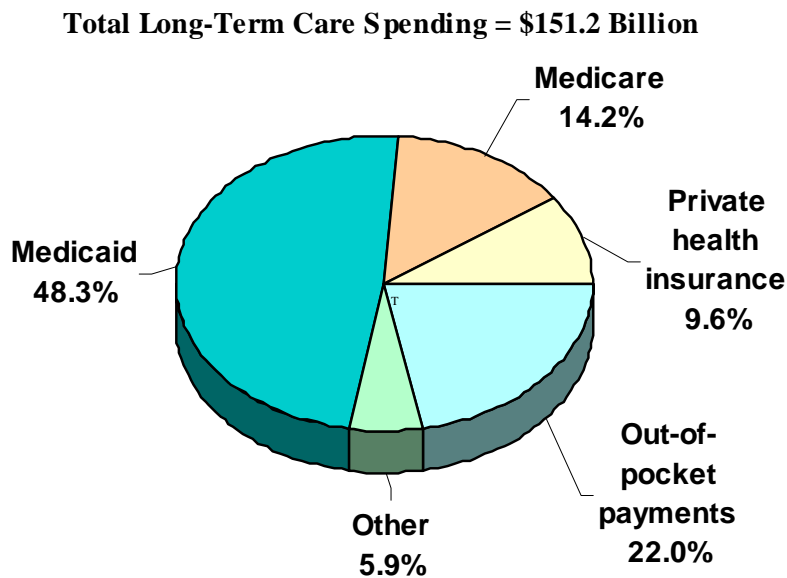
Family and friends, that is, unpaid caregivers, are the major providers of long-term care. Nearly three-quarters of persons age 18-64 receiving long-term care assistance in the community rely exclusively on unpaid caregivers. Only 6% rely exclusively on paid services. Similarly, almost 60% of elderly persons receiving long-term care assistance

rely exclusively on unpaid caregivers, primarily spouses and children. Only 7% rely exclusively on paid services.

How Much is Spent on Long-Term Care?¹

Of the \$1.24 trillion spent on all U.S. personal health care services in 2001, \$151.2 billion, or about 12.2%, was spent on long-term care. This amount includes spending for institutional care (nursing homes and intermediate care facilities for the mentally retarded (ICFs/MR)), and a wide range of home and community-based services, such as home health services, personal care services, adult day care, among others.

Figure 1. Sources of Long-Term Care Spending, 2001



Source: Chart prepared by CRS based on data from Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group.

What Role does Medicaid Play in Financing Long-Term Care?

Long-term care is chiefly financed through the federal-state Medicaid program. Of all U.S. long-term care spending in 2001, the Medicaid program financed 48.3%, or \$73.1 billion (**Figure 1**). Most of this spending – 64.3% – was for institutional care (care in nursing facilities and ICFs/MR). The balance was spent on home and community-based services.

Many observers have noted that Medicaid's eligibility and benefit structure has created a bias toward providing care in institutions. In order to correct this bias, in 1981 Congress created new authority for expansion of home and community-based services under the Medicaid program. The program, known as the Medicaid home and

¹ This section of this report has been updated to present the most recent data from 2001.

community-based waiver program (authorized under Section 1915(c) of the statute) 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 institutions.² A wide range of services may be provided to persons with disabilities of all ages, including case management, respite services for caregivers, habilitation,³ and personal care services. Spending for the Section 1915(c) waiver program has increased rapidly since FY1990, reaching \$14.5 billion in FY2001.

How Much is Spent for Long-Term Care Services by Individuals and Families Out-of-Pocket?

After Medicaid, private out-of-pocket spending is the next primary source of funding for long-term care. In 2001, out-of-pocket spending for long-term care was \$33.2 billion, representing 22% of all U. S. spending on long-term care (**Figure 1**). Most out-of-pocket long-term care spending was for nursing home care – 81% of the \$33.2 billion total.

What Role Does Medicare Play in Financing Long-Term Care?

Medicare spent \$21.5 billion on skilled nursing facility care and home health services in 2001, representing 14.2% of all U.S. spending on long-term care. Although the Medicare program covers skilled nursing home and home health care services, it is not intended to be a primary funding source for long-term care. Its role is limited to financing care in skilled nursing facilities (up to 100 days after a hospitalization for persons who need continued skilled care), and home health services for persons who need skilled nursing care on a part-time or intermittent basis, or physical or speech therapies.

Of the \$21.5 billion Medicare spent on long-term care in 2001, about 54% was for skilled nursing facility care, and the balance was for home health care.

What Other Federal Programs Support Long-Term Care Services?

A variety of other federal programs support long-term care services; however, funding is limited compared to spending by the Medicaid program. Primarily these are the Older Americans Act and the Social Services Block Grant Program (SSBG) (Title XX of the Social Security Act), both of which fund a variety of home and community-based

² States may waive the following Medicaid requirements: (1) statewideness – states may cover services in only a portion of the state, rather than in all geographic jurisdictions; (2) comparability of services – states may cover state-selected groups of persons, rather than all persons otherwise eligible; and (3) financial eligibility requirements – states may use more liberal income requirements for persons needing home and community-based waiver services than would otherwise apply to persons living in the community. For further information, see CRS Report RL31163, *Long-Term Care: A Profile of Medicaid 1915(c) Home and Community-based Services Waivers*, by Carol O'Shaughnessy and Rachel Kelly.

³ 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.

services. In 2001, the Older Americans Act was amended to authorize the National Family Caregiver Support program which offers assistance to family caregivers of the frail elderly.

Many states supplement the federal Supplemental Security Income (SSI) cash welfare payments to low income elderly and disabled persons to enable them to pay for home and community-based services, or to reside in non-medical residential services, such as board and care homes. Certain programs authorized under the Rehabilitation Act of 1973 provide a range of supportive services to persons with disabilities. The Department of Veterans Affairs (DVA) provides a wide range of long-term care services to the Nation's veterans, including nursing home, domiciliary, home health care, and assistance to caregivers. Tax benefits for long-term care include a limited deduction for long-term care expenses and insurance premiums, tax-exempt insurance benefits, and the dependent care tax credit.

What Role does Private Long-term Care Insurance Play in Financing Long-Term Care?

The private long-term care insurance market has grown substantially over the last decade. Growth in the number of policies purchased averaged about 18% per year between 1987-2001, reaching more than 700 thousand policies sold by 37 companies in 2001. Spending by private health insurers for long-term care totaled \$14.5 billion in 2001, representing 9.6% of all U.S. spending on long-term care. Of the amount financed through private insurance, 52% was for nursing home care with the balance for home health care.

Data Sources

Data for the Chart Book was culled from a wide range of surveys and special studies. *Appendix A* presents sources and explanatory notes to accompany each section of the chart book. Data on persons receiving care was drawn primarily from the 1994 National Health Interview Survey (NHIS) Disability Supplement and the 1994 National Long-Term Care Survey (NLTC), and the Medical Expenditure Panel Survey (MEPS).⁴ Data on long-term care expenditures was drawn primarily from the Office of the Actuary, Centers for Medicare and Medicaid Management, (formerly the Health Care Financing Administration). Projections of future expenditures for long-term care were drawn from special analyses by The Lewin Group for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE).

⁴ As presented in William D. Spector, et. al. *The Characteristics of Long-Term Users*. Paper commissioned by the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.