



# *Long-Term Care:*

CONSUMERS,  
PROVIDERS,  
AND FINANCING  
**A CHART BOOK**

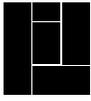


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## *Long-Term Care:*

Dear Reader:

Long-term care affects people of all ages. It refers to a wide range of supportive and health services for those who are too ill or frail to care for themselves. The importance of long-term care services to the public is growing for two major reasons. First, advances in medical care are enabling those with disabilities who receive long-term care services to live longer. Second, in coming decades long-term care services will be in greater demand due to the growing population of older people, especially those in the oldest age categories.

Over the next several years, Congress may be called upon to address many unresolved long-term care issues such as:

- whether to offer more assistance to families and other unpaid caregivers, who provide the bulk of long-term care assistance to people with disabilities;
- whether to expand home and community-based services—the type of care that people with disabilities tend to prefer over institutional care; and
- how to combine public and private sources of financing for long-term care in ways that are effective, equitable, and economical.

To give Congress the background information necessary to address some of these issues, the Congressional Research Service (CRS) contracted with the Urban Institute to prepare, in collaboration with CRS, a chart book on long-term care. The CRS report to Congress, *Long-Term Care Chart Book: Persons Served, Payors, and Spending*, by Carol O'Shaughnessy, Rachel Kelly, Gary Sidor, Susan Goldenson, Jessica Kasten, and me, was completed in May 2000.

This chart book is adapted from that report, and provides for the first time to the general public recent and relevant federal and state data on long-term care consumers—children, people with mental retardation or developmental disabilities, adults and older adults—paid and unpaid providers, and public and private financing. As public debate over long-term care policy unfolds, this chart book offers a comprehensive and easy to understand guide to the demographic and financial landscape of long-term care services. We hope you find it useful.

Sincerely,

Jane Tilly, Dr. P.H.  
Urban Institute  
March 2001

## ACKNOWLEDGMENTS

Urban Institute authors would like to acknowledge and thank CRS colleagues who co-authored the chart book for Congress, specifically Carol O'Shaughnessy, Rachel Kelly, and Gary Sidor.

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This chart book was produced by the Urban Institute's Office of Public Affairs with generous support from Aetna Inc., a Fortune 50 company that provides more than 45 million people worldwide with quality products, services, and information. Aetna is the leading health and related benefits organization, with 19.4 million health members, 14.6 million dental members, and 11.5 million group insurance members, including long-term care. Information about Aetna Inc. is available at [www.aetna.com](http://www.aetna.com).

*\*formerly of DHHS*

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## DATA SOURCES

Data for the chart book have been culled from a wide range of surveys and special studies. Data on persons receiving care were 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).\*

Data on long-term care expenditures were drawn primarily from the Office of the Actuary, HCFA, and special analyses. The Lewin Group drew projections of future expenditures for long-term care from special analyses for the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE).

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\*As presented in W.D. Spector, et. al., *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.



# Long-Term Care:

## OVERVIEW

The need for long-term care assistance affects people of all ages, not just elderly populations. Accordingly, this chart book provides relevant information on long-term care assistance for *all* people with disabilities, using a variety of state and federal data sources. Using this chart book, policymakers, researchers, advocates, and practitioners will be able to understand the scope of the long-term care system.

Information is organized into three major categories: consumers, providers, and financing.

### CONSUMERS

Children and adults with disabilities all use long-term care services and are profiled in this chart book. Consumer profiles are organized by age of children, presence of mental retardation or developmental disability, age of adults. The chart book pays special attention to the aging population due to its growing impact on the demand for long-term care services.

### PROVIDERS

Consumers receive long-term care services through a variety of community-based and institutional care providers. This chart book profiles services delivered by family and friends, or unpaid caregivers, as well as services delivered by paid home health care providers, adult day services programs, nursing homes, and assisted living facilities.

### FINANCING

Sources of public and private spending on long-term care services include out-of-pocket spending and a variety of state and federal programs. This chart book specifically illustrates spending through Medicare, Medicaid and its waiver program for home- and community-based services, and private long-term care insurance.

## HELPFUL DEFINITIONS

**Activities of Daily Living, or ADLs**, are activities necessary to carry out basic human functions, such as bathing, dressing, eating, getting around inside the home, toileting, and transferring from a bed to a chair.

**Instrumental Activities of Daily Living, or IADLs**, are tasks necessary for independent community living, including 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.

**Mental Retardation (MR)** refers to low intellectual functioning and significant limitation in adaptive skills (such as communication, self-care, direction, home and community living, social skills, health and safety, and functional activities), which is present from childhood.

**Developmental Disabilities (DD)** are severe impairments due to physical or mental disabilities that are manifested before the age of 22, will continue indefinitely, and result in substantial functional limitations in major life activities.

**Mental Disorder** refers to 1) having a specific mental or emotional disorder within the past 12 months for at least two weeks, having an occurrence of specific mental health symptoms such as frequent depression, or using prescription medication for an ongoing mental or emotional condition during the past 12 months, and 2) a condition that seriously interferes with the ability to work, attend school, or manage day-to-day activities. Those with mental disorders due to substance abuse are categorized differently.

**Difficulty in learning** includes having significant problems at school understanding materials, paying attention in class, controlling behavior, or having a problem or delay in mental development, a problem or delay in emotional development, or a reported learning disability.

**Difficulty with communication** includes difficulty for 12 months or more communicating with persons, family or non-family, difficulty understanding others, or having a problem or delay in speech development.

**Difficulty with mobility** includes difficulty getting around the home and use of special equipment for a period of 12 months or more, or having a physical delay.

**Difficulty with self-care** is defined as having difficulty for 12 months or more with bathing, dressing, eating, or toileting.

**Serious emotional disturbances** are found in children who in the past 12 months have had a diagnosable mental, behavioral, or emotional disorder that substantially interfered with their ability to participate in family, school, or community activities. Substantial and extreme functional impairment are determined by scores on a global functioning assessment scale.



## Long-Term Care: CONSUMERS

The need for long-term care is contingent on a person's need for assistance with activities of daily living (ADLs) necessary for basic human functions, and/or instrumental activities of daily living (IADLs), necessary for independent community living. People of all ages and levels of disability have long-term care needs:

**Children.**<sup>1</sup> About 459,000 children ages 5 to 17 living in the community have difficulty performing some activities of daily living, or ADLs, and are likely to need long-term care assistance. As parental education levels and income rise, the prevalence of children with difficulty performing everyday activities (learning, communication, mobility, and self-care) decreases. Boys are almost twice as likely to have difficulty performing everyday activities as girls. Between 9 and 13 percent of children ages 9 to 17 have serious emotional disturbances with *substantial* functional impairment. Between 5 and 9 percent of children ages 9 to 17 have serious emotional disturbances with extreme functional impairment.

**People with Mental Retardation/Developmental Disabilities (MR/DD).** Many people with MR/DD can live in their community with their families or others who provide care, with appropriate supports. In the last two decades, proportionately more people with MR/DD live in community-based settings. Others may require more intensive care, due to the severity of their disabilities, and live in institutional settings that offer more comprehensive, continual care. Children with developmental disabilities before the age of 5 have substantial developmental delay or conditions that are very likely to result in developmental delays without provision of services.

**Adults.** Individuals who are older than 18 and in receipt of hands-on assistance, supervision, or standby help with one or more ADLs or IADLs due to a physical, mental, or emotional problem are defined as adults who need long-term care services. About 9 million adults received long-term care assistance either in community settings or in nursing homes in 1994. Over 80 percent of adults who receive long-term care assistance reside in the community, not in institutions.

**Older Adults.** Individuals age 65 and over, defined as older adults, who need human assistance or standby help with one or more ADLs or IADLs need long-term care assistance. Older adults are more likely to receive long-term care assistance in the community than in nursing homes.

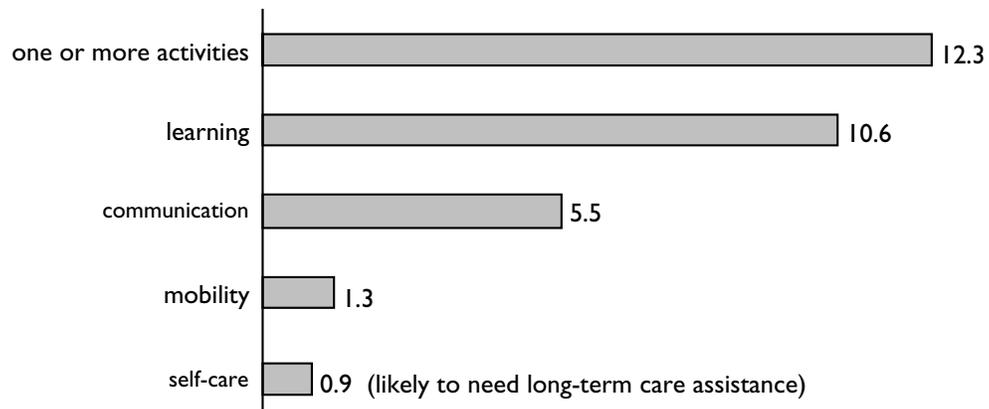
**The Aging Population.** The aging of the baby boom generation will have a dramatic impact on long-term care services in the future. Over time, the demand for long-term care services will grow because the older population is growing rapidly.

<sup>1</sup>*America's Children: Key National Indicators of Well-being*, Federal Interagency Forum on Child and Family Statistics, 1999; and R.M. Friedman, et al., "Prevalence of Serious Emotional Disturbance: an Update," *Mental Health, United States*, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, 1998.

**CHILDREN**

Of the 51 million children age 5 through 17 in 1994, less than 1 percent are likely to need long-term assistance.

PERCENTAGE OF CHILDREN AGE 5 THROUGH 17 IN 1994 WHO HAD DIFFICULTY WITH ACTIVITY



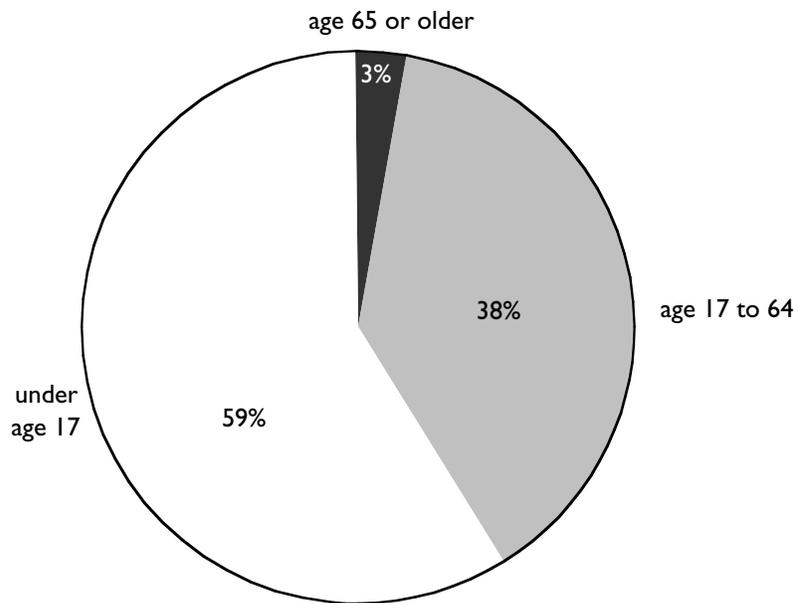
Source: Urban Institute, 2001. Based on *America's Children: Key National Indicators of Well-being*, Federal Interagency Forum on Child and Family Statistics, 1999.

**PEOPLE WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES (MR/DD)**

Most people with MR/DD are under the age of 17.

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ESTIMATED POPULATION WITH MR/DD IN 1994/95: 3.8 MILLION

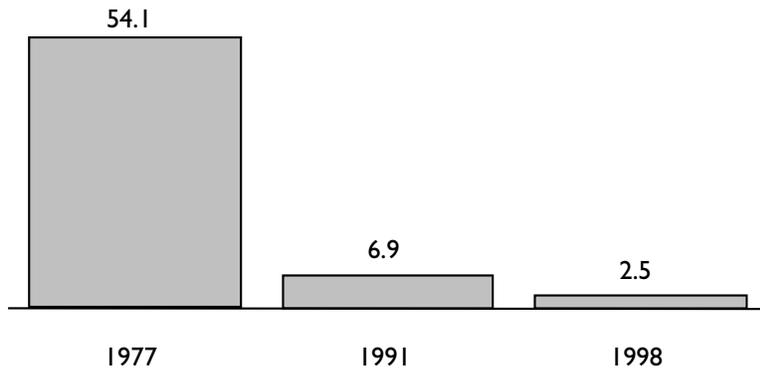


Source: *Urban Institute, 2001*. Based on S. A. Larson and L. Anderson, *Excerpts from an Analysis of the 1994 and 1995 NHIS-DS*, Research and Training Center on Community Living, University of Minnesota, 2000.

**PEOPLE WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES (MR/DD)**

The number of younger people with MR/DD who receive care in large state institutions (16 or more beds) has dramatically declined.

THOUSANDS OF PEOPLE AGE 21 AND YOUNGER WITH MR/DD LIVING IN LARGE STATE INSTITUTIONS

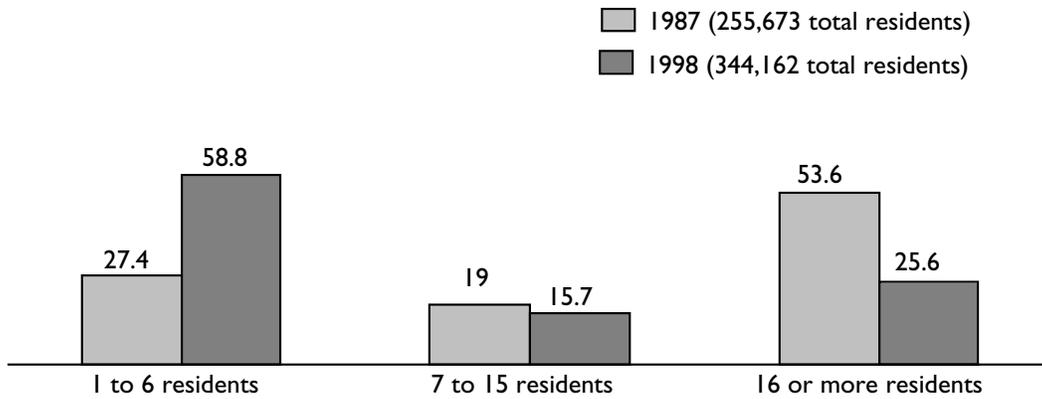


Source: Urban Institute, 2001. Based on R. Prouty et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998*, Institute on Community Integration, University of Minnesota, May 1999.

**PEOPLE WITH MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES (MR/DD)**

In 1998, more than half of people with MR/DD were living in small group residences.

PERCENTAGE OF PEOPLE WITH MR/DD IN RESIDENTIAL SETTINGS



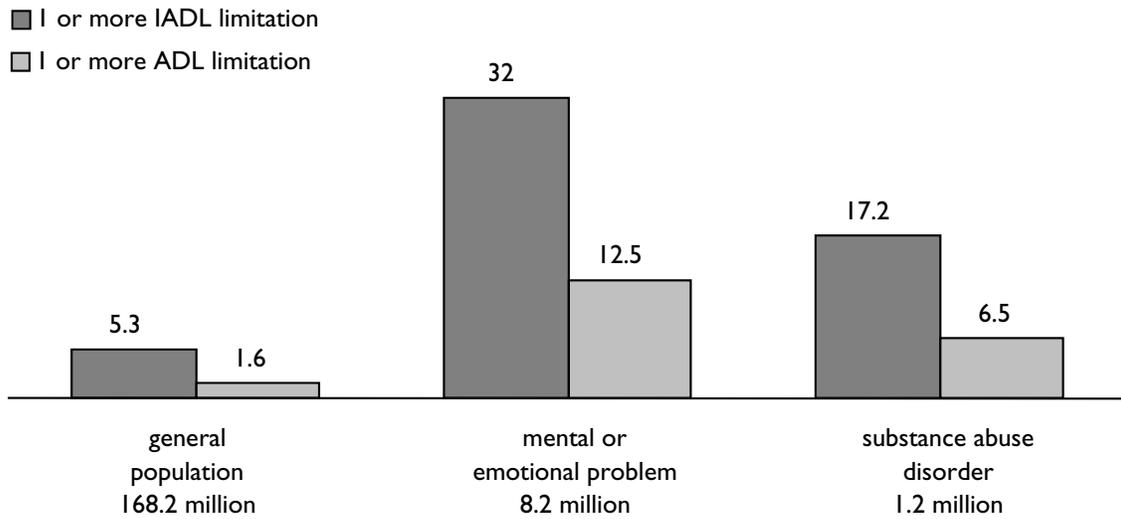
NOTE: Percentages do not sum to 100 due to rounding.

Source: Urban Institute, 2001. Based on R. Prouty et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998*, Institute on Community Integration, University of Minnesota, May 1999.

**ADULTS**

Adults age 18 through 69 with mental/emotional problems or substance abuse disorders are more likely to have limitations in instrumental activities of daily living (IADLs) than the general population.

PERCENTAGE OF ADULTS AGE 18 THROUGH 69 IN 1994

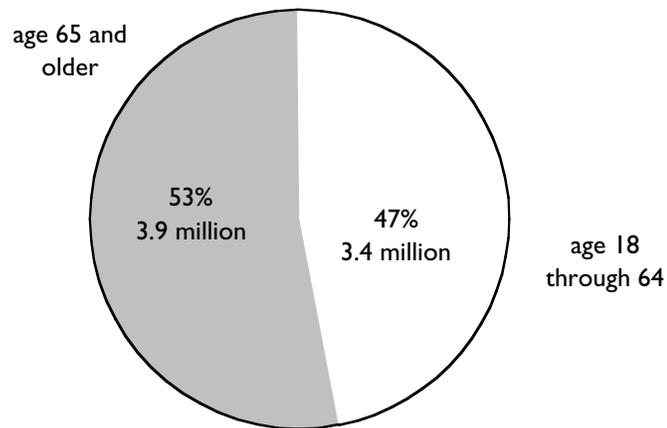


Source: Urban Institute, 2001. Based on A.G. Willis, et al., "Mental Illness and Disability in the U.S. Adult Household Population, in Mental Health," United States, 1998, SAMHSA, DHHS, 1998.

**ADULTS**

Over 80 percent of all people receiving any long-term care assistance receive it in community settings.

ADULTS RECEIVING LONG-TERM CARE ASSISTANCE IN THE COMMUNITY IN 1994: 7.3 MILLION



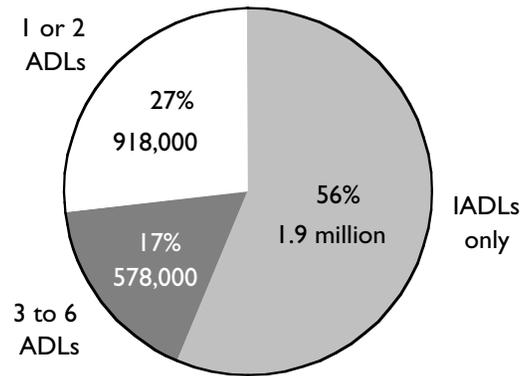
NOTE: People age 65 or older receiving long-term care assistance are those who receive human assistance or stand-by help with one or more ADLs or IADLs. People between the ages of 18 and 64 receiving long-term care assistance are those who receive human help for IADLs and ADLs.

Source: *Urban Institute, 2001*. Based on 1994 National Health Interview Survey, Disability Supplement, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**ADULTS**

About 25 percent of adults of all ages receiving long-term care assistance in the community have severe impairments and receive assistance with 3 to 6 activities of daily living (ADLs).

SEVERITY OF DISABILITY AMONG ADULTS AGE 18 THROUGH 64 RECEIVING LONG-TERM CARE ASSISTANCE IN THE COMMUNITY IN 1994: 3.4 MILLION



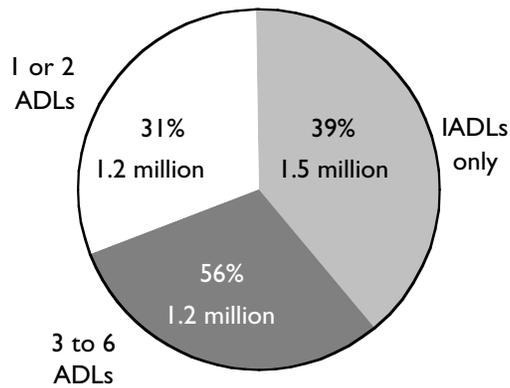
NOTE: People between the ages of 18 and 64 receiving long-term care assistance are those who receive human help for IADLs and ADLs.

Source: *Urban Institute, 2001*. Based on 1994 National Health Interview Survey, Disability Supplement, and 1994 National Long-Term Care Survey, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**ADULTS**

About 47 percent of adults of all ages receiving long-term care assistance in the community receive assistance with instrumental activities of daily living (IADLs).

SEVERITY OF DISABILITY AMONG ADULTS AGE 65 AND OLDER RECEIVING LONG-TERM CARE ASSISTANCE IN THE COMMUNITY IN 1994: 3.9 MILLION



NOTE: People age 65 or older receiving long-term care assistance are those who receive human assistance or stand-by help with one or more ADLs or IADLs.

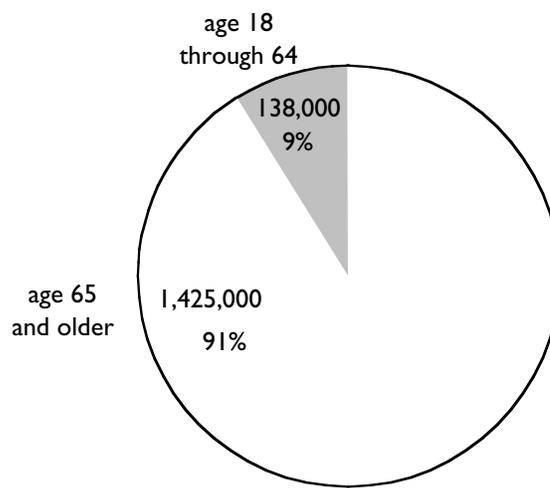
Source: *Urban Institute, 2001*. Based on 1994 National Health Interview Survey, Disability Supplement, and 1994 National Long-Term Care Survey, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**ADULTS**

Most adults who live in nursing homes are age 65 and older.

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NURSING HOME RESIDENTS IN 1994: 1.6 MILLION



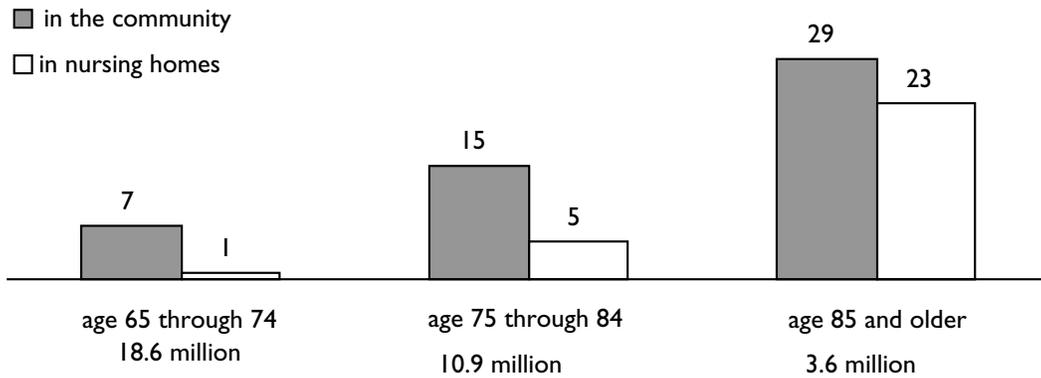
NOTE: These numbers do not include adults with MR/DD or mental illness who live in institutions other than nursing homes.

Source: *Urban Institute, 2001*. Based on 1996 Medical Expenditure Panel Survey from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**OLDER ADULTS**

Over half the population age 85 and older received long-term care assistance in 1994, compared to only 12 percent of adults age 65 to 85.

PERCENTAGE OF OLDER ADULTS RECEIVING LONG-TERM CARE ASSISTANCE IN 1994



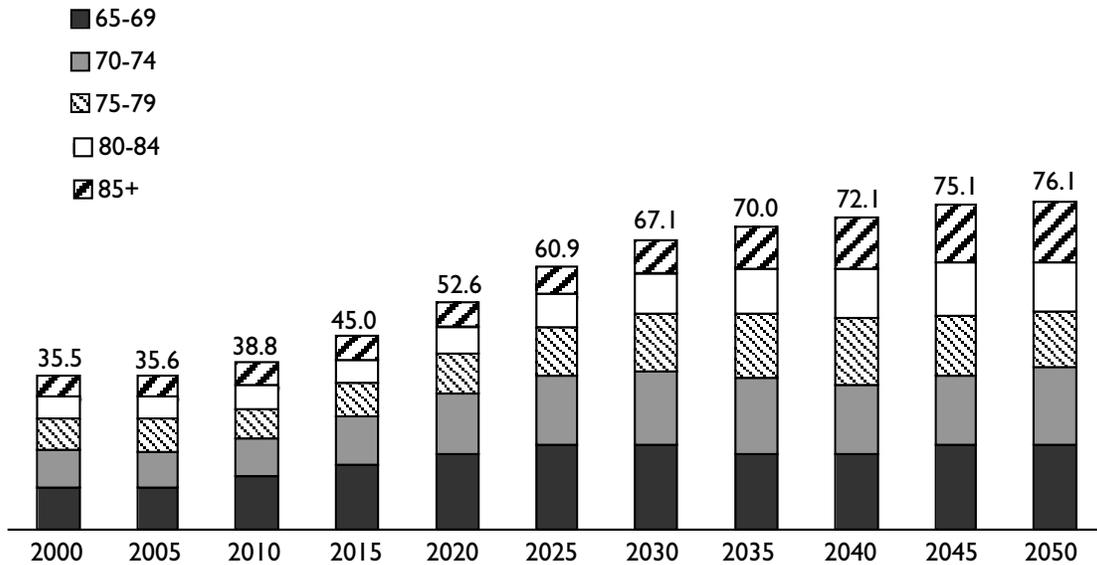
NOTE: Nursing home data do not include older adults with MR/DD or mental illness who live in institutions other than nursing homes. People age 65 and older receiving long-term care assistance are those who receive human assistance or stand-by help with one or more ADLs or IADLs.

Source: *Urban Institute, 2001*. Based on 1994 National Long-term Care Survey from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**TRENDS IN THE AGING POPULATION**

The aging of the baby boom generation will increase the demand for long-term care services. By 2011, the first group of baby boomers will turn 65. By 2031, all baby boomers will be over age 65 and the oldest will turn 85.

MILLIONS OF OLDER ADULTS BY AGE



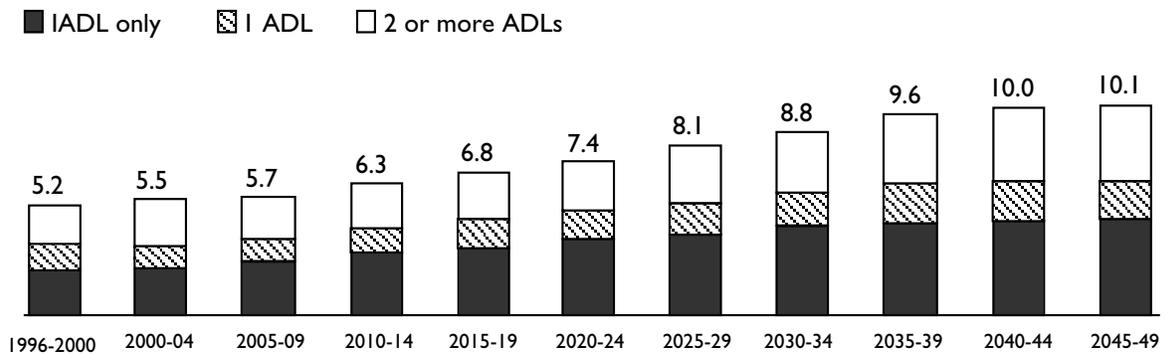
NOTE: The projections of the number of people in the general population age 65 and older assume reductions in mortality of 0.6 percent a year.

Source: Urban Institute, 2001. Based on *The Long-Term Care Financing Model*. Prepared by The Lewin Group, Inc., for the Office of the Assistant Secretary for Planning and Evaluation, DHHS, 2000.

**TRENDS IN THE AGING POPULATION**

Over the next 25 years, the number of older adults with at least two limitations in activities of daily living (ADLs) is projected to grow by one-third.

MILLIONS OF OLDER ADULTS WITH LIMITATIONS



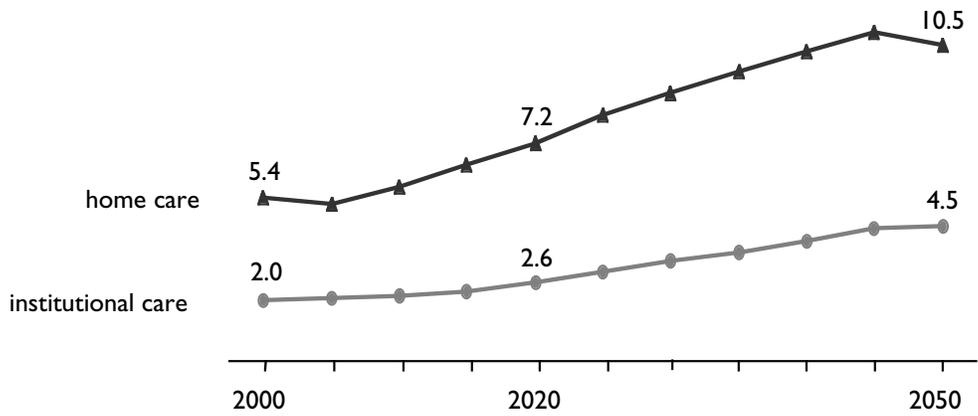
NOTE: The projections assume reductions in mortality of 0.6 percent a year and a reduction of 0.6 percent a year in disability rates.

Source: Urban Institute, 2001. Based on *The Long-Term Care Financing Model*. Prepared by The Lewin Group, Inc., for the Office of the Assistant Secretary for Planning and Evaluation, DHHS, 2000.

**TRENDS IN THE AGING POPULATION**

The older populations receiving home care and institutional care are expected to grow in the next 50 years.

MILLIONS OF OLDER ADULTS AGE 85 AND OLDER RECEIVING CARE



NOTE: The projections of the number of people in the general population age 65 and older, the segment of this population with disabilities, and the number using institutional and home care assume reductions in mortality of 0.6 percent a year and a reduction of 0.6 percent a year in disability rates as well as current age- and gender-specific use rates for institutional and home care services.

Source: *Urban Institute, 2001*. Based on *The Long-Term Care Financing Model*. Prepared by The Lewin Group, Inc., for the Office of the Assistant Secretary for Planning and Evaluation, DHHS, 2000.



## *Long-Term Care:* PROVIDERS

A variety of providers in community-based and institutional settings offer long-term care services:

### COMMUNITY-BASED CAREGIVERS

**Unpaid Caregivers.** Most adults receiving long-term care assistance in the community rely exclusively on unpaid caregivers—predominantly family or friends—to meet their long-term care needs. Most of these caregivers are women. Paid care is used less frequently.

**Home Health Care.** Home health care is a rapidly growing sector of the health care industry. It is provided to persons in their place of residence to promote, maintain, or restore health and to maximize their independence. Advances in technology now allow complex illnesses, once treated only in hospitals, to be treated at home.

**Adult Day Services Programs.** Adult day services programs provide health and social services on a part-time basis in a group setting to people with physical, emotional, or mental disabilities. Services generally provided to participants include nursing, social services, personal care, rehabilitation therapies, meals, counseling, and transportation. Most participants live with a spouse, adult children, or other family members or friends; about one-quarter live alone. Over half of the participants have cognitive impairments, and over 40 percent require assistance with three or more ADLs.

### INSTITUTIONAL SETTINGS

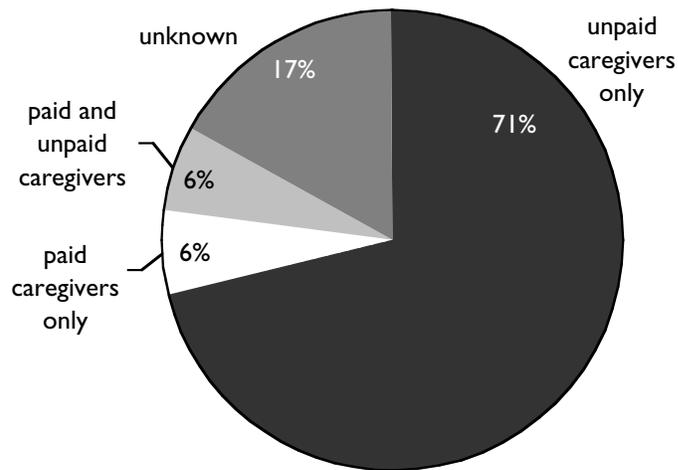
**Nursing homes.** Nursing homes serve residents with ADL and IADL limitations, as well as those with cognitive impairments. About 1.4 million people age 65 and older live in nursing homes, compared to about 138,000 people age 18 through 64. The average age of a resident in 1997 was 81. Nursing homes provide nursing, related services, food and shelter to residents. They have three or more beds that routinely provide nursing services, and may be free-standing or part of a larger facility. Nursing homes that receive Medicaid and Medicare reimbursement are subject to federal laws and regulations regarding quality of care.

**Assisted Living Facilities (ALFs).** Like nursing homes, ALFs serve residents with limitations in ADLs and IADLs, and cognitive impairments. These facilities represent a fast-growing housing and service option for people with disabilities. ALFs generally offer 24-hour staff supervision, housekeeping, meals, personal assistance, medication reminders, and nursing staff. They are not subject to federal laws or regulations.

### UNPAID CAREGIVERS

Nearly three-quarters of adults age 18 through 64 who receive long-term care assistance rely exclusively on unpaid caregivers.

ADULTS AGE 18 THROUGH 64 RECEIVING LONG-TERM CARE ASSISTANCE IN THE COMMUNITY IN 1994: 3.4 MILLION



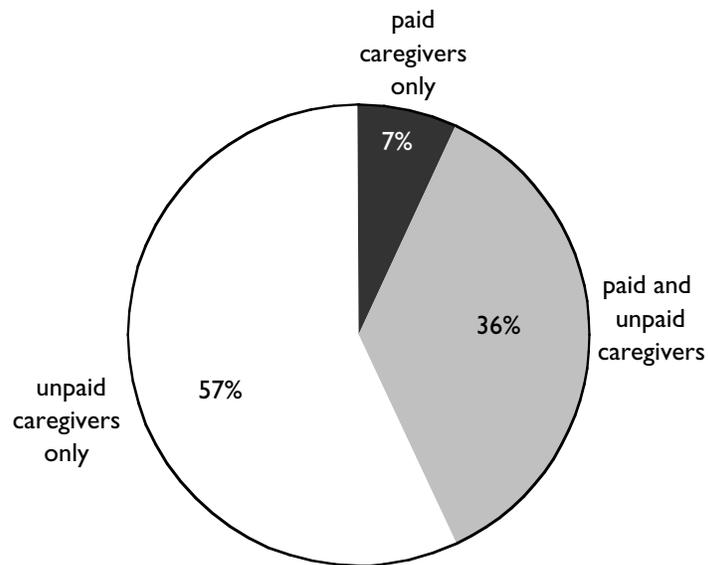
NOTE: The proportion "unknown" could change the proportions in other categories.

Source: Urban Institute, 2001. Based on 1994 NHIS-DS, from W. Spector, J. Fleischman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**UNPAID CAREGIVERS**

Adults age 65 and older are more likely than younger adults to receive care from both paid and unpaid caregivers.

ADULTS AGE 65 AND OLDER RECEIVING LONG-TERM CARE ASSISTANCE IN THE COMMUNITY IN 1994: 3.9 MILLION

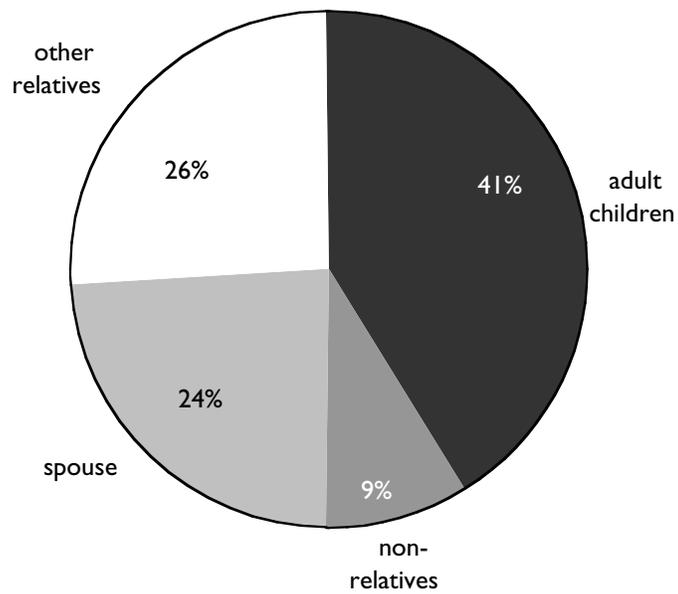


Source: *Urban Institute, 2001*. Based on 1994 National Long-Term Care Survey, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

**UNPAID CAREGIVERS**

Adult children and spouses make up the majority of unpaid caregivers of older adults receiving long-term care assistance in the community.

RELATIONSHIP OF UNPAID CAREGIVERS TO ADULTS AGE 65 AND OLDER IN 1994

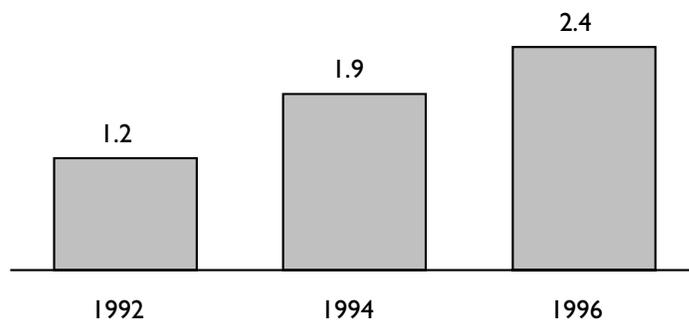


Source: *Urban Institute, 2001*. Based on 1994 National Long-Term Care Survey, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, in *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality, U.S. DHHS, 2000.

### HOME HEALTH CARE

The number of home health care patients doubled between 1992 and 1996.\*

MILLIONS OF HOME HEALTH CARE PATIENTS



\*Some estimates show a decline in the number of patients in recent years due to the impact of the Balanced Budget Act of 1997.

NOTE: Patients are current patients as of the date of the survey.

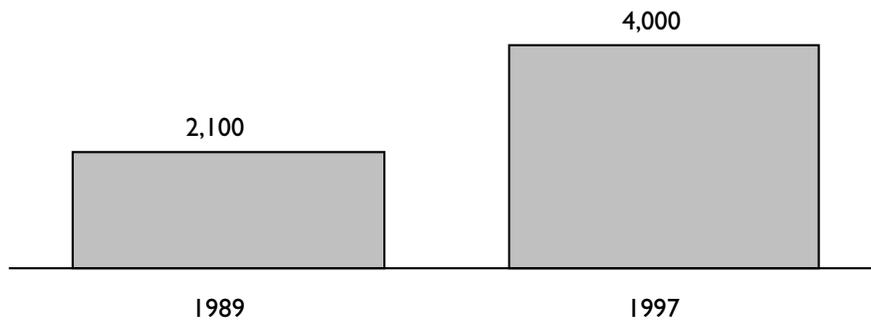
Source: Urban Institute, 2001. From B. Haupt, *An Overview of Home Health and Hospice Care Patients: 1996 National Home and Hospice Care Survey*, National Center for Health Statistics (NCHS), DHHS, 1998 and G.W. Strahan, *An Overview of Home Health and Hospice Care Patients: 1994 National Home and Hospice Care Survey*, NCHS, DHHS, 1996 (and similar survey for 1992 data). Data are from the NCHS surveys of home and hospice care agencies. Patients are current patients as of the date of the survey.

**ADULT DAY SERVICES PROGRAMS**

The average age of participants in adult day services programs is 76; two-thirds of participants are women.

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NUMBER OF ADULT DAY SERVICES PROGRAMS

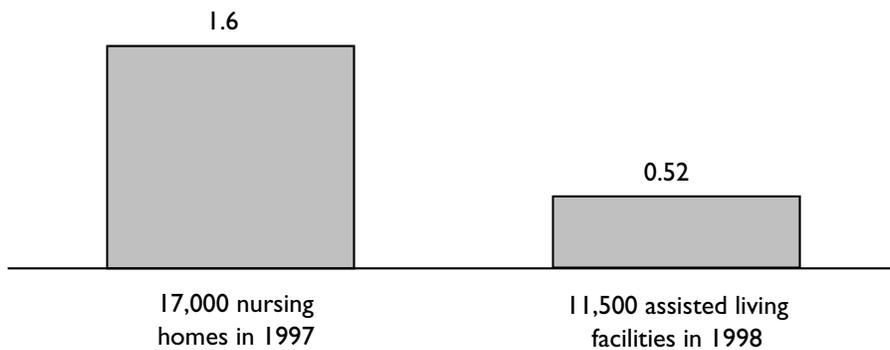


Source: *Urban Institute, 2001*. Based on National Council on Aging, National Adult Day Services Association (NADSA), 1997 and [www.ncoa.org/nadsa/ADS\\_factsheets.htm](http://www.ncoa.org/nadsa/ADS_factsheets.htm). The NADSA surveyed more than 4,000 adult day service programs and received 1,699 valid responses. The data reflect these responses and responses from a similar 1989 survey, and do not represent the entire industry.

**INSTITUTIONAL SETTINGS**

Nursing homes, primarily serving older adults, had an average bed size of 107 in 1997. Assisted living facilities, serving people of all ages, had an average bed size of 53 in 1998.

MILLIONS OF RESIDENTS IN LONG-TERM CARE FACILITIES

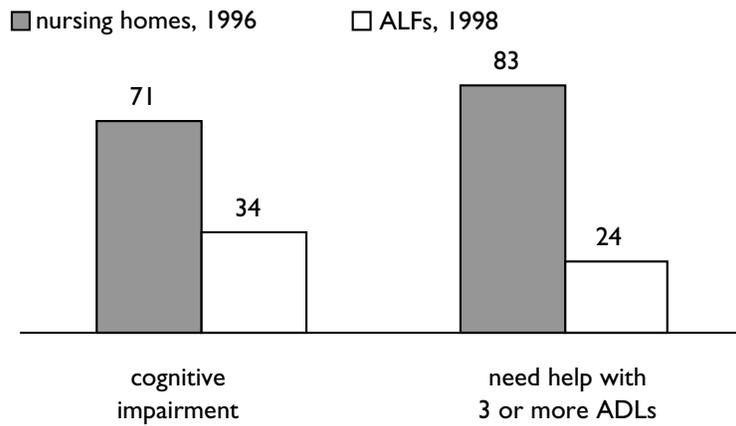


Source: Urban Institute, 2001. From NCHS, DHHS, Advance Data, No. 311, March 1, 2000, *An Overview of Nursing Home Facilities: Data from the 1997 National Nursing Home Survey*. C. Hawes, et al., *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities*, OASPE, Office of Disabilities, Aging, and Long-term Care Policy, DHHS, December 1999. To be included in the survey's nationally representative sample of 2,945 assisted living facilities (ALFs), facilities had to serve older adults, have more than 10 beds, and indicate that they were ALFs or that they provided 24-hour staff oversight as well as housekeeping, meals, and assistance with medications, bathing, and dressing.

**INSTITUTIONAL SETTINGS**

Assisted living facilities (ALFs) are generally not able to care for residents who need skilled nursing care.

PERCENTAGE OF RESIDENTS IN INSTITUTIONAL SETTINGS



Source: Urban Institute, 2001. Based on C. Hawes, et al., *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities*, OASPE, DHHS, 1999. Hawes used nursing home data from the nursing home component of the Medical Expenditure Panel Survey (MEPS) as presented in N. Krauss and B. Altman, *Characteristics of Nursing Home Residents 1996, 1998 MEPS Research Findings No. 5*, DHHS, Agency for Healthcare Research Quality, 1998.



## Long-Term Care: FINANCING

Long-term care services are financed through sources including out-of-pocket spending, Medicare, Medicaid, the Medicaid home and community-based services waiver program, and private long-term care insurance.

**Overall Spending.** The Health Care Financing Administration (HCFA) estimates that in 1998 over \$117 billion—almost 12 percent of U.S. personal health expenditures—was spent on nursing facility care, including care in intermediate facilities for the mentally retarded (ICFs/MR), and home health care services not affiliated with hospitals. Medicaid and out-of-pocket spending—the two major sources of long-term care financing—make up nearly half the amount.

Out-of-pocket spending represented almost 30 percent of total long-term care spending on nursing facilities and home health care in 1998—about \$35 billion. A recent survey by AARP indicated that 39 states reported one or more state-only funded home and community-based services programs for the elderly: total state spending for these programs was more than \$1.2 billion in 1996.<sup>2</sup>

**Medicare.** In 1998, Medicare funded 17.8 percent of long-term care spending. Medicare is not intended to be a primary long-term care funding source, and is not intended to support people in need of assistance with only ADLs and/or IADLs. It covers a limited amount of long-term care services in a skilled nursing facility that follow a three-day hospital stay, and offers a home health benefit for those with medically related needs. Medicare's coverage of skilled nursing home care is limited to up to 100 days, following hospitalization, for persons who need continued skilled nursing care and/or skilled rehabilitation on a daily basis. Home health visits are limited to people who need skilled nursing care on a part-time or intermittent basis, or physical or speech therapies. Medicare is the largest public payor of home health care. Skilled nursing facility and home health care represented 10 percent of total Medicare spending in 1998.

<sup>2</sup>E. Kassner, and Williams, *Taking Care of Their Own: State-funded Home and Community-based Care Programs for Older Persons*, AARP, 1997.

**Medicaid.** Medicaid spending on long-term care includes spending for institutional nursing facilities, ICFs/MR, and home and community care. Half of all Medicaid spending on long-term care pays for nursing home care.

Medicaid paid about \$59 billion for institutional and home and community-based services in 1997.<sup>3</sup> Of this amount, 73 percent was spent for care in nursing homes and in ICFs/MR. The balance was spent on home and community-based services, such as home health, case management, personal care, and respite services for caregivers.

Medicaid spending almost doubled from 1991 to 1997, with an increase in the share devoted to home and community-based services and a decline in the share devoted to ICFs/MR. This shift reflects, in part, greater state use of Medicaid waivers for home and community-based services.

While most states' Medicaid programs devote the majority of their public funding for people with MR/DD to institutions, many states allocate most of their funding to home and community-based services. The trend toward de-institutionalizing people with MR/DD in favor of care in community-based settings began during the 1970s.

### **Medicaid Home and Community-Based Services Waiver**

**Program.** Medicaid law allows HCFA to waive certain requirements so that states may offer a broad range of home and community-based services to persons who would otherwise need institutional care.<sup>4</sup> States can define the specific populations with disabilities and services to be covered, which include case management, respite services for caregivers, habilitation (assistance in developing skills necessary to residing successfully in home and community-based settings), and personal care services.

<sup>3</sup>Based on data from HCFA Form 64 reports.

<sup>4</sup>Statutory requirements that may be waived are: requirements that Medicaid services be available throughout the state, and that any covered services be equal in amount, duration, and scope for certain recipients.

Waivers are one of the most important funding sources for home and community-based care for persons of all ages. Services most frequently provided by states are case management (arrangement of services under a plan of care for each individual); respite (part-time relief for caregivers); habilitation (assistance to help people reside successfully in the community); and personal care services.<sup>5</sup>

Medicaid waiver program spending nearly quadrupled in five years, growing from \$2.2 billion in 1992 to almost \$8 billion in 1997. More than three-quarters of this spending is devoted to services for people with MR/DD, and another 20 percent is for the aged and other people with disabilities. The number of recipients of these services more than doubled, rising from 236,000 in 1992 to 562,000 in 1997.

**Private Long-Term Care Insurance.** The private long-term care insurance market has grown substantially over the last decade. The size of the market may grow even larger if policies are purchased at earlier ages when premiums are lower, or if government subsidies are offered.

The vast majority of policies (80 percent) sold has been sold through individual and group association markets. The balance has been sold through employer-sponsored life insurance markets.

According to the Health Insurance Association of America, growth in the number of policies purchased averaged about 21 percent per year between 1987 and 1997. Yet, according to HCFA data, payments from private health insurance represented only about 7 percent of total long-term care expenditures in 1998.

Purchasers of private long-term care insurance who are age 55 or older are on average better off financially than their peers in the general population. Some experts estimate that over the next 20 years, between 10 and 35 percent of retirees will have the financial resources necessary to pay for long-term care policies.<sup>6</sup> In turn, others argue that the private market may be an option for only those with middle and upper incomes.<sup>7</sup>

**Other Federal Sources.** A variety of other federal programs support long-term care services that are not specifically illustrated in this chart book but are summarized in a table in this section.

These sources include the Older Americans Act and the Social Services Block Grant Program (SSBG), which both fund home and community-based services. Various housing programs, including Section 202 housing for the elderly, Section 811 housing for the disabled, congregate housing, and the newly authorized assisted living programs, administered by the U.S. Department of Housing and Urban Development, finance supported living arrangements for people with disabilities.

Many states supplement federal Supplemental Security Income cash welfare payments to low-income elderly and disabled people to help pay for home and community-based services, or to help pay for 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 people 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.

<sup>5</sup>CRS analysis of the American Public Human Services Association (APHSA) 1915(c) waiver database, 1998.

<sup>6</sup>M.A. Cohen and A.K. Nanda Kumar, "The Changing Face of Long-Term Care Insurance in 1994," *Inquiry*, 34, Spring 1997, p. 50-61, and J. Wiener, et al. *Sharing the Burden: Strategies for Public and Private Long-Term Care Insurance*. Brookings Institution, 1994.

<sup>7</sup>*Ibid.*, M.A. Cohen

## FINANCING

### FEDERAL PROGRAMS FOR PEOPLE WITH DISABILITIES

	<b>Eligibility</b>	<b>Services</b>	<b>Administration</b>
Medicaid	Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests	Nursing facility, home health care, personal care services, and adult day care	State
Medicaid Waivers	Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests who would otherwise be in an institution	Wide array of non-medical support services excluding room and board	State
Medicare	Adults age 65 and older and certain younger people with disabilities	Short-term skilled nursing facility and home health care	Federal
Social Services Block Grant	Determined by states	Wide array of special support and home and community-based services	State
Older Americans Act of 1965	Adults age 60 and older	Include nutrition, home care, adult day services, respite, transportation, and preventive health services	State
Supplemental Security Income	Children and adults who are blind, disabled, and/or 65 and older who meet state income and asset tests	Cash payments can be used for services	State
Rehabilitation Act of 1973	Adults who have a physical or mental impairment that results in a substantial impediment to employment who can benefit from vocational rehabilitative services	Include vocational rehabilitation, employment training, education, and independent living services	State
Supportive Housing and Congregate Housing Services Act of 1978	Certain adults with disabilities	Variety of supportive housing options	Federal
Department of Veterans Affairs	Based on statutory priorities, including service-connected disabilities and other factors	Range of institutional, residential, and supportive services	Federal

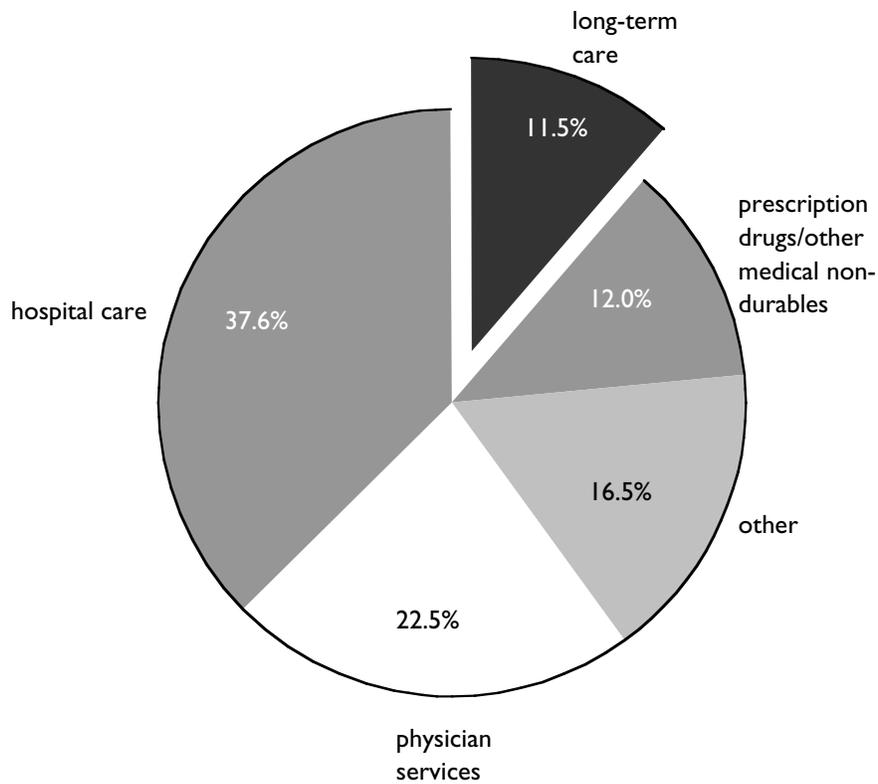
Source: Prepared by the Congressional Research Service, 2000.

Urban Institute, 2001

**OVERALL SPENDING**

Out of all U.S. personal health spending, \$117 billion was spent on long-term care services in 1998.

PERSONAL HEALTH SPENDING IN THE UNITED STATES IN 1998: \$1.02 TRILLION



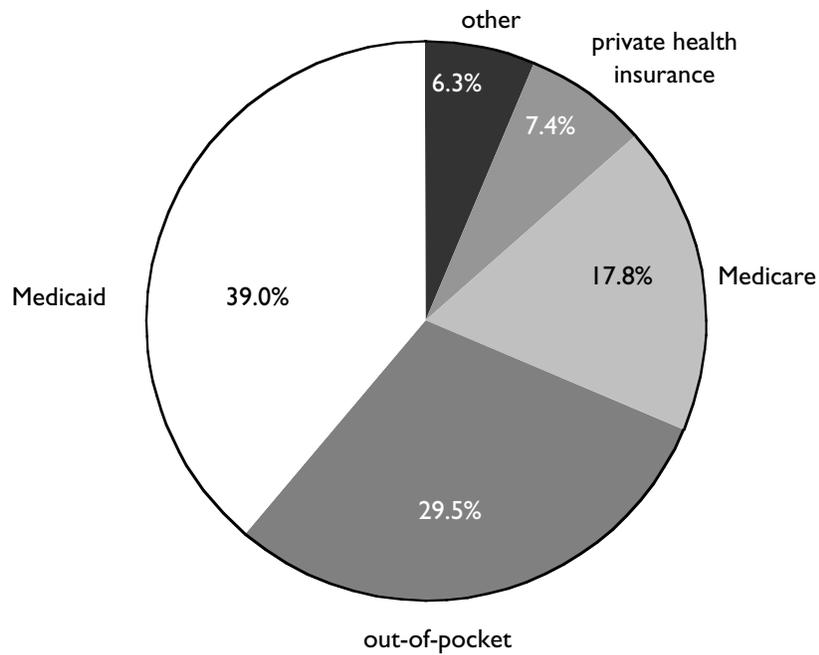
NOTE: Percentages do not sum to 100 due to rounding. Although the data capture most long-term care spending, some expenditures, such as those on Medicaid home and community-based services waivers, are not included.

Source: *Urban Institute, 2001*. Based on Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, HCFA, DHHS, 2000.

**OVERALL SPENDING**

Medicaid is the primary funding source for long-term care services.

SOURCES OF LONG-TERM CARE FINANCING IN 1998

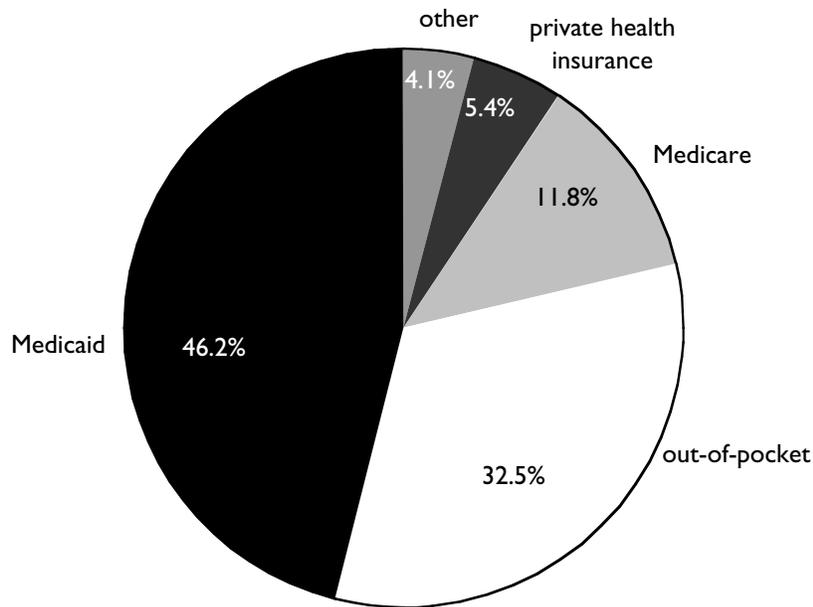


Source: *Urban Institute, 2001*. Based on Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, HCFA, DHHS, 2000. Long-term care expenditures include spending on nursing homes, ICF/MR, and certain home health services supplied by agencies not affiliated with institutions. Although the data capture most long-term care spending, some expenditures, such as those through Medicaid home and community-based services waivers, are not included.

**OVERALL SPENDING**

Spending for nursing homes and intermediate care facilities for the mentally retarded (ICFs/MR) represents 75 percent of all long-term care spending.

SPENDING FOR NURSING HOMES AND ICFs/MR IN 1998: \$87.8 BILLION



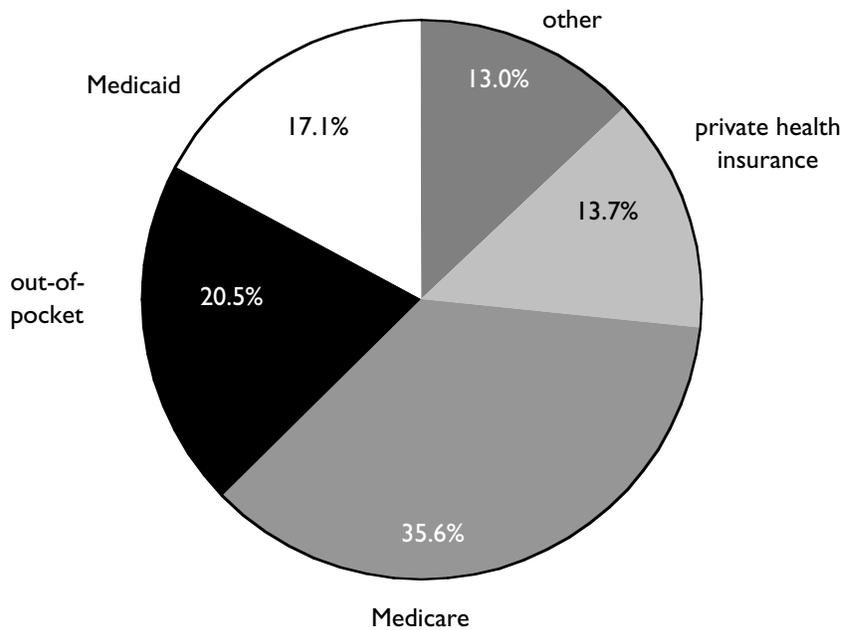
NOTE: Nursing home expenditures include spending on nursing homes and ICFs/MR that are not affiliated with institutions or hospitals. Although the data capture most long-term care spending, some expenditures are not included.

Source: *Urban Institute, 2001*. Based on Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, HCFA, DHHS, 2000.

**OVERALL SPENDING**

Spending for home health care represented one-quarter of all long-term care spending in 1998.

SPENDING FOR HOME HEALTH CARE IN 1998: \$29.3 BILLION



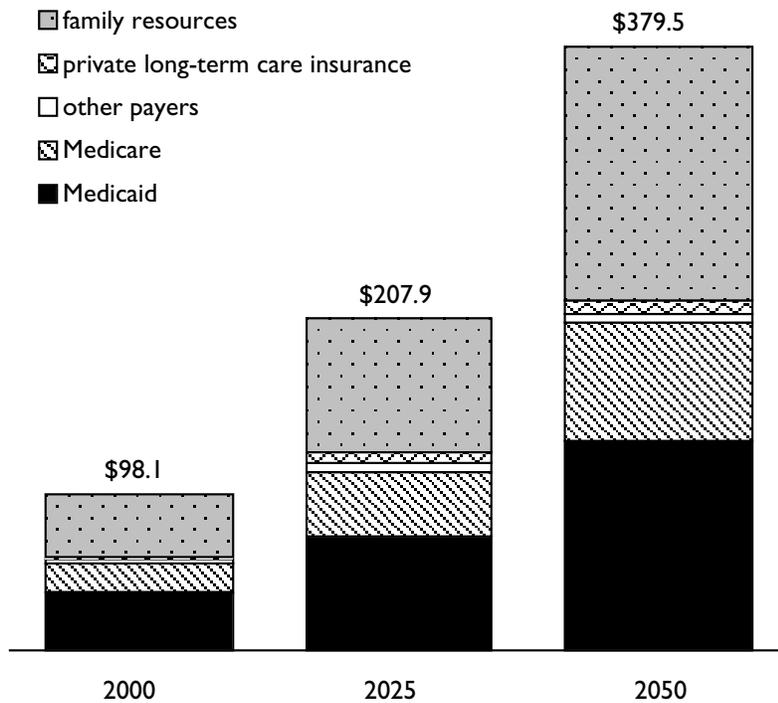
NOTE: Home health expenditures are from data supplied by agencies that are not affiliated with institutions such as hospitals. Although the data capture most spending, some expenditures, such as those on Medicaid home and community-based service waivers, are not included.

Source: *Urban Institute, 2001*. Based on Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, HCFA, DHHS, 2000.

**OVERALL SPENDING**

Spending on institutional and home care for adults age 65 and older is projected to more than double from 2000 to 2025, and to nearly quadruple by 2050.

BILLIONS OF 1999 DOLLARS PROJECTED TO BE SPENT



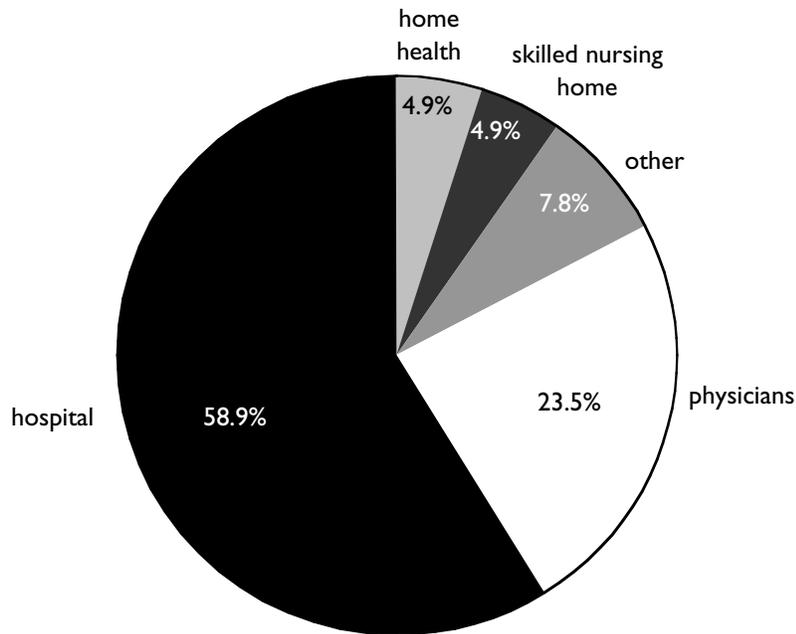
NOTE: The projected expenditure increases assume reductions in mortality of 0.6 percent a year and 0.6 percent a year in disability rates in the older population, current age- and sex-specific use rates for institutional and home care services, static public policies, and a real inflation rate of 1.2 percent for long-term care services.

Source: Urban Institute, 2001. Based on *The Long-Term Care Financing Model*. Prepared by The Lewin Group, Inc., for OASPE, DHHS, 2000.

**MEDICARE**

Home health care and skilled nursing facility care represented about 10 percent of all Medicare personal health care spending in 1998.

MEDICARE PERSONAL HEALTH CARE SPENDING IN 1998: \$210.5 BILLION



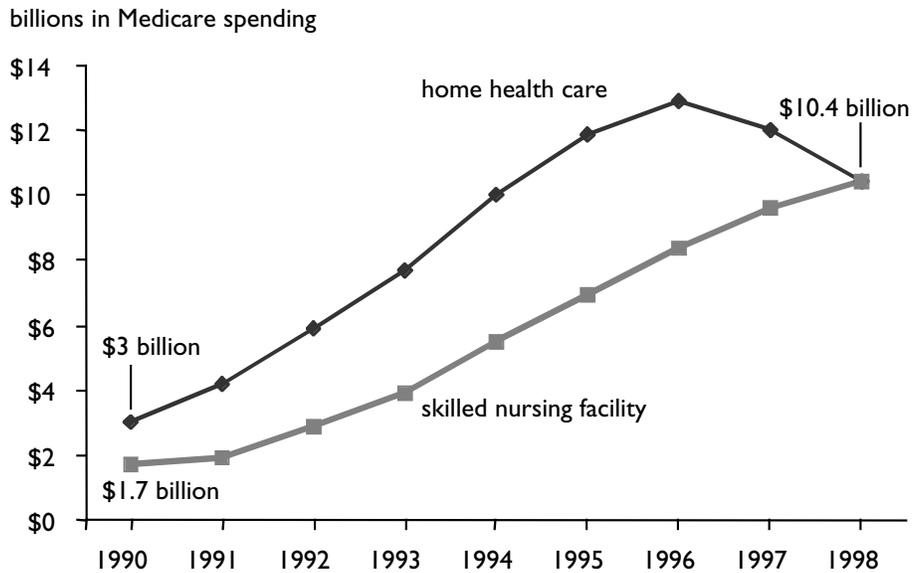
NOTE: Home health expenditures declined in recent years due to the impact of the Balanced Budget Act of 1997, and fraud and abuse initiatives. Medicare nursing home expenditures include spending on skilled nursing homes that are not affiliated with institutions such as hospitals. Medicare home health expenditures are from data supplied by agencies that are not affiliated with institutions such as hospitals.

Source: *Urban Institute, 2001*. Based on data from the Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, HCFA, DHHS, 1998.

**MEDICARE**

Between 1990 and 1998, Medicare spending for skilled nursing facility care increased more than 500 percent. Spending for home health care increased by 250 percent.

TRENDS IN MEDICARE SPENDING BY TYPE OF CARE



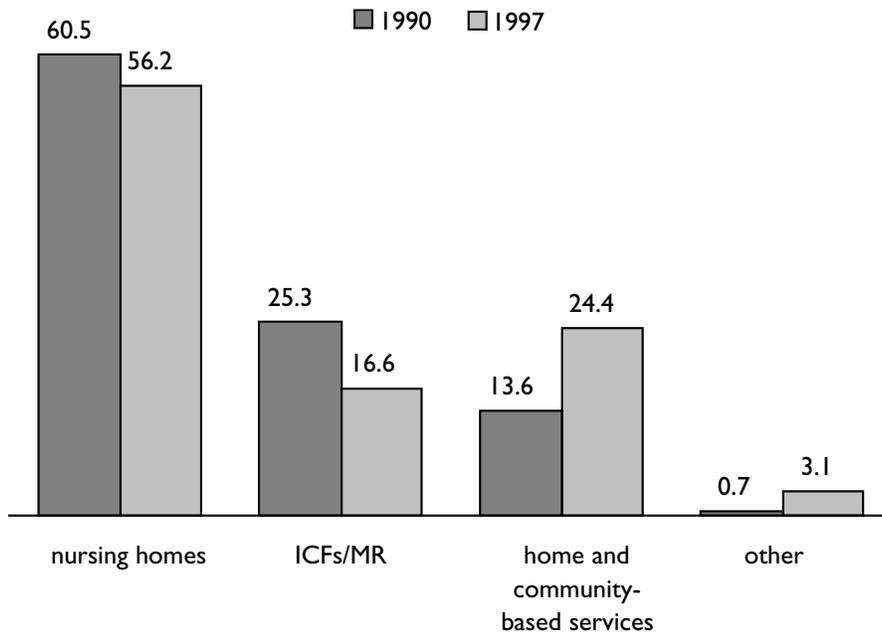
NOTE: Home health expenditures declined in recent years due to the impact of the Balanced Budget Act of 1997, and fraud and abuse initiatives. Medicare nursing home expenditures include spending on skilled nursing homes that are not affiliated with institutions such as hospitals. Medicare home health expenditures are from data supplied by agencies that are not affiliated with institutions such as hospitals.

Source: *Urban Institute, 2001*. Based on data from the Office of the Actuary, National Health Statistics Group, HCFA, DHHS, 1990-1997.

**MEDICAID**

In 1990, total Medicaid spending on long-term care amounted to \$30.3 billion. By 1997 the amount had grown to \$58.7 billion.

PERCENTAGE OF TOTAL MEDICAID SPENDING ON LONG-TERM CARE



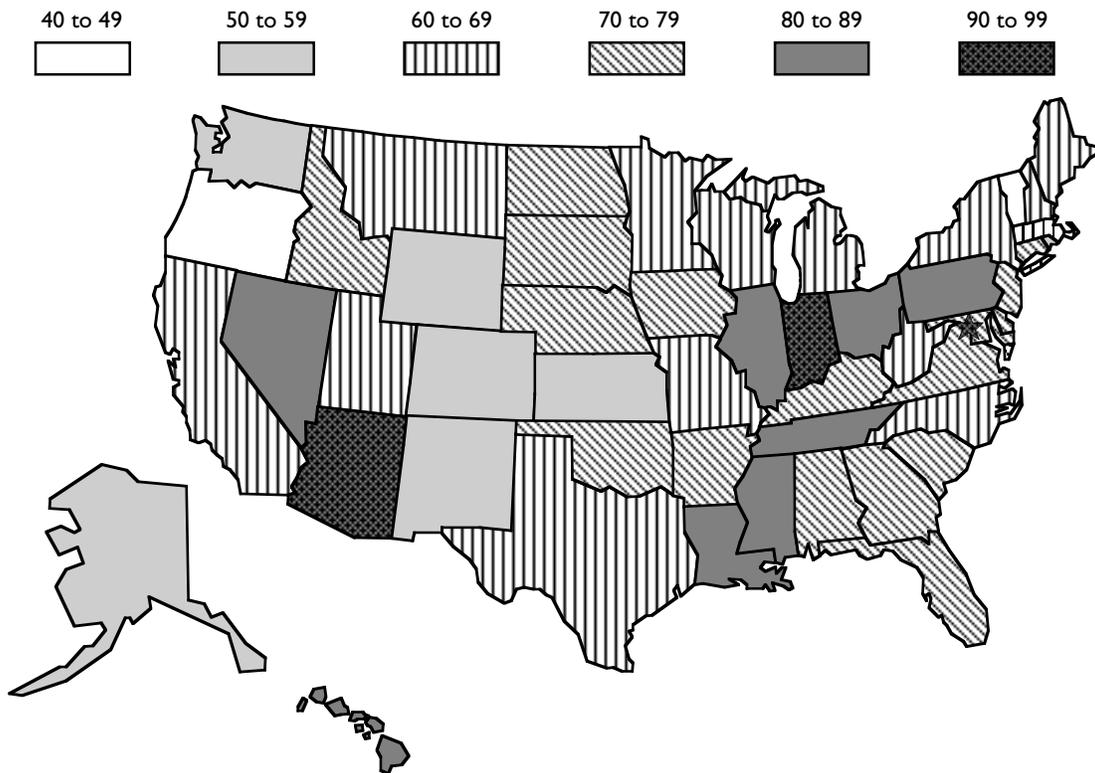
NOTE: Medicaid expenditures include spending for nursing facilities, ICFs/MR, and home care including Medicaid home and community-based waivers and personal care.

Source: Urban Institute, 2001. Based on data from HCFA-64 reports.

**MEDICAID**

States' Medicaid spending tends to focus on institutional long-term care. In all but two states—Oregon and Vermont—most Medicaid long-term care expenditures are for institutions.

PERCENTAGE OF MEDICAID DOLLARS SPENT BY STATES ON LONG-TERM INSTITUTIONAL CARE, FY 1998



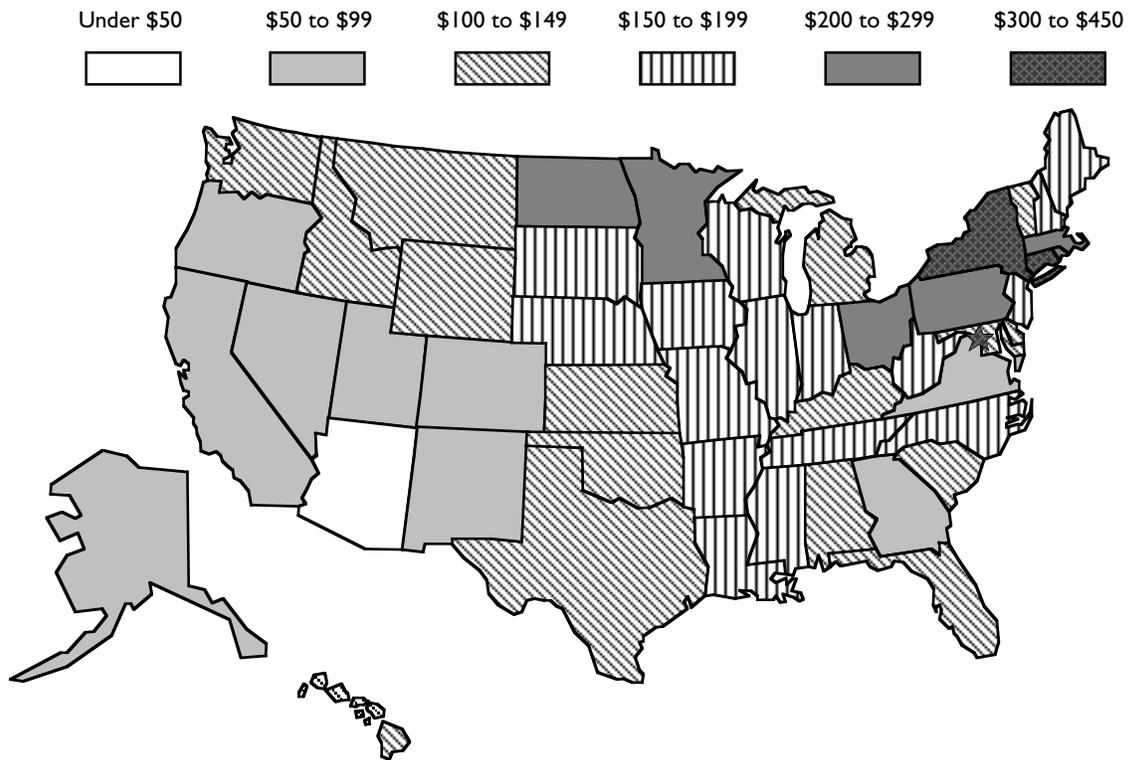
NOTE: Arizona provides most of its long-term care services through a prepaid plan, spending for which is not reported in HCFA-64 reports. This map does not reflect all of Arizona's spending on long-term care services. Institutional long-term care includes nursing facilities and intermediate care facilities for the mentally retarded. HCBS expenditures are comprised of HCBS for frail elderly (home and community-based care for the functionally disabled elderly), home/community-based waiver services, community supported living arrangement programs, and hospice benefits.

Source: Urban Institute, 2001. Based on data from HCFA-64 reports.

**MEDICAID**

Per capita Medicaid spending on long-term institutional care varies tremendously by state. In 1998, per capita spending was less than \$50 in two states, while it ranged between \$300 and \$450 in two other states and the District of Columbia.

PER CAPITA MEDICAID LONG-TERM CARE INSTITUTION EXPENDITURES BY STATE  
POPULATION, FY 1998



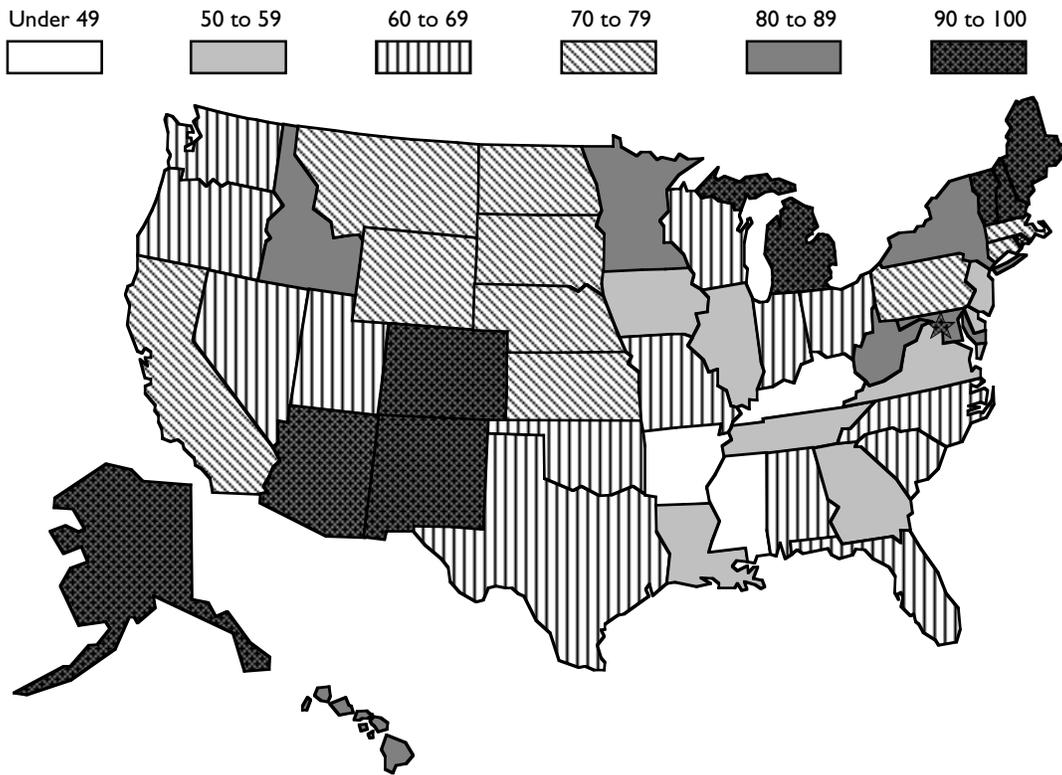
NOTE: Arizona provides most of its long-term care services through a prepaid plan, spending for which is not reported in HCFA-64 reports. This map does not reflect all of Arizona's spending on long-term care services. Institutional long-term care includes nursing facilities and intermediate care facilities for the mentally retarded.

Source: Urban Institute, 2001. Based on data from HCFA-64 reports.

**MEDICAID**

Nationally, 72 percent of total public spending on MR/DD (mental retardation/developmental disabilities) services is for services delivered in the home and community.

PERCENTAGE OF TOTAL PUBLIC SPENDING ON MR/DD SERVICES IN THE COMMUNITY, BY STATE IN 1998



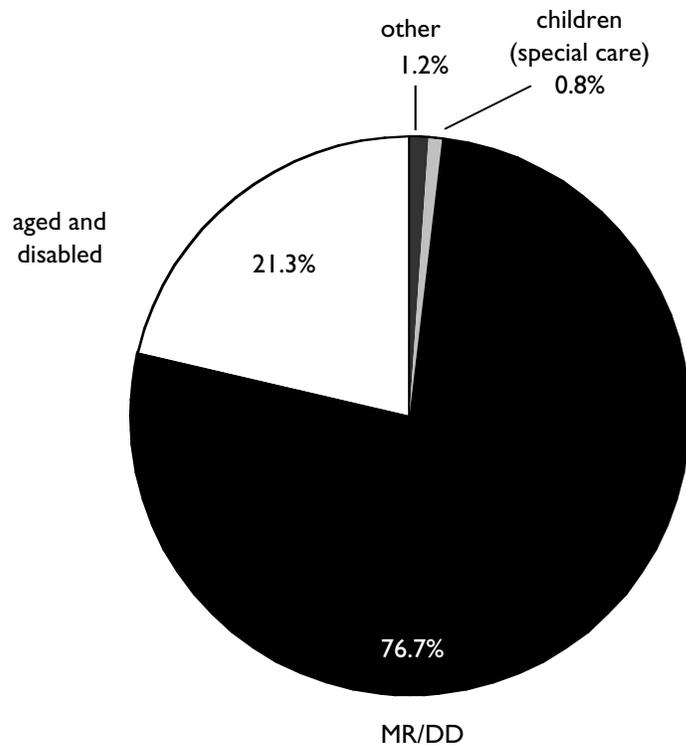
NOTE: Institutional spending includes those serving 16 or more people and does not include nursing homes. Community services includes residential programs for 15 or fewer persons and non-residential community services as well as family support, supported employment, and supported living/personal assistance.

Source: Urban Institute, 2001. Based on Braddock, Hemp, Parish, and Rizzolo, *The State of the States in Developmental Disabilities: 2000 Study Summary*, Department of Disability and Human Development, University of Illinois at Chicago.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

Medicaid waiver spending grew by almost 260 percent between 1992 and 1997.

MEDICAID WAIVER SPENDING IN 1997: \$7.9 BILLION



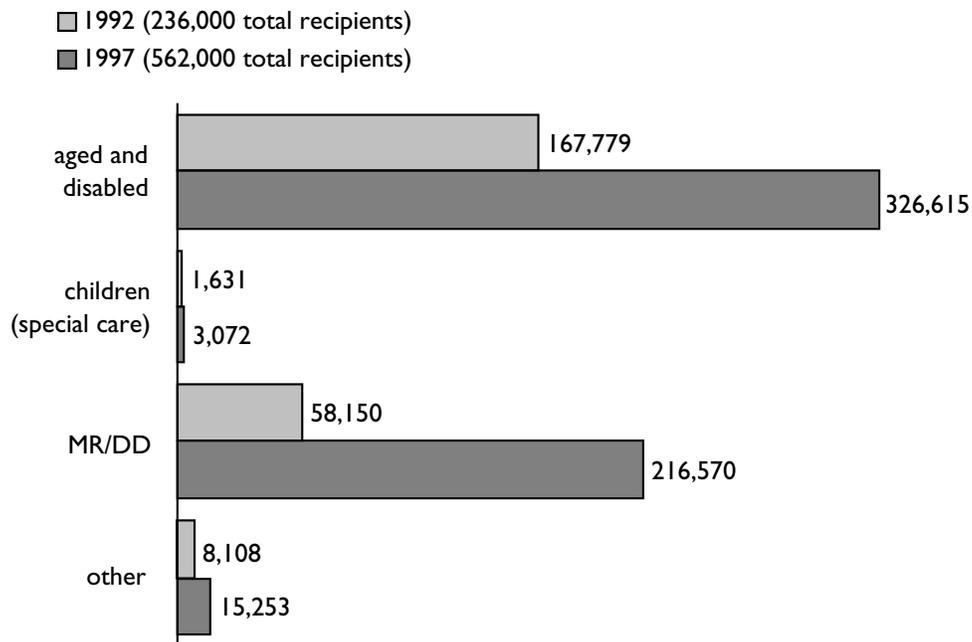
NOTE: The “other” category in this chart includes people with AIDS and AIDS-related complex, people with mental disabilities, and people with traumatic brain or head injuries. The “aged and disabled” population includes people age 65 and older, and people between ages 18 and 64 with disabilities.

Source: *Urban Institute, 2001*. Based on C. Harrington, et al. *1915(c) Medicaid Home and Community-Based Waiver Participants, Services, and Expenditures, 1992-1997*. Department of Social and Behavioral Sciences, University of California at San Francisco, March 2000.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

The number of people served in the waiver program grew by nearly 140 percent in five years.

TYPES OF MEDICAID WAIVER RECIPIENTS



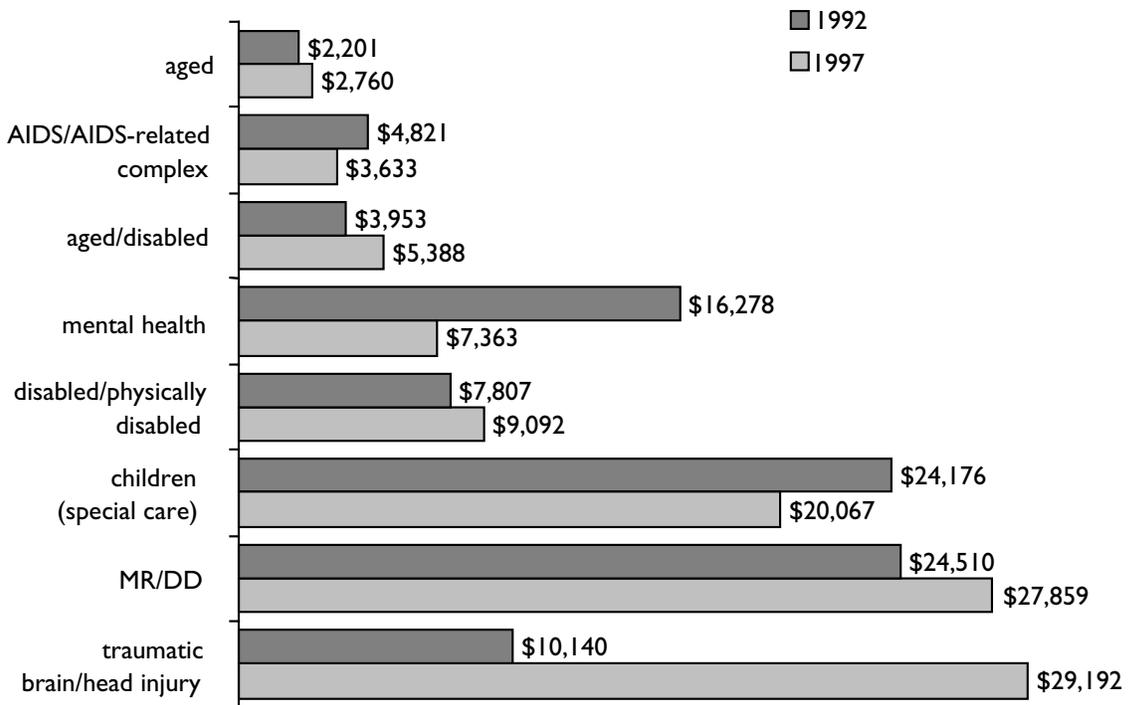
NOTE: The “other” category in this chart includes people with AIDS and AIDS-related complex, people with mental disabilities, and people with traumatic brain or head injuries. The “aged and disabled” population includes people age 65 and older, and people between ages 18 and 64 with disabilities.

Source: Urban Institute, 2001. Based on 1915(c) Medicaid Waiver Program Data from HCFA Form 372 reports, collected from states in C. Harrington, H. Carillo, V. Wellin, F. Norwood, and N. Miller, *1915(c) Medicaid Home and Community-Based Waiver Participants, Services, and Expenditures, 1992-97*, Department of Social and Behavioral Sciences, University of California at San Francisco, November 1999. Harrington et al. collected HCFA Form 372s from states for the years 1992 and 1997. In a few states, the states or the researchers estimated the numbers because data were not available. Edits were made to correct state calculations or to identify missing data. No effort was made to estimate missing service expenditure data.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

In 1997, average annual spending per waiver recipient ranged from about \$2,800 to \$29,200.

AVERAGE ANNUAL MEDICAID WAIVER SPENDING PER TYPE OF RECIPIENT

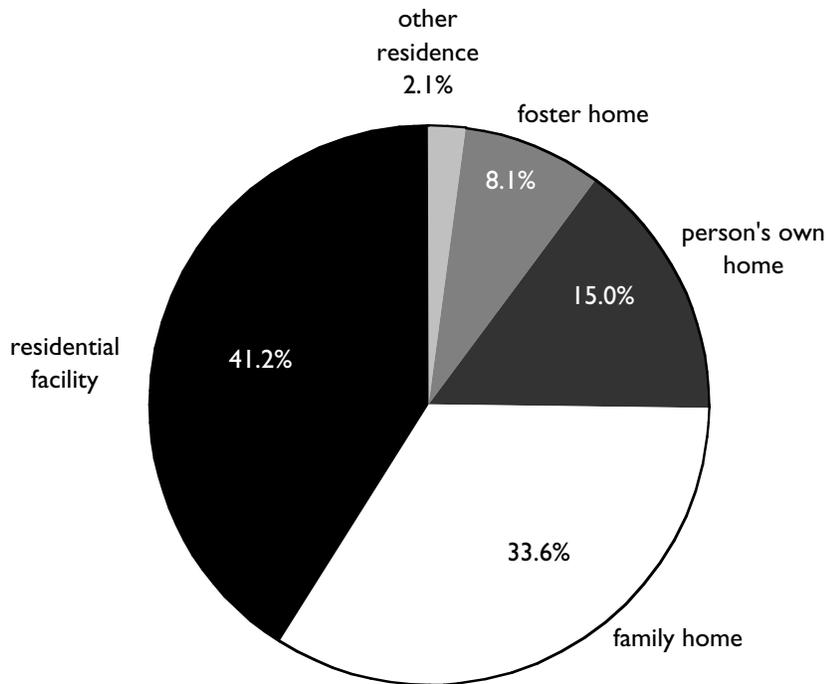


Source: Urban Institute, 2001. Based on 1915(c) Medicaid Waiver Program Data from HCFA Form 372 reports, collected from states in C. Harrington, H. Carillo, V. Wellin, F. Norwood, and N. Miller, *1915(c) Medicaid Home and Community-Based Waiver Participants, Services, and Expenditures, 1992-97*, Department of Social and Behavioral Sciences, University of California at San Francisco, November 1999. Harrington et al. collected HCFA Form 372s from states for the years 1992 and 1997. In a few states, the states or the researchers estimated the numbers because data were not available. Edits were made to correct state calculations or to identify missing data. No effort was made to estimate missing service expenditure data.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

The waiver program has significantly expanded service options for people with mental retardation/developmental disabilities (MR/DD).

SERVICE LOCATIONS FOR MEDICAID WAIVER RECIPIENTS WITH MR/DD IN 1998



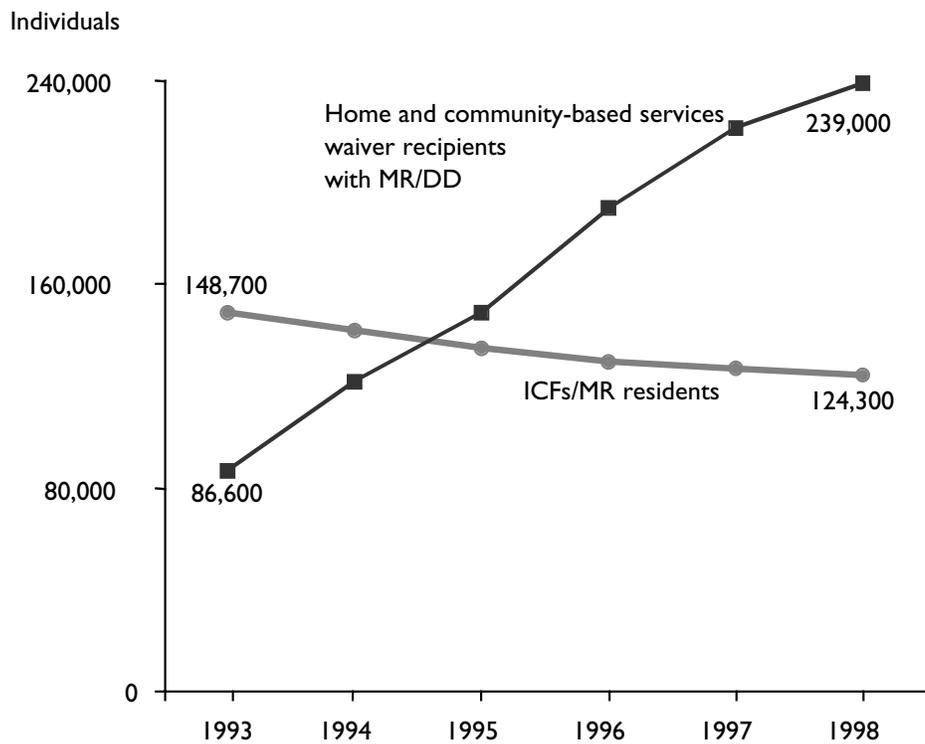
NOTE: Data on the MR/DD population that Prouty et al. report come from annual surveys of each state's MR/DD programs and administrators of all large (16 or more residents) state MR/DD facilities. A residential facility is a place of residence owned, rented, or managed by an agency, in which staff provide care, instruction, supervision, and support to residents with MR/DD.

Source: *Urban Institute, 2001*. Based on R. Prouty et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998*, Institute on Community Integration, University of Minnesota, May 1999.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

A 16 percent drop in the use of intermediate care facilities (ICFs/MR) has accompanied a 175 percent jump in the use of the waiver program by people with mental retardation/developmental disabilities (MR/DD).

CHANGE IN THE USE OF LONG-TERM CARE SERVICES BY PEOPLE WITH MR/DD

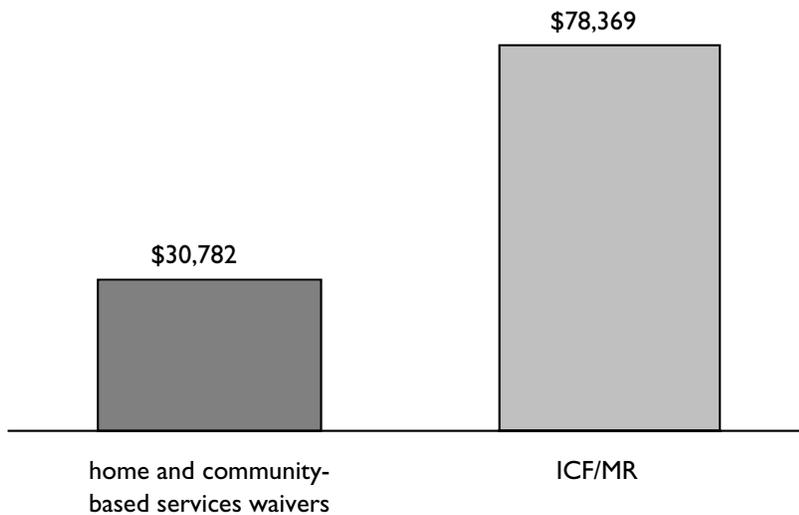


Source: Urban Institute, 2001. Based on R. Prouty et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998*, Institute on Community Integration, University of Minnesota, May 1999.

**MEDICAID WAIVERS FOR HOME AND COMMUNITY-BASED SERVICES**

Spending on a person receiving services through home and community-based services waivers is much lower than spending on an individual in an intermediate care facility for the mentally retarded (ICF/MR).

ANNUAL SPENDING ON SERVICES FOR A PERSON WITH MR/DD IN 1998

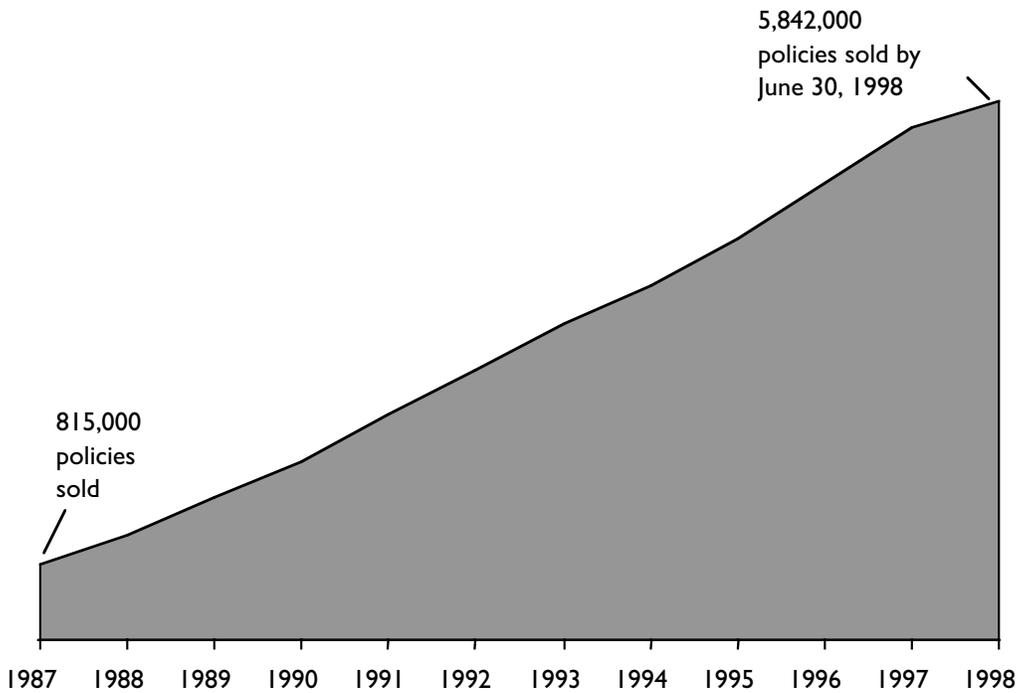


Source: Urban Institute, 2001. Based on R. Prouty et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998*, Institute on Community Integration, University of Minnesota, May 1999.

**PRIVATE LONG-TERM CARE INSURANCE**

Between 1987 and 1998, 119 companies sold over 5.8 million long-term care insurance policies.

CUMULATIVE NUMBER OF LONG-TERM CARE INSURANCE POLICIES SOLD



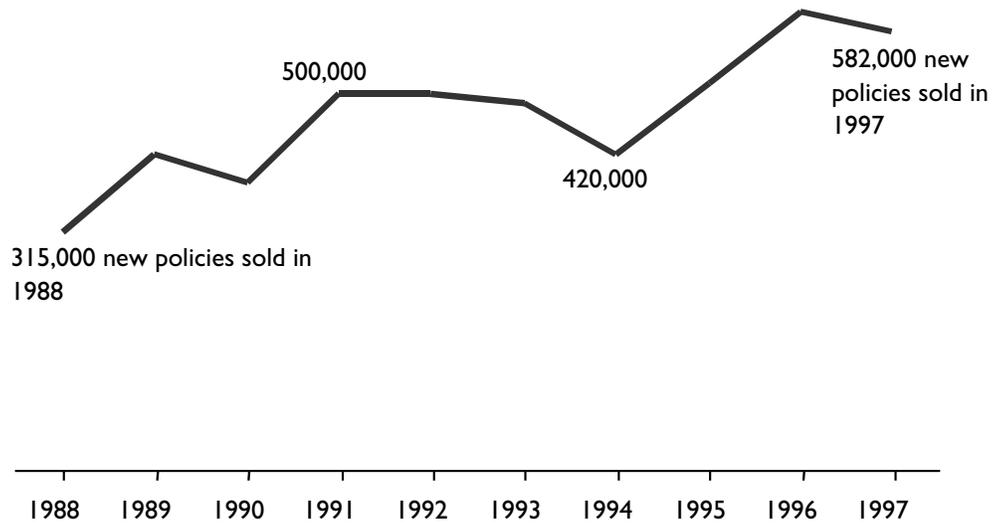
NOTE: The cumulative number of policies sold does not equal the number of policies in force.

Source: *Urban Institute, 2001*. Based on Health Insurance Association of America (HIAA), *Long-Term Care Insurance in 1987-1998*, March 2000. The HIAA data came from an annual written survey of all known long-term care insurance sellers in the individual and group association, employer-sponsored, and riders to life insurance markets. Each participating firm was asked to send HIAA a copy of its most recent policy and marketing materials.

**PRIVATE LONG-TERM CARE INSURANCE**

The number of new long-term care insurance policies sold each year has been on the rise. Life Plans, Inc., estimates that between 55 and 65 percent of policies sold were still in effect in 1998.

GROWTH IN SALES OF NEW LONG-TERM CARE INSURANCE POLICIES

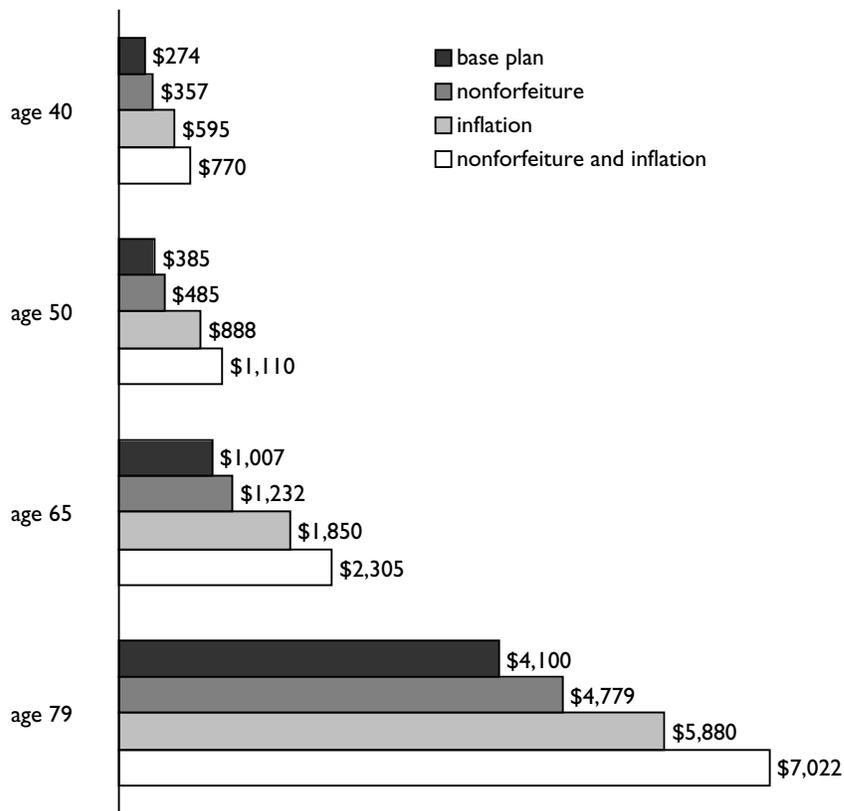


Source: Urban Institute, 2001. Based on data in Health Insurance Association of America, *Long-Term Care Insurance in 1987-1998*, March 2000. The HIAA data came from an annual written survey of all known long-term care insurance sellers in the individual and group association, employer-sponsored, and riders to life insurance markets. Each participating firm was asked to send HIAA a copy of its most recent policy and marketing materials.

**PRIVATE LONG-TERM CARE INSURANCE**

A non-forfeiture benefit protects the policyholder’s investment if he or she decides to drop the policy. Without inflation protection, the purchasing power of a policy erodes over time. Both protections boost policy premiums.

AVERAGE ANNUAL PREMIUMS FOR LEADING LONG-TERM CARE INSURANCE SELLERS IN 1997



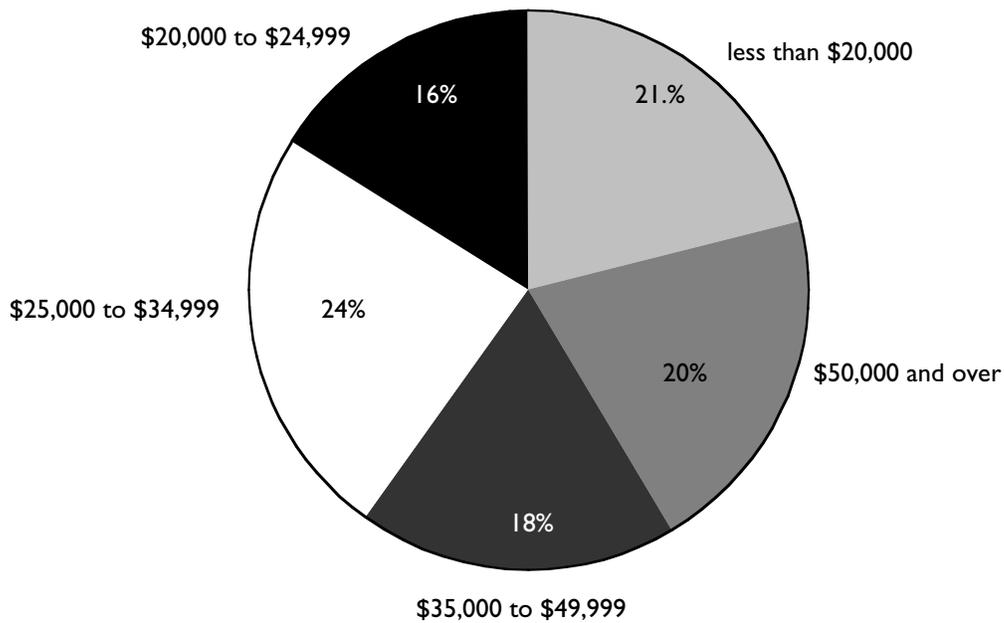
NOTE: Premiums are generally for policies that provide: \$100 a day in nursing and home care; at least \$80 a day in assisted living facility care; at least \$50 a day in home care; four years of coverage and a 20-day elimination, or deductible, period.

Source: Urban Institute, 2001. Based on Health Insurance Association of America, *Long-Term Care Insurance in 1987-1998*. March, 2000. The data come from an annual written survey of all known long-term care insurance sellers in the individual and group association, employer-sponsored, and riders to life insurance markets. Each participating firm was asked to send a copy of its most recent policy and marketing materials.

**PRIVATE LONG-TERM CARE INSURANCE**

Purchasers of private long-term care insurance age 55 and older tend to have higher incomes.

ANNUAL INCOMES OF INDIVIDUAL PURCHASERS OF LONG-TERM CARE INSURANCE AGE 55 AND OLDER IN 1994

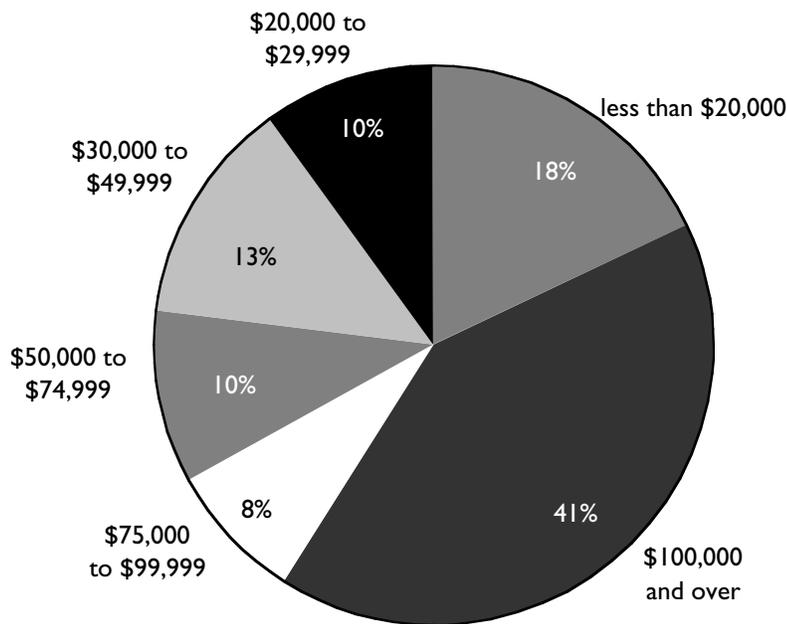


Source: *Urban Institute, 2001*. Based on M.A. Cohen and A. K. N. Kumar, "The Changing Face of Long-Term Care Insurance in 1994: Profiles and Innovations in a Dynamic Market," *Inquiry*, 34, Spring 1997, p. 50-61. Data reported come from a survey of individual purchasers and non-purchasers of long-term care insurance from nine companies representing more than 65 percent of total individual sales in 1994. Response rates were 63 percent for purchasers and 38 percent for non-purchasers. Data on the general population came from a survey of a representative sample of persons age 55 and over.

**PRIVATE LONG-TERM CARE INSURANCE**

Purchasers of private long-term care insurance age 55 and older tend to have more liquid assets.

LIQUID ASSETS OF INDIVIDUAL PURCHASERS OF LONG-TERM CARE INSURANCE AGE 55 AND OLDER IN 1994



Source: *Urban Institute, 2001*. Based on M.A. Cohen and A. K. N. Kumar, "The Changing Face of Long-Term Care Insurance in 1994: Profiles and Innovations in a Dynamic Market," *Inquiry*, 34, Spring 1997, p. 50-61. Data reported come from a survey of individual purchasers and non-purchasers of long-term care insurance from nine companies representing more than 65 percent of total individual sales in 1994. Response rates were 63 percent for purchasers and 38 percent for non-purchasers. Data on the general population came from a survey of a representative sample of persons age 55 and over.

## ADDITIONAL RESOURCES

This chart book highlights the three major components of long-term care services: consumers, providers, and financing. For more information on issues related to long-term care and disabled and elderly populations, consider the following resources available from the Urban Institute Publications Sales Office and Web site. Resources are listed in reverse chronological order.

### **Consumer-Directed Home and Community Services: Policy Issues**

By Jane Tilly and Joshua M. Wiener, January 2001

An examination of eight states' consumer-directed home and community services for older persons and their policy implications.

### **Consumer-Directed Home and Community Services Programs in Five Countries: Policy Issues for Older People and Government**

By Jane Tilly, Joshua M. Wiener, Alison Evans Cuellar, October 2000

An analysis of the development, design, and experience of consumer-directed home care programs in Austria, Germany, France, the Netherlands, and the United States (US). The US states included in this study are California, Colorado, Kansas, Maine, Michigan, Oregon, Washington, and Wisconsin.

### **State Welfare to Work Policies for People with Disabilities: Implementation Challenges and Considerations**

By Pamela A. Holcomb and Terri S. Thompson, August 2000

A report on key operational issues associated with serving welfare recipients with disabilities.

### **Parental Care at Midlife: Balancing Work and Family Responsibilities Near Retirement**

By Richard W. Johnson and Anthony T. Lo Sasso, March 2000

A report on findings from a recent Urban Institute study of the characteristics of persons in their fifties and early sixties who provide care to their elderly parents and the trade-offs that families face when they divide their time between the provision of informal care and paid work.

### **The Trade-Off between Hours of Paid Employment and Time Assistance to Elderly Parents at Midlife**

By Richard W. Johnson and Anthony T. Lo Sasso, February 2000

A study that shows that although the family has traditionally been the primary caregiver for the frail elderly, the rising labor force participation rates of married women may interfere with their historical caregiving responsibilities.

### **Long-Term Care for the Elderly in the District of Columbia: Issues and Prospects**

By Joshua M. Wiener and David G. Stevenson, May 1999

An examination of the challenges facing the District of Columbia in organizing, financing, and assuring quality in long-term care for the elderly. The paper analyzes issues related to long-term care policy development and implementation, home and community-based services, and nursing homes.

## ADDITIONAL RESOURCES

### **Controlling the Supply of Long-Term Care Providers at the State Level**

By Joshua M. Wiener, David G. Stevenson, and Susan M. Goldenson, December 1998

An analysis of the use of certificate of need (CON) programs and moratoria as a long-term care cost-control strategy across 13 states: Alabama, California, Colorado, Florida, Massachusetts, Michigan, Minnesota, Mississippi, New Jersey, New York, Texas, Washington, and Wisconsin.

### **State Welfare-to-Work Policies for People with Disabilities: Changes Since Welfare Reform**

By Terri S. Thompson, Pamela A. Holcomb, Pamela Loprest, and Kathleen Brennan, December 1998

A new national study that finds that most states are beginning to require participation in welfare-to-work programs by individuals who previously had been exempt due to a disability.

### **Long-Term Care for the Elderly: Profiles of Thirteen States**

By Joshua M. Wiener and David G. Stevenson, August 1998

An examination of long-term care for the elderly in 13 states: Alabama, California, Colorado, Florida, Massachusetts, Michigan, Minnesota, Mississippi, New Jersey, New York, Texas, Washington, and Wisconsin; with particular attention to efforts to control the rate of increase in Medicaid long-term care expenditures for the elderly.

### **Policy Challenges Posed by the Aging of America**

By Len Burman, Rudolph Penner, Gene Steuerle, Eric Toder, Marilyn Moon, Larry Thompson, Michael Weisner, and Adam Carasso, May 1998

A discussion paper that outlines one of the nation's greatest challenges as it moves into the 21st century. Topics include the dramatic demographic shift already taking place, economic policies affecting Social Security and Medicare, and the need for additional research.

### **Can Private Insurance Solve the Long-Term Care Problems of the Baby Boom Generation?**

Testimony by Joshua M. Wiener, presented at a hearing held by the Special Committee on Aging, United States Senate, Washington, D.C., March 9, 1998.

An argument that serious long-term care reform that seeks to make life better for the great majority of the elderly will require expansions of public programs—Medicare, Medicaid, and others—that currently are the major source of third-party funding.

### **State Level Databook on Health Care Access and Financing**

By David W. Liska, Niall J. Brennan, and Brian K. Bruen, Third Edition, 1998

A comprehensive picture of the current health system at the state level, including state-level data on the insurance coverage of different groups of people; the characteristics of the uninsured; Medicaid enrollees and expenditures; health status; health care costs, access, and utilization; and state-specific demographics and economic profiles. It also reports totals for the entire United States and averages for nine Census regions.

## ADDITIONAL RESOURCES

### **Long-Term Care for the Elderly and State Health Policy**

By Joshua M. Wiener and David G. Stevenson, November 1997

A discussion of three broad strategies that states could use to control spending for Medicaid long-term care services for the elderly, including an overview of utilization and expenditures patterns associated with long-term care for the elderly.

### **Supplemental Security Income for Children with Disabilities: Part of the Federal Safety Net**

By Pamela J. Loprest, July 1997

A brief that estimates, by state, the number of children in low-income families likely to lose cash benefits from Supplemental Security Income (SSI) under the 1996 welfare reform law. The estimates highlight the potential fiscal risks states face as low-income families lose federal SSI benefits and need replacement income to fill the gap.

### **Profile of Disability among AFDC Families**

By Pamela J. Loprest and Gregory P. Acs, 1996

An assessment of the extent to which women and families receiving Aid to Families with Dependent Children had a limited ability to work due to their own disabilities or those of their children.

## ABOUT THE AUTHORS

*Long-Term Care: Consumers, Providers, and Financing—A Chart Book*, is based on *Long-Term Care Chart Book: Persons Served, Payors, and Spending*, a report to Congress that was written by the following authors.

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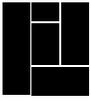
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