



Del Mar Caregiver Resource Center
A program of Health Projects Center

Fact Sheet

Selected Long-Term Care Statistics

What is Long-Term Care?

Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks, called *activities of daily living* (ADLs), or household chores, known as *instrumental activities of daily living* (IADLs). Long-term care often involves the most intimate aspects of people's lives — what and when they eat, personal hygiene, getting dressed, using the bathroom. Other less severe long-term care needs may involve household tasks such as preparing meals or using the telephone.

A report prepared by the U.S. Senate Special Committee on Aging (February, 2000) described long-term care as follows:

It [long-term care] differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning....Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity

for self-care because of a chronic illness or disabling condition.¹

Because long-term care needs and services are wide-ranging and complex, statistics may vary from study to study. Sources for the following information are cited at the conclusion of this Fact Sheet. For additional information, see the *FCA Fact Sheet on Selected Caregiver Statistics*.

Who Needs Long-Term Care?

- An estimated 12.1 million Americans need assistance from others to carry out everyday activities.²
- Most but not all persons in need of long-term care are elderly. Approximately 53% are persons aged 65 and older (6.4 million); 44% are working-age adults aged 18 to 64 (5.3 million); and 3% are children under age 18 (400,000).³
- Of the older population with long-term care needs in the community, about 30 percent (1.5 million persons) have substantial long-term care needs (3 or more ADL limitations). Of these, about

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25% are 85 and older and 70% report they are in fair to poor health.⁴

- 40% of the older population with long-term care needs are poor or near poor (with incomes below 150% of the federal poverty level).⁵
- Between 1984 and 1994, the number of older persons receiving long-term care remained about the same, while the prevalence of long-term care use declined from 19.7% to 16.7% of the 65+ population. In comparison, 2.1% of the population aged 18-64 received long-term care in the community in 1994.⁶
- While there was a decline in the proportion (i.e., prevalence) of the older population receiving long-term care, the level of disability and cognitive impairment among those who received assistance with daily tasks rose sharply. The proportion receiving help with three to six ADLs increased from 35.4% to 42.9% between 1984 and 1994. The proportion of cognitive impairment among the 65+ population rose from 34 to 40 percent.⁷
- The prevalence of cognitive impairment among the older population increased over the decade, while the prevalence of physical impairments remain unchanged.⁸
- In 1998, the percentage of older persons with moderate or severe memory impairment ranged from about 4% among persons aged 65-69 to about 36% among persons aged 85 or older.⁹
- Individuals 85 years and older, the *oldest old*, are the fastest growing segment of the population. In 2000, there were an estimated 4 million people 85+ in the United States¹⁰. This figure is expected to increase to 18 million in the next 50 years¹¹. This means that there could be an increase from 1.4 million to 6.3

million people over the age of 85 with severe or moderate memory impairment fifty years from now.

Where do People Receive Long-Term Care and from Whom?

Family and Informal Caregivers

Informal caregiver and *family caregiver* are terms used to refer to unpaid individuals such as family members, friends and neighbors who provide care. These persons can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. *Formal caregivers* are volunteers or paid care providers associated with a service system.^{12, 13}

Estimates vary on the number of informal caregivers in the U.S., depending on the definitions used for both caregiver and care recipient:

- **52 million** informal and family caregivers provide care to someone aged 20+ who is ill or disabled.¹⁴
- **25.8 million** family caregivers provide personal assistance to adults (aged 18+) with a disability or chronic illness.¹⁵
- Nearly **one out of every four households** (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over.¹⁶
- By the year 2007, the number of caregiving households in the U.S. for persons aged 50+ could reach **39 million**.¹⁷
- **5.8¹⁸ - 7¹⁹ million** people (family, friends and neighbors) provide care to a person (65+) who needs assistance with everyday activities.²⁰
- **5 million** informal caregivers provide care for someone aged 50+ with dementia.²¹

- Most people—nearly 79% — who need LTC live at home or in community settings, not in institutions.²²
- About two-thirds (64%) of older persons living in the community and in need of long-term care depend on family and friends (i.e., informal caregivers) as their only source of help; 28% receive a combination of informal and formal care (i.e., paid help); only 8% used formal care or paid help only.²³
- Even among the most severely disabled older persons living in the community, about half rely solely on family members and other informal help, often resulting in great strain for the family caregivers.²⁴
- There is a trend towards people receiving a combination of formal and informal caregiving. In 1982, 73.6% of Medicare beneficiaries age 65+ received home care services from informal caregivers alone. In 1994 this figure dropped to 64.3% but was accompanied by a rise in the number of individuals in this population receiving both formal and informal care from 21% to 28%.²⁵

Home and Community-Based Care

- Approximately 1.7 million people age 65 and older received formal home health care on any given day in 1996.²⁶
- Between 1997 and 1998, 1,028,997 individuals received Medicaid personal care services or home and community based services through a Medicaid Waiver program.²⁷
- The trend towards community-based services as opposed to nursing home placement was formalized with the *Olmstead Decision* (July, 1999) — a court case in which the Supreme Court upheld the right of individuals to receive

care in the community as opposed to an institution whenever possible.

- About one-third of disabled, elderly persons use paid care, either alone or in combination with informal care.²⁸
- In 1998, the average number of home care visits per client for those covered by Medicare fee-for-service was 51 visits per year for a total of almost 155 million home visits.²⁹
- Reflecting changing trends in the health and long-term care system, older persons receiving paid care averaged fewer paid hours of help a week in 1995 compared to help received in 1985.³⁰
- 4.6 million people age 65+ received home health care services in 1996 compared to 2.6 million under the age of 65.³¹
- 39% of Medicare home health users require help with three or more ADLs.³²
- Based on the figures for Medicare recipients, those using home care services are more likely to live alone than non-users.³³
- Between 1998 and 2000, the number of assisted living and board and care facilities increased from 24,572 to 32,886 nationally reflecting the trend towards community-based care as opposed to nursing homes.³⁴
- Most assisted living facilities (ALFs) discharge residents whose cognitive impairments become moderate or severe or who need help with transfers (e.g. moving from a wheelchair to a bed.) This limits the ability of these populations to find appropriate services outside of nursing homes or other institutions.³⁵

Nursing Home Care

- The risk of nursing home placement increases with age — 31% of those who are severely impaired and between the ages of 65 and 70 receive care in a nursing home compared to 61% of those age 85 and older.³⁶
- There were 1,465,000 people in nursing homes in 1997 nationally, approximately 4% of the older population.³⁷
- In 1997, 46% of the nursing home population was aged 85 or older compared to 33% aged 75 - 84, 13% aged 65 - 74, and 8.5% under age 65.³⁸

What Does Long-Term Care Cost?

- Public and private spending on long-term care services was estimated to exceed \$127 billion in 1998. About \$78.4 billion of this money was federal and state government funds. \$34.5 billion was paid for out-of-pocket by individuals and families.³⁹
- In 1997, \$83 billion were spent on nursing home care compared to \$32 billion for home care. It is estimated that the value of informal (i.e., unpaid) caregiving is more than both of these combined — \$196 billion.⁴⁰
- Despite the trend toward community based care as opposed to institutionalized care, only 18.2% of long-term care expenditures for the elderly are for community based care.⁴¹
- For the family caregiver forced to give up work to care for a family member or friend, the cost in lost wages and benefits is estimated to be \$109 per day.⁴²
- In 1999, Medicaid paid \$62.4 billion for long-term care services, 26.2% of which

went to home and community based services.⁴³

- Medicaid coverage of assisted living may have grown by 50%.⁴⁴
- 40% of the annual estimated home care expenditures were paid for by Medicare in 1997, a little over 21% were paid for out-of-pocket, and approximately 15% were covered by Medicaid.⁴⁵
- Only 7% of residents receive Medicaid coverage for assisted living.⁴⁶
- Studies have consistently found that the delivery of community-based, long-term care services is a cost effective alternative to nursing homes. Annual cost estimates in 2000 were \$13,000 for adult day care, \$25,300 for assisted living and \$44,100 for nursing home care.⁴⁷
- Spending for home and community-based services through Medicaid waiver programs averaged \$485 per month per recipient compared to \$2,426 per month for nursing home services.⁴⁸
- Over two-thirds of the current health care dollar goes to treating chronic illness; for older persons the proportion rises to almost 95%.⁴⁹
- The aging of the population is expected to result in a tripling of long-term care expenditures in the next 40 years from \$115 billion to \$346 billion annually.⁵⁰

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Del Mar Caregiver Resource Center supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

For residents of Central California, Monterey, Santa Cruz and San Benito Counties, Del Mar CRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

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