

Who needs long-term care?

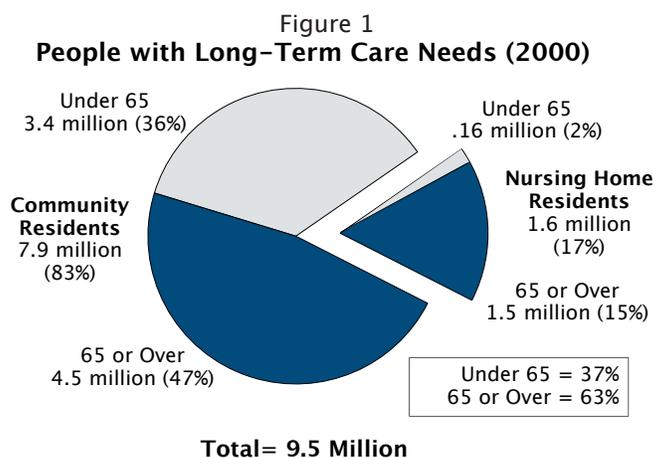
Although long-term care is often needed by people who have the greatest medical care needs, medical care and long-term care are quite different. Medical care consists mainly of services and products for preventing, diagnosing, and treating health conditions and is typically delivered or directed by a physician or other highly-trained medical professional.

Long-term care, in contrast, consists predominantly of assistance with essential, routine tasks of life—such as bathing, getting around the house, and preparing meals—provided to people who need this assistance because of physical or mental conditions or disability. This help may be delivered in a hands-on fashion or may be stand-by or supervisory in nature, such as providing reminders or prompts. Long-term care also includes therapies that help improve a person’s functioning and special equipment (such as walkers, wheelchairs, and grab bars) that enhance a person’s ability to function.

People receive long-term care in a variety of settings including: private homes; other community settings such as adult day care centers, assisted living facilities, and board and care homes; and nursing homes. Family members and friends provide a substantial amount of long-term care. The bulk of formal (paid) care is provided by home health aides, certified nursing assistants, and personal care assistants, often under the direction of nurses.¹

People Who Need Long-Term Care

The need for long-term care arises from various causes, including diseases, disabling chronic conditions, injury, severe mental illness, and developmental disabilities. In estimating the number of people with long-term care needs, researchers usually define a person as needing long-term care if he or she requires another person’s help with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are fundamental tasks, defined here to include bathing, eating, dressing, using the toilet, getting in and out of a bed or chair, and getting around inside the home. IADLs are additional activities necessary

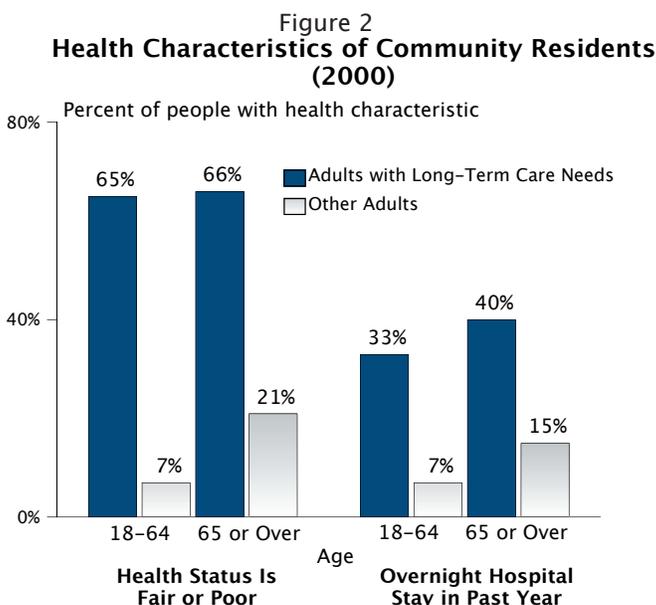


NOTE: Components may not sum to totals because of rounding.
 SOURCES: Health Policy Institute, Georgetown University, analysis of data from the 2000 National Health Interview Survey; and A. Jones, "The National Nursing Home Survey: 1999 Summary," *Vital Health Statistics* 13 (152) (2002).

for independence, such as meal preparation, managing money, managing medications, using the telephone, doing light housework, and shopping for groceries and other necessities.

Nearly 10 million people need long-term care—that is, need help with ADLs or IADLs (see Figure 1). Most are age 65 or older, but 37 percent are under age 65. The risk of needing long-term care does, however, rise steeply with age. Among people age 65 or over, 14 percent need long-term care, in contrast to 1.4 percent of people under age 65. Among people age 85 and older, half need some long-term care.²

Not surprisingly, the need for long-term care is often accompanied by other health-related needs. About two-thirds of adults living at home with long-term care needs are in fair or poor health (see Figure 2). Furthermore, among community-dwelling adults with long-term care needs, one-third of those under age 65, and 40 percent of those age 65 or over, have spent a night in the hospital during the previous



SOURCE: Health Policy Institute, Georgetown University, analysis of data from the 2000 National Health Interview Survey.

year (compared with 7 percent and 15 percent, respectively, of community adults without long-term care needs).

The majority of people with long-term care needs are women. Among community residents with long-term care needs, 60 percent of those age 18 to 64, and 69 percent of those age 65 and older, are women.³ Among nursing home residents of all ages, 72 percent are women.⁴

More than four-fifths (83 percent) of people with long-term care needs live in the community (see Figure 1). The proportion is higher among younger people with long-term care needs—96 percent for those under 65, compared with 75 percent for those age 65 or older and 61 percent for those age 85 or older.

Community Residents. There is considerable variation in the extent of long-term care need among community residents. Some people need assistance for a few hours each week, while others need full-time support. Many people have substantial need—21 percent of community adults with long-term care needs, or 1.8 million people, require assistance in three or more ADLs.⁵

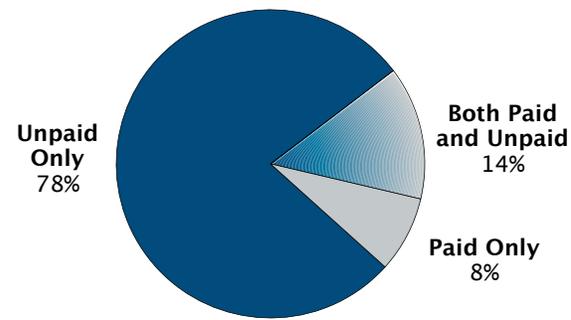
More than three-quarters of community-dwelling adults with long-term care needs rely exclusively on unpaid assistance from family members, friends, or volunteers (see Figure 3). The other 22 percent receive varying amounts of paid assistance—usually in combination with unpaid assistance—including services provided by home health or home care agencies, self-employed individuals, and adult day care providers. Only 8 percent of adults receiving long-term care at home depend solely on paid care. Even among community residents with substantial long-term care needs—those who need assistance with three or more ADLs—two-thirds rely exclusively on unpaid help.⁶

Nursing Home Residents. People living in nursing homes generally have high levels of disability. Three in four require assistance in three or more ADLs.⁷ One in two have some form of dementia.⁸ In addition to substantial disability, a lack of family support can be an important factor in nursing home entry.⁹

Policy Concerns

The quality of life for people with long-term care needs depends on their ability to obtain care in an environment and manner they prefer. Several trends, including the increased availability of alternative residential settings (such as assisted living facilities), growing awareness of the importance of giving people control over their care, and technological

Figure 3
Distribution of Adults Receiving Long-Term Care at Home, by Type of Care



SOURCE: Health Policy Institute, Georgetown University, analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability, Phase II.

advances that enable people to better manage at home, are helping improve the quality of life for people with long-term care needs.

However, people with long-term care needs continue to face considerable barriers to obtaining needed care. Some cannot afford care or are unaware of how to arrange for care (or unable to do so without help). Others cannot obtain care of the desired quality and type where and when they need it. Findings from a national survey indicate that one-fifth of community-dwelling adults with long-term care needs do not receive enough assistance with basic activities.¹⁰ Despite reforms in nursing home regulations, problems with quality of care still exist and many nursing home residents live in facilities that have serious deficiencies.¹¹

Notes

¹ R. Stone, *Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-first Century* (New York: Milbank Memorial Fund, 2000).

² Health Policy Institute (HPI), Georgetown University, analysis of data from the 2000 National Health Interview Survey.

³ *Ibid.*

⁴ A. Jones, "The National Nursing Home Survey: 1999 summary," *Vital Health Statistics* 13 (152) (2002).

⁵ HPI analysis of data from the 2000 National Health Interview Survey.

⁶ HPI analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability.

⁷ Jones.

⁸ N.R. Sahyoun et al., "The Changing Profile of Nursing Home Residents: 1985 - 1997," *Aging Trends* 4 (Hyattsville, MD: National Center for Health Statistics, 2001).

⁹ W. Scanlon, "Possible Reforms for Financing Long-Term Care," *Journal of Economic Perspectives* 6 (3): 43-58 (1992).

¹⁰ HPI analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability.

¹¹ U.S. General Accounting Office, *Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards* (Washington, DC: GPO, 1999).



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About the Project

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