

Who Needs and Who Uses Long-Term Care?

The LTC Fundamentals Series is produced by The SCAN Foundation to highlight and describe the organization and financing of long-term care (LTC) in California. This brief focuses on who uses long-term care, their demographic and functional characteristics, and the risk of using long-term care services.

Introduction

California is the most populous state in the nation with just over 36.5 million residents. It is anticipated that this number will increase by 27% in the next 20 years, in part due to the aging of the population.¹ In 2011, the largest generation in history – the Baby Boomers – will start turning 65, resulting in a rapid increase in the number of older Americans in the United States. In California, the number of individuals age 65 and older is projected to increase 100% in the next 20 years (from 4.41 million in 2010 to 8.84 million in 2030).² In addition to the aging population, the number of working-age adults with disabilities is expected to grow by approximately 20% in the next 20 years.³

In 2010, the projected average life expectancy is almost 81 years for women and almost 76 years for men.⁴ Not only is the population aging but it is also living longer, often with disabling conditions. In 2000, 125 million, or 45.4% of Americans had one or more chronic conditions. By 2030, it is anticipated that this number will increase by 37% to 171 million, thereby increasing the demand and need for LTC services.⁵

This LTC Fundamentals brief considers both the need for and the use of LTC services. We define “need” based on the presence of functional and cognitive impairment (further described below). We define “services” as those generally provided by informal caregivers (friends and family members) or formal caregivers (paid LTC providers). It is important to note, however, that not all individuals defined as needing LTC use these services, due to cost, other lack of access, lack of awareness of services, or other factors.

What is Long-Term Care and How is Need Defined?

Long-term care (LTC) refers to a broad range of services provided by paid or unpaid providers that can support people who have limitations in their ability to care for themselves due to a physical, cognitive, or chronic health condition that is expected to continue for an extended period of time. These care needs may arise from 1) an underlying health condition as is most common among older adults, 2) an inherited or acquired disabling condition among younger adults, and/or 3) a condition present at birth.

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LTC services can be provided in a variety of settings including one’s home (e.g., home care or personal care services), in the community (e.g., adult day care), in residential settings (e.g., assisted living or board and care homes), or in institutional settings (e.g., intermediate care facilities or nursing homes). The term “home- and community-based services” (HCBS) refers collectively to those services that are provided outside of institutional settings.

Generally, a person needing LTC is one who requires assistance with activities of daily living (ADLs, including bathing, dressing, eating, transferring, walking) or instrumental activities of daily living (IADLs, including meal preparation, money management, house cleaning, medication management, transportation), regardless of the cause of their disability.

ADL and/or IADL impairments stem from either a physical, cognitive or mental health issue resulting from an underlying health condition or a traumatic injury, as well as conditions that are inherited at birth or acquired later in life. In comparison to persons with physical disabilities, persons with cognitive impairment or mental health issues may be fully capable of performing ADLs and/or IADLs but may not always be able to perform them safely on their own, putting themselves and others at risk.

Table 1 describes the prevalence of different types of disability in the United States and California, by age group. Overall, the prevalence of any disability among older adults in California is comparable to the nation as a whole.

Population aging, increasing longevity, and a corresponding increase in disability prevalence will likely amplify the need for LTC services. Given that public dollars fund a substantial amount of paid LTC

services, it is likely that this projected increase in demand will place significant fiscal pressure on federal, state, and local governments.

What is the Likelihood that One Might Use Long-Term Care Services?

The likelihood of using LTC services increases with age. The likelihood of becoming disabled in two or more ADLs or of developing cognitive impairment is 68% among those age 65 and older, meaning that almost 7 out of 10 seniors will have substantial needs for supportive care.⁶ Almost half of all seniors will enter a nursing home at some point in their lives, even if only for a short rehabilitative stay. And the likelihood of any use of HCBS is 71.8% among those age 65 and older, representing over 7 out of 10 seniors.⁷ Among those who use any LTC services, the average person will require at least three years of care.⁸

Characteristics of Individuals Who Need Long-Term Care

As many as 12 million people nationally have a need for LTC due to a physical impairment.⁹ This figure may under-represent the number of individuals who need LTC due to a mental illness or cognitive impairment because surveys reporting this information often base need solely on ADL and IADL needs. About 1.8 million of these individuals receive LTC support in a nursing home. Among those who have LTC needs residing in the community, only about 13% receive these services from formal, or paid, LTC

TABLE 1 Prevalence of Disability in the United States and California, by Age and Type of Disability*		
	United States	California
<i>Persons age 65+</i>		
Any sensory disability	16%	16%
Physical disability	31%	31%
Mobility disability	18%	19%
Self-care disability	10%	12%
Cognitive/mental disability	12%	14%
Any disability	41%	41%
Cognitive/mental disability plus any other disability	11%	12%
<i>Persons age 18-64</i>		
Any disability	11%	10%
Cognitive/mental disability and any other disability	3.2%	2.7%

Source: AARP (2009). Across the States: Profiles of Long-Term Care and Independent Living, 8th edition. Accessed at: http://assets.aarp.org/rgcenter/il/d19105_2008_atl.pdf.

* The data for this table come from the 2007 American Community Survey. “Sensory disability” is defined as deafness, blindness, or long-lasting severe vision or hearing impairment. “Physical disability” describes an individual who has a condition that limits one or more physical activities including: walking, climbing stairs, reaching, lifting, or carrying. “Mobility disability” describes someone who, because of a physical, mental or emotional condition lasting six months or more, has difficulty going outside the home alone to shop or visit a doctor’s office. “Self-care disability” describes someone who, because of a physical, mental or emotional condition lasting six months or more, has difficulty dressing, bathing, or getting around inside the home. “Cognitive/mental disability” describes someone who, because of a physical, mental or emotional condition lasting six months or more, has difficulty learning, remembering, or concentrating.

sources.⁹ These statistics are based on large, national surveys. Based on the 2003 California Health Interview Survey (CHIS), 259,000 Californians age 65 and older, or 6.9%, need special equipment or help for daily activities.¹⁰ These state-specific data undercount those who may have functional needs but do not currently access LTC services and, just as with the national data, these data may undercount those with mental illness or cognitive impairment.

Data suggest that some populations are more likely to need and use LTC than others, and certain characteristics are more strongly associated with receiving that care in institutional or community-based settings. For example, the majority of those who need LTC are over the age of 65 (58%).⁹ The need for LTC services is nearly four times higher for persons age 85 and older as compared to persons age 65 to 84.¹¹ Seniors comprise only 45.2% of those with LTC needs residing in the community.⁹ In comparison, almost 82% of nursing home residents are over age 65.⁹

In addition, women are more likely to need LTC services than men; additionally, women are more likely to use institutional services than HCBS (66.8% vs. 59.5%, respectively).⁹ Women may be more likely to need LTC because they live longer and generally have higher rates of disability than men. Women may also be more likely to use institutional LTC because they live longer than their spouses and may be lacking a ready source for informal care supports in the community, or they may lack access to HCBS. About a quarter of individuals who need HCBS live alone.⁹ People who use HCBS are more likely to be married as compared to individuals residing in institutional settings (40.7% vs. 18.0%, respectively), primarily because they have a spouse who can provide help in addition to formal services and can also help to maintain a home in the community.⁹

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Conclusions

Identifying the need for and the use of LTC services is a critical component of LTC policy planning and development. Equally important is understanding why individuals in need of LTC may not be accessing or using LTC services. While there are data defining national estimates on LTC need, there are few current and reliable data sources available to characterize LTC need within California. Regardless of the challenges with measurement, the population with LTC needs is sizeable. More complete data are necessary to help define the needs of the population, including cognitive impairment, mental health, functioning, as well as the current sources of LTC support. At the policy level, these data can support the case for expanding access to and availability of community-based services and supports as an alternative to institutionalization.

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