Center for Home Care Policy & Research

POLICY BRIEF

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Long-Term Care: An Overview

This brief provides an overview of long-term care (LTC), a term that refers to a broad range of health and supportive services delivered in a variety of service settings, including people's own homes and nursing homes. People of all ages and with many different health conditions may need LTC. Although the demand for these services is increasing, funding sources for LTC remain unstable. Moreover, lack of societal agreement about the goals of LTC makes it difficult to establish an effective LTC policy for the future. This brief discusses these issues and reviews the key challenges that must be confronted in order to build a strong infrastructure for LTC.

AUTHOR'S NOTE – This brief is a summary of the material in Feldman, P.H., Nadash, P., & Gursen, M.D. (2005). Long-term care. In A.R. Kovner & S. Jonas (Eds.), *Jonas and Kovner's Health Care Delivery in the United States (8th ed.)*. New York: Springer Publishing Company.

What is LTC?

Although LTC is often thought to take place only in nursing homes, LTC actually consists of a wide range of medical, rehabilitative, supportive and palliative services provided in diverse settings to people with a wide variety of needs and health conditions (see Table 1).

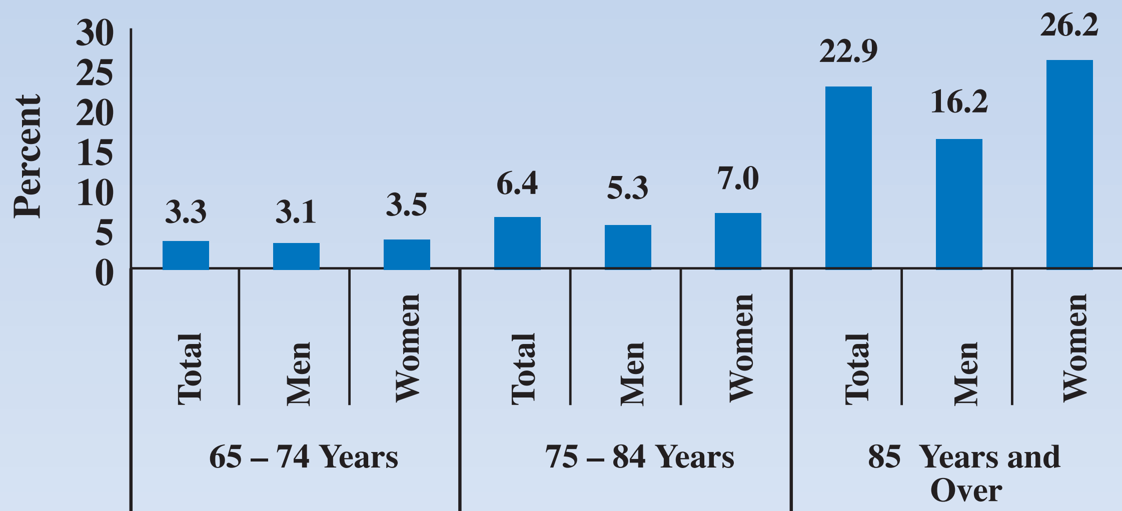
Most people who need LTC are older adults (see Figure 1). Approximately 63 percent of the 9.5 million Americans who reported a need for LTC services in 2000 were aged 65 years or older–and the older a person is, the more likely he or she may need LTC (Centers for Disease Control and Prevention [CDC], 2004). LTC users grapple with a wide variety of chronic conditions such as arthritis, cancer, diabetes, and Alzheimer's Disease, and with impairments such as hearing loss, blindness and loss of mobility from injury or stroke.

Only one fifth of people who need LTC services live in institutions (Rogers & Komisar, 2003).

Table 1. Description of LTC Services	
Supportive services	• These services are the core of LTC and include help with activities of daily living (ADLs) such as bathing, eating, walking, or going to the toilet (Stone, 2000). • They also include help with instrumental activities of daily living (IADLs) such as household chores, shopping, cooking, managing money, and paying bills (Stone, 2000).
Medical and rehabilitative services	• People with chronic disabling conditions often need ongoing medical monitoring and intervention. • Some people require rehabilitative services to recover, or to delay a decline in physical or mental functions.
Palliative care services	• These are services usually provided near the end of life that comprehensively manage the physical, social, spiritual, and existential needs of patients (Kaplan & Urbina, 2000).

Source: Feldman et al, 2005

Figure 1. Percent of Adults Aged 65 Years and Over Who Need Help with Personal Care, by Age Group and Sex (January - September 2003)



Source: Centers for Disease Control and Prevention, 2004.

The need for LTC will expand as the older population grows. The number of people aged 65 and older is projected to double between 2000 and 2030, increasing their share of the population from 12 percent to nearly 20 percent (see Figure 2). Moreover, the most significant growth will be among the group most likely to need LTC–people aged 85 or older. Their numbers are projected to increase from about 4.2 million to 9.6 million between 2000 and 2030, increasing their share of the population from 1.5 percent to 2.6 percent (U.S. Administration on Aging [AoA], 2004).

How much does the U.S. spend on LTC?

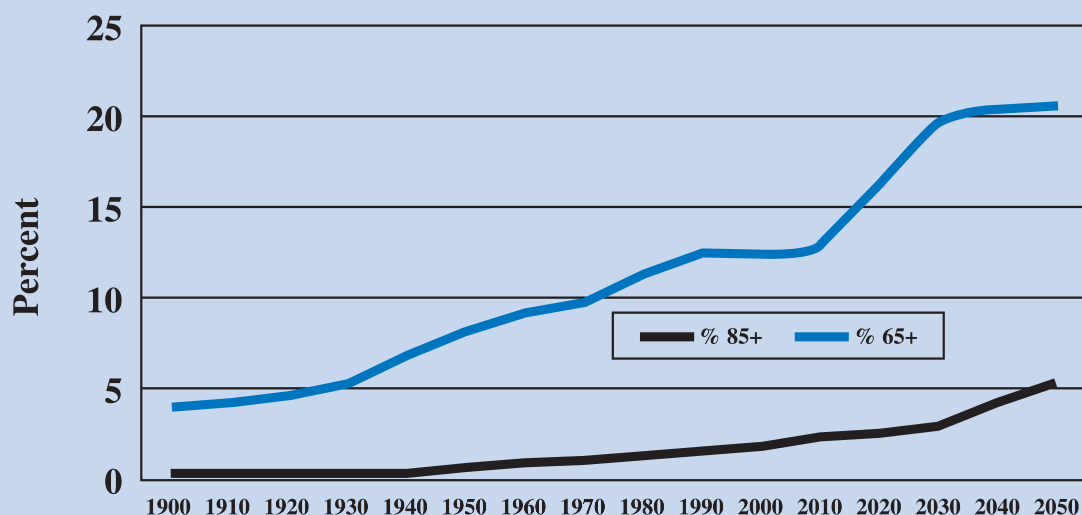
Estimates vary regarding how much of the $1.6 trillion spent by the United States on personal health in 2002 went toward LTC. One analysis estimates that at least $160 billion was spent on LTC–two thirds of which went to nursing home care (Feldman et al., 2005). In addition, the economic value of unpaid caregiving (by family and friends, for example) is large. Estimated at $257 billion in 2000, its value vastly exceeds the value of paid care (Arno, 2002).

Who pays for LTC?

Although Medicare covers some services provided by nursing homes and home health agencies, Medicaid is the main source of financing for paid LTC, followed by out-of-pocket personal payments by individuals (see Figure 3). Many people are not covered by public payment sources at all. Furthermore, even when individuals are covered, necessary services often are not covered or not covered fully. The problem of inadequate LTC coverage will become more pressing as more people come to need supportive care.

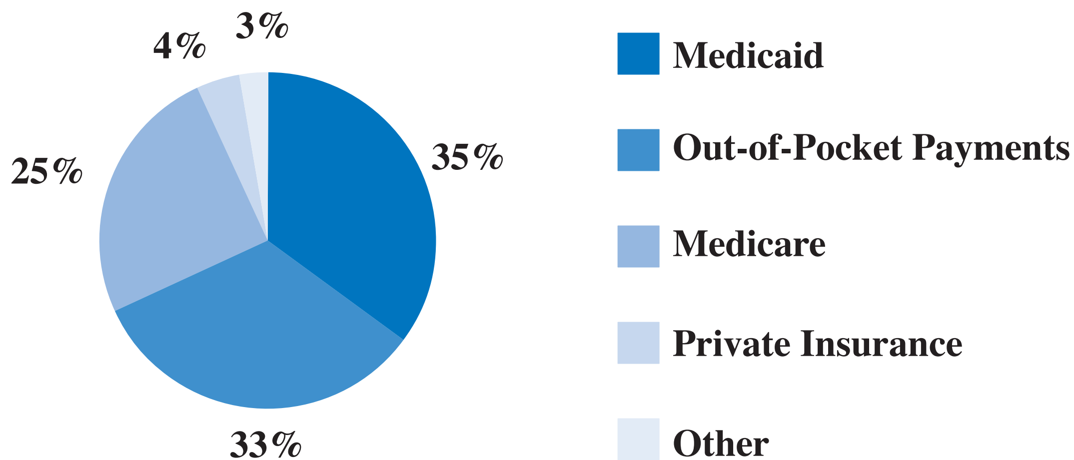
The Medicaid program serves qualifying low-income individuals, including many formerly middle-income older adults who qualify after depleting their assets to pay for LTC. Administered by states, it is the only national program with a clear mandate to cover LTC. In 2002, Medicaid accounted for 49 percent of all nursing home expenditures (Centers for Medicare & Medicaid Services [CMS], 2004a), and was the principal source of coverage for about two thirds of current nursing home residents (American Health Care Association [AHCA], 2003). Medicaid also covers home and community-based services (HCBS) such as personal care, skilled nursing, services in

Figure 2. Older Population by Age: 1900-2050



Source: U.S. Administration on Aging, 2004.

Figure 3. Estimated Percentage Shares of Spending on Long-Term Care for the Elderly, 2004 (excluding informal care)



Source: Congressional Budget Office, 2004.

assisted living settings, and home-delivered meals, although the specific services covered vary by state.

The Medicare program, which pays for skilled nursing home care (up to 100 days after a hospitalization for people who need continued nursing or therapy services) and home health services on a "part-time" or "intermittent" basis, was originally intended to provide a finite, post-acute care benefit. During the 1990s the Medicare home health benefit became an increasingly important source of LTC. However, changes in Medicare payments embodied in the Balanced Budget Act of 1997 decreased spending from a peak of $18 billion in 1997 to about $7.5 billion in 2003 (U.S. Department of Health & Human Services, 2003). With re-assertion of its post-acute medical orientation, Medicare has become a less important, but still significant, payer of LTC.

Private health insurance payments covered 7.5 percent of nursing home expenditures in 2002, down from 8.4 percent in 1999, but this share is predicted to rise to 17 percent by 2020 (CMS, 2004a). Despite the projected growth in the private LTC insurance market, however, the high cost of these private policies suggests that for the foreseeable future they will continue to play a limited role in financing LTC.

Who supplies LTC?

LTC is provided by a variety of caregivers, some paid and some unpaid. It is delivered in a variety of settings, including institutions, homes, and home-like environments.

Home care agencies and nursing homes are the traditional paid providers of LTC and provide most of the paid LTC in the United States; however, other types of providers are becoming increasingly important (see Table 2).

Family, friends, neighbors and other unpaid caregivers, known as informal caregivers, provide the vast majority of LTC in the United States. Data on informal care from the National Long Term Care Survey found that among older adults who lived in the community and used LTC (Spector, et al.,1998):

- Approximately 57 percent relied solely on unpaid caregivers for assistance with at least one ADL or IADL
- About 36 percent relied on a mix of unpaid caregivers and paid services
- Only five percent relied solely on paid help

Table 2. Types of Paid LTC Providers

Home Care Agencies:

- Medicare-certified home health agencies (CHHAs) provide skilled nursing, rehabilitation, and home health aide services to individuals in their place of residence to promote, maintain, or restore health and/or to maximize independence.
- In 2002 nearly 7,000 CHHAs served Medicare beneficiaries (Medicare Payment Advisory Commision, 2004), while a larger but unknown number of agencies–generally unlicensed–provided non-medical personal care, housekeeping, or chore services (including, for example, "meals on wheels") in individual homes and congregate residential settings.
- In 2000, roughly 7.2 million people received services from home care agencies (CDC, 2004).

Nursing Homes:

- While in the past many institutions served as homes for frail individuals, especially for older adults to live out the last years of their lives, nursing homes today often provide medically intensive, rehabilitative services to patients who stay for a short time only, and a number have added special care units for patients with special needs.
- In 2003, the industry consisted of approximately 16,400 nursing homes with approximately 1.7 million beds (AHCA, 2003).

Adult Day Services:

- Adult day services are community-based programs that provide a variety of health, social, and other support services in group settings during the day, thus providing informal caregivers with respite or the ability to be employed.
- Many participants (52 percent) have memory impairment, but the programs also serve frail older adults with no dementia (41 percent); persons with mental retardation/developmental disabilities (24 percent); and individuals with physical disabilities (23 percent) (Partners in Caregiving, 2003).
- In 2002 there were 3,407 operating adult day centers (Partners in Caregiving, 2003).

Hospice Services:

- Hospice is a palliative care program that provides physical, psychological, social, and spiritual services to terminally ill individuals, as well as support to their families and loved ones.
- Hospices' interdisciplinary teams include physicians, nurses, medical social workers, therapists, and counselors, complemented by volunteers.
- In 2002, nearly 2,300 Medicare-certified hospices delivered more than $3.6 billion worth of services (Hospice Association of America, 2002).

Community-Based Residential Alternatives to Institutional Care:

- This category includes a range of supportive housing options that provide housing, food, supervision or protective oversight, and personal assistance in a group setting other than a nursing facility.
- They are most commonly called "assisted living facilities" (ALFs)—but also include "board and care," "adult family homes," and "personal care homes."
- The services provided and facilities themselves vary enormously, as does the regulatory regimen they fall under.
- Due to classification and nomenclature issues it is impossible to determine their exact number, though one estimate put the number of licensed residences for older adults at about 36,000 with approximately 910,000 "beds" in 2002 (Mollica, 2002).

Unfortunately, informal caregivers receive little public support, despite the fact that availability of families willing to care for their loved ones is probably the pivotal factor in preventing or postponing nursing home placement, thus limiting government's financial responsibility for the institutional care of indigent older adults.

What are the goals of LTC?

Setting public policy for LTC is difficult because of the many parties involved and the different goals they aim to achieve. Four key policy questions are:

1) Who should pay for LTC?
2) What services should be made available and to whom?
3) What role should LTC play in the health care system?
4) How should LTC be regulated and how can quality be assured?

Policymakers must balance the needs and goals of individuals with broader societal goals (see Table 3), taking into account the availability of services and appropriate housing. Legislators aim to satisfy their constituents by providing alternatives to institutional care; however, they operate under severe budget constraints and must respond to other pressing claims on the public purse, such as the need to fund education and prisons.

What are the challenges for LTC?

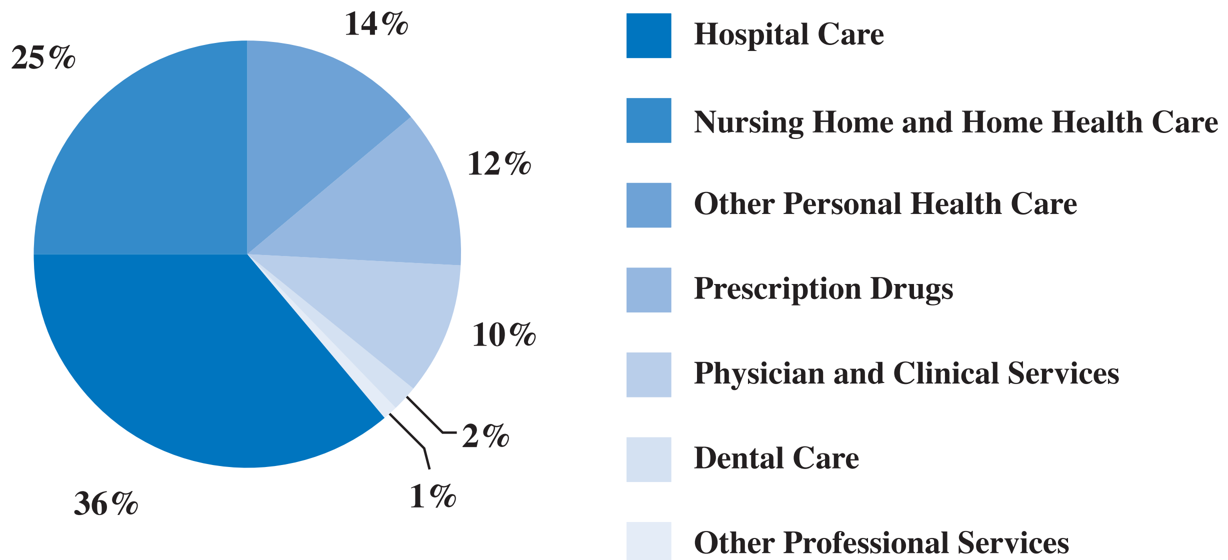
Creating a viable LTC system faces numerous challenges, including the ability to contain costs, increase access, and assure quality of needed services.

1) <u>Cost</u>: LTC is a large and growing compo-

Table 3. Individual Versus Societal Goals for LTC

INDIVIDUAL	SOCIETAL
Meet needs for care and assistance	Provide an adequate level of services to meet basic needs
Ensure comfort, safety, and freedom from pain	Target those most in need
Remain "at home" as long as possible in the face of disability and dependence	Promote the efficient production of cost-effective services
Maximize function; prevent or delay deterioration of functional abilities	Maximize individual responsibility
Access services readily	Promote a fair and equitable distribution of services
Maintain and improve physical, psychological, and social health and well being	Provide comprehensive services
Improve self-knowledge and self-care abilities	Encourage reliance on "informal" systems of family provided care
Maximize independence, autonomy, and individual choice	Facilitate consumer choice
Receive highest quality care	Ensure acceptable quality of services
Find information easily	Integrate and coordinate services
Minimize out-of-pocket costs	Contain costs to government and taxpayers

Source: Benjamin, 1999; Feldman, 1999; Kane, 1999.



Source: Centers for Medicare & Medicaid Services, 2004b.

nent of health care expenditures. LTC expenditures made up about 12 percent of U.S. personal health care spending in 2002 (Feldman et al., 2005). State and local governments spent even more (see Figure 4), with a quarter of Medicaid dollars going toward nursing homes and HCBS.

Consequently, states have experimented with three broad strategies to control their LTC costs: 1) substituting private or federal dollars for state dollars, 2) shifting the cost control burden to providers by controlling nursing home bed supply or cutting provider payment rates, and 3) attempting to reform the health care delivery system through some combination of integrating acute and LTC services and/or increasing the availability of HCBS alternatives to institutional care.

2) <u>Access</u>: The supply of LTC and the ability of individuals to pay for it are both serious concerns. Affordable alternatives to nursing home care are limited due to a bias toward institutional care in the LTC system. Moreover, the future availability of an adequate range of LTC services (including the necessary infrastructure for HCBS) is uncertain. In addition, reliance on Medicaid and personal savings as the two main sources of LTC financing means that many people forego services until they urgently need them. Many people then use up their savings to pay for LTC.

3) <u>Quality</u>: There is little consensus on how best to ensure quality LTC. On the one hand, the attempt to assure quality in nursing homes has resulted in monitoring requirements and complicated regulations that address everything from the width of hallways to the length of time between residents' meals. Despite these efforts and recent improvements, it is generally agreed that many nursing homes still deliver substandard care. On the other hand, alternatives to the highly regulated approach used for nursing homes are comparatively untested. One new approach comes from the federal government, which has focused

on the publication of information about the quality of nursing homes and certified home health agencies. Such information is meant to enable consumers to make more informed choices and thus improve quality, but the success of this approach is unknown.

Conclusion

LTC tends to attract little attention in the public policy world, except when scandals erupt. The growing number of older people, the prevalence of disabilities associated with chronic health conditions, and escalating costs will soon make it an issue that will become impossible to ignore. Solutions will require changes in health care practice and to the health care system itself. Most importantly, Americans will need to reach some kind of agreement on how LTC services should be paid for and how to provide services where people most often want to receive them–at home. There has been little political will to deal with the impending LTC crisis, however, and near term political prospects for such a comprehensive overhaul appear slim.

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