
Long-Term Care: Coming of Age in the 21st Century

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Long-term health care for older adults has emerged as a significant issue, both in terms of quality and financing, during the past 30 years. This article provides an overview of long-term care in this country, highlighting why it is an issue, who uses care, what types of settings are available, and how family members play a role as caregivers. It concludes with a discussion of policy trends for the future financing and delivery of long-term care.

Long-term care public policy issues have been a major concern in the United States for 30 years and will continue to pose challenges in the next century. In 1995, 13 million Americans of all ages needed long-term care. A much larger number of relatives, friends, and others faced decisions about long-term care. For example, 80% of disabled older adults living in the community receive unpaid assistance from family and others; three out of five rely only on unpaid help, usually from wives and daughters. Many relatives provide indirect help, including making care arrangements and providing unpaid help to older adults living in nursing homes.

The demand for long-term care is expected to skyrocket as the baby boomers age. Between now and the year 2040, the U.S. older adult population will more than double. For the first time in history, one in five Americans—77 million people—will be age 65 or over. The number of people age 85 and older will triple by the year 2040, to 14 million. Even if estimated declines in disability rates among older adults are accurate, the sheer volume of very old adults probably will increase long-term care demands. Survey data applied to U.S. Census Bureau projections estimate that those 65 and over with activity limitations will rise from 12 million in 1994 to 22 million 2020, and to 28 million in 2030. At the same time, the pool of available family caregivers—especially adult daughters—will shrink. As more women work outside the home, have children later in life, and find adult children returning to the nest, the competing demands of child care, employment, and elder care could put a great strain on the backbone of the current long-term care system.

Given our changing society, major issues include how to design and implement a system of long-term care that best meets the needs of future older adults and their families, and how to pay for this system. Although these issues are not new, the aging baby boomer generation raises the stakes. This paper offers a brief history and an overview of the current status of long-term care in the United States, highlighting the implications of demographic and policy trends for the financing and delivery of future long-term care.

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What Is Long-Term Care?

Long-term care includes a broad range of services needed by people with chronic illness or disabling conditions over a long period of time. Long-term care needs are highly correlated with medical conditions such as arthritis, paraplegia, dementia, traumatic brain injury, or chronic mental illness. These services focus on providing assistance with daily activities to minimize, rehabilitate, or compensate for loss of independence. The services include assistance with (a) daily living activities such as bathing, dressing and eating; and/or (b) instrumental activities of daily living such as household chores, meal preparation, cleaning, shopping, money management, and transportation.

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Most long-term care is low-tech, but it may include high-tech medical interventions such as intravenous drug therapy, ventilator assistance, and wound care. Long-term care may be provided by unpaid family members or friends (informal caregivers) or by specially trained paid professionals and paraprofessionals (formal caregivers.) Services include human assistance and the use of assistive devices and technology. Long-term care occurs in a range of settings, depending on the person's needs, the availability of informal support, and the source of reimbursement. The most restrictive end of the continuum is nursing home or facility care. Home and community-based care is a catchall for a wide variety of noninstitutional options. Residential care, such as assisted living facilities and adult foster homes, falls in this category, although the boundaries between institutional and noninstitutional settings are gray. In general, residential care, which combines room and board with some level of care, is an option for people who do not require nursing homes but are no longer able to live independently. Other home and community-based settings include adult day care and care in one's own home. In the home, care is further differentiated between home health care, which includes some level of skilled nursing and custodial care, and home care, which includes personal care services and homemaking chores.

Who Needs and Uses Long-Term Care?

People using long-term care are diverse in age and level of need. Of the 12.8 million Americans with long-term care needs in 1995, 57% were over age 65. Another 40% were working-age adults; 3% were children. The need for care generally increases with age. Among Americans under age 65, one tenth of 1% relied on institutional care and 2% lived in the community with some care. In contrast, among the 34 million older adults, 5% lived in nursing homes and 12% received community-based care. Among those age 85 or older, 21% lived in nursing homes, and nearly half received community-based care. More than 80% of older adults who needed support with daily living skills lived in the community, and they tended to be much less disabled than those in nursing homes.

Who Pays the Bill?

The proportion of older adults likely to use nursing homes ranges from 39% to 49%. Nationwide, the average lifetime nursing home use is one year, and the average home care use is just over 200 visits. Whereas many users receive care for just short periods of time, a small proportion uses much more long-term care. The vast majority of long-term care is provided free by unpaid, informal caregivers, usually family and friends. In fact, less than 1 in 10 disabled older adults living in the community receives only formal, paid care. The availability of informal caregivers is often the decisive factor in whether a person's care needs can be met outside an institution. As an example, half of all older adults with long-term care needs and no family network are in nursing homes, compared with only 7% of those with needs who have family caregivers.

The financing of long-term care services is a patchwork of public (federal, state, and local) funds and private dollars. An estimated \$106 billion were spent on long-term care in the United States in 1995, and long-term care costs have increased from 4% in 1960 to more than 11% of all personal health care expenses in 1993. Public resources accounted for 57% of long-term care costs, with Medicaid being the largest payer (21% of federal and 17% of state dollars), followed by Medicare (18%) and other federal and state funds, such as Veterans Affairs, Older Americans Act, and Social Services Block Grant. Private insurance made up only 6% of costs, with 1 in 3 dollars spent on out-of-pocket costs.

Medicaid

Medicaid, the federal/state health insurance program for low-income people, is the major public program covering long-term care for older adults and people with disabilities. Despite public interest in and demand for home care, Medicaid continues to show a strong institutional bias, with more than 80% of the \$50 billion spent on long-term care in 1995 going to nursing homes and institutions for people with cognitive disabilities. Although the institutional bias prevails in most states, movement has occurred toward home and community-based options. Several states have explicitly recognized nursing home placement as the setting of last resort and have intentionally reduced the number of nursing home beds. With an aggressive home and community-based care policy, Oregon has placed many seriously disabled adults in alternative assisted living facilities and adult foster homes, while providing a strong case management program that allows disabled people to stay in their own homes.

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Medicare

Medicare has not been considered a major payer for long-term care in the past, primarily covering acute care costs. Skilled nursing and home health benefits have been covered only short term to meet post-acute-care needs after a hospital stay. However, Medicare now supports more long-term, nonskilled personal care as a result of administrative changes since 1989, and Medicare spending for

home health services increased tenfold from 1987 to 1995. Most of this growth has been attributed to an increase in the number of home visits, particularly for personal care. The other Medicare area of growth is in the fuzzy area of sub-acute care, which is described by proponents as a set of intensive and coordinated treatments and services for post-acute-care patients to minimize or bypass expensive hospital stays.

Private Long-Term Care Insurance

Private insurance finances only a tiny proportion of long-term care—less than 6% of nursing home and home care costs in 1995. However, the market for private insurance policies has grown. Controversy surrounds the issue of private long-term care insurance, with the private sector arguing that public programs will never meet the demand, while consumers and regulators voice concerns about affordability and fraudulent marketing practices surrounding private long-term care policies. A recent *Consumer Reports* article suggests that only 10% to 20% of older adults can afford long-term care insurance.

Emerging Trends in Long-Term Care

Policymakers, practitioners, and consumers see the need to address long-term care costs while maintaining and improving quality. These two objectives have led to several trends in financing and delivering long-term care with important implications for the future, when aging baby boomers will increase the demand for a broad array of long-term care services.

Managed Care

Managed care has become a buzzword of the 1990s, both as a panacea for exploding costs and as the nemesis of quality care. The major definitions of managed care include (a) per-person payment to a plan or system of providers, (b) assumption of full or partial risk by the plan or provider, and (c) a gatekeeping mechanism to assure delivery of the most efficient and appropriate type and level of care. Managed care has been sold as a way to save money, but the growth of plans with profits and shareholder obligations as the bottom line has raised concerns about trading quality care for cost savings. Medicare managed care now covers 14% of beneficiaries. However, there is evidence that plans have been “cherry-picking” healthy older adults, resulting in questions about whether the plans have really saved the government any money. Given the healthier population served, most managed care plans have not covered long-term care. Most plans and provider networks also do not have the trained workforce to provide long-term care.

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Integration of Acute and Long-Term Care Services

Although no exact definition exists, these elements are part of integration:

- Broad, flexible benefits, including primary, acute and long-term care;
- far-reaching delivery systems that can go beyond traditional HMOs to community-based long-term care, case management, and specialty providers;
- adoption of mechanisms for integrating care, such as case management and care planning protocols, interdisciplinary care teams, and centralized member records;
- overarching quality systems with a single point of accountability; and
- integrated financing with flexible funding and the incentives to align payers and eliminate cost shifting.

Although people talk about integration, little experimentation has occurred. Fragmented funding sources are one barrier. Another is concern about financial risk and fear of trying to address the special challenges of acute and long-term care for high-risk, high-cost people. Perhaps the most overlooked barrier is lack of knowledge, information, and training to offer a coordinated, well-managed array of services. Most of the research on integrating acute and long-term care has been conducted through federal demonstration projects, which have not been very successful at demonstrating true savings. However, the idea behind integration seems to make intuitive sense, and the models have helped shed light on better ways to coordinate care across a broad range of services and systems. Despite a lack of proof of cost savings, several states have begun implementing integrated systems, especially for their “dual eligible” population—those who qualify for both Medicare and Medicaid. However, these projects are in the very early stages, and results of these studies will not be available for some time.

An estimated 15% to 70% of nursing home residents could live in residential care.

Assisted Living

Another trend receiving attention from policymakers and consumers is assisted living. However, the term is not consistent across providers, regulators, and policymakers. Some states have tried to use residential care to save money on institutions. One recent study (Spector, Reschovsky, & Cohen, 1996) estimates that 15% to 70% of nursing home residents could live in residential care. Some hospital discharge planners refer disabled older adults to nursing homes rather than other arrangements, although Kane (1997) has found that in reality, little nursing care is provided in nursing homes. Research, however, has not been clear on whether substituting residential care for nursing home care is suitable or saves money.

The major difference between assisted living and nursing home care seems to be philosophy and emphasis on care and housing arrangements (Kane, 1997). Some suggest residential care is for people who can afford to pay, whereas nursing care is for people who rely on federal and state money to cover costs. A few states use the terms “assisted living” and “residential care” interchangeably. For other states, differences between assisted living and residential care are that assisted living offers

- a focus on privacy, autonomy and independence;
- an emphasis on apartment settings shared by a choice of residents; and
- the direct provision or arrangement of personal care and some nursing, focusing on various levels of disability and need.

Although assisted living is a trend to consider, barriers do exist. Assisted living is now mostly for well-off older adults, with little available to moderate or low-income consumers because of inadequate public financing to subsidize costs. State policymakers and potential private providers also have concerns about balancing consumer choice and privacy with health, safety, and fear of liability. The extent of care actually provided in these facilities also is questionable. As providers look for new markets, there is concern that skilled nursing facilities will lay down carpet, install doors with locks, and call themselves assisted living.

Consumer Direction

The 1990s seem to be the coming of age of the health and long-term care consumer, starting with younger physically disabled people voicing strong opposition to facilities and desiring a range of home and community-based options with consumers in control. That movement is now taking hold among older adults, who want privacy, autonomy, and the right to “manage one’s own risk.” Consumer direction in long-term care is a way of leveling the playing field between institutions and home and community-based care. It also may be a potential way to save money. Consumers now have involvement ranging from care planning and decision making, to purchasing their own services.

Much of the consumer direction at the state level has been through Medicaid home and community-based waiver and state-funded personal assistance services programs. At least 35 states have programs providing some form of financial payment to relatives and other informal caregivers for chores and personal services (Linsk, Keigher, & Simon-Rusinowitz, 1992). Some compensate for work done or out-of-pocket expenses incurred by caregivers. Medicaid does not allow direct cash payments to care recipients. However, four states will soon apply for a Medicaid waiver to experiment with providing cash to recipients of home and community-based care.

Historically, U.S. policymakers have been comfortable providing cash benefits to certain groups, like veterans, while being less willing to provide cash payments to individuals perceived to be less deserving, such as Supplemental Security Income

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(SSI) beneficiaries. Depending on the perspective, consumer-directed programs can be seen as a safe and low-cost way to satisfy consumer needs and allow payment of informal caregivers, or as a vehicle for depressing wages, exploiting workers, and jeopardizing the health and well-being of vulnerable consumers who cannot supervise their own care (Feldman, 1997).

The Future of Long-Term Care Demand

Many factors will shape the scope and nature of the future, including changing demographics, the health of older adults, the availability of family and informal caregivers, the financial status of future generations, their degree of planning for long-term care needs, and the availability and cost of institutional and community-based alternatives.

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The Impact of Population Aging

The 21st century will see unprecedented growth in the elderly population as baby boomers age. Although most older adults are not disabled, the likelihood of long-term care increases with age. The number of very old—over 85—is estimated to increase from 4 million in 1998 to 8.5 million in 2030 to 14 million in 2040.

Life Expectancy and Disability

Part of the projected increase in number and proportion of older adults in the future is due to an increase in life expectancy at age 65. At age 65, men can expect to live another 18 years in 2020 and 19 years in 2030, up from 16 years in 1995. Women can be expected to live 21 more years in 2020 and 22 years in 2030, compared with 19 years in 1994. But the extent to which people can live those years without disability is debatable. Some studies indicate medicine has increased life expectancy without changing the onset of illness. Declining death rates could actually increase long-term care needs.

Geographic Diversity

The number of elderly and its impact on long-term care demand varies greatly among states. As baby boomers begin to reach retirement in 2011, the size of the 65 and older population will increase in every state, with California and Florida ranking first and second. But by 2025, Texas will rank third, passing New York and Pennsylvania. Currently, only five states have at least 15% of the population age 65 or older. But by 2025, 48 states will reach or exceed that proportion.

The Future of Informal Caregiving

Several factors will affect the future supply of informal caregivers. The most important predictor of a strong informal network is being married because spouses and children are most often providers of care. Researchers estimate that 1.2 million people 65 or older will live alone and have no living children or siblings in 2020—up from 682,000 in 1990. These are the people most likely to use formal services and have no informal care. Another basic measure of the availability of

informal caregivers is the ratio of population in the average caregiving range, which is 50 to 64, to the population age 85 and older. In 1990, the ratio was 11 to 1; by 2050, the ratio will be only 4 to 1.

Researchers have found that informal caregivers typically adjust their level of care when meeting other family needs, such as the needs of their own children. As women delay having children, they are more likely to juggle childrearing and elder care, resulting in fewer care hours for a disabled parent. The more children a disabled parent has, the greater the volume of help. Another consideration is women's work outside the home. The proportion of women age 45 to 54 in the labor force is expected to increase from just over 75% in 1996 to nearly 80% in 2006.

A large unknown in this area is related to how new family structures will affect the pool of informal caregivers. Increases in divorce and remarriage mean many older adults have step-in-laws and step-grandchildren. Researchers do not know if this will affect caregiving.

Economic Status of the Future Elderly

Another factor affecting the future of long-term care is the extent to which older adults will be able to afford services. One measure of elderly economic status and their potential use of formal services is educational level because more highly educated people are more likely to be wealthy and to purchase care. Older adults will clearly be more educated in the next century. In 1997, 40% of those aged 75 and older had less than a high school education, and only 13% had a college degree. In contrast, only 13% of people ages 45 to 54 have less than a high school education, and 28% have a college degree. Only one in eight older adults is below the poverty level, although many elderly remain poor. Nearly 80% of older adults ages 55 to 64 were homeowners in 1997.

Assuming reasonable economic growth, baby boomers should have higher real incomes during retirement than today's retirees. Married couples will be better off than singles; with single men better off than single women. However, boomers have few financial assets. The typical boomer has assets of only \$1,000, and the lowest one quarter have liabilities that exceed their assets. A recent survey found almost half of boomers had done little or no long-term care planning.

The Future Supply of Long-Term Care Services

Another factor affecting the future of long-term care is whether nursing homes will remain the dominant setting for services. Much depends on public and private incentives to develop more community-based alternatives, including assisted living. Currently, little substitution between nursing homes and assisted living exists. Most institutional care is supported by Medicaid, and people must be low income or become poor to qualify. In contrast, assisted living is used primarily by the wealthy with few attempts to reach a modest or low-income market. The

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assisted living market is estimated at \$13 to \$15 billion, with an expected increase to \$20 billion in 2020. However, it is unclear whether the industry will expand its consumer base.

Sinking or Swimming Into the Future

The rapidly changing health and long-term care environments make it hard to predict what kind of financing and delivery system will emerge in the future. Some factors, however, are known. First, a major demographic shift is overtaking the world. The number and proportion of elderly, including the very old, will increase dramatically, expanding the need for long-term care.

Another trend is the role of family and friends in providing long-term care. Policy discussions continue to focus on how to support informal caregiving, with one objective being to avoid formal, paid care when family care is possible. The nature and character of these informal networks may change. There will be more adult children available as potential caregivers. However, by the year 2025, the potential pool of caregivers will decrease. More women in the labor force and a trend toward delayed childbearing will increase the “sandwich generation,” comprised of individuals who must juggle multiple caregiving and work demands.

Researchers have noted that family caregivers tend to experience stress. Whether the stress comes from anxiety and grief associated with having a sick family member, or whether it is the physical and mental toll of caregiving tasks is less well known. One study found the greater the number of problems caregivers reported, the greater the chance that their care recipients would eventually be institutionalized (McFall & Miller, 1992).

The most prominent workplace initiative aimed at supporting informal caregivers is the Family and Medical Leave Act of 1993, which requires employers with more than 50 workers to permit employees to take up to 12 weeks of unpaid leave to care for a newborn, adopted child, or ailing family member. Some employers and unions also have established “family-friendly” programs to reduce conflict between work and family caregiving, including flexible scheduling; part-time work options with benefits; information and referral services; and caregiver support groups. Financial benefits like dependent care assistance programs and reimbursement accounts are less often available.

Respite care frequently is requested to help relieve family stress. Many services, including home care aides, companion care, adult day care, and short-term residential placement are considered respite if the focus is on giving caregivers time off while meeting the disabled person’s needs. Yet, evaluations of programs that provide free or subsidized respite care found as many as 30% to 50% of participating families did not use available services. Overall, respite seems to have a modest positive impact on preventing residential placement.

The more problems reported by caregivers, the greater the chance of their care recipients being institutionalized.

Caregiver support groups and training in coping skills can alleviate some stress. Support groups and other counseling and educational programs draw on professional expertise, but are often sponsored by voluntary associations of caregivers. These programs are particularly successful for caregivers of people with Alzheimer's disease and other conditions causing cognitive impairment.

Some states are increasingly paying family members instead of hiring strangers for care. Formal helpers who supplement informal caregivers also are on the rise. President Clinton recently proposed a \$1,000 tax credit that compensates for the formal or informal costs to Americans of all ages with long-term care needs or the family caregivers who support them. The proposed initiative also includes a new National Family Caregiver Support Program (\$625 million over 5 years) administered through state units and local area agencies on aging, and a \$10 million nationwide campaign to educate Medicare beneficiaries about long-term care options. Although an extremely modest proposal, the President has put long-term care on the national agenda with this initiative.

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What role long-term care insurance will play remains unclear. As mentioned before, limits on the market do not bode well for this option. However, future elders will be more highly educated and wealthier, and may be able to buy this insurance. One long-term care product—the disability option—needs serious attention. Currently offered by a few insurers, it provides claimants with a set dollar amount tied to level of disability, rather than access to certain services. This model might appeal to people who want to know what they will be buying 30 years into the future and who want maximum flexibility.

Recognizing the need for a group long-term care market, the President's recent long-term care initiative also calls on Congress to pass a new proposal that allows the federal government's Office of Personnel Management to use its market leverage and set a national example by offering nonsubsidized quality private insurance to all federal employees, retirees, and their families at group rates.

Although no clear answer exists for balancing public and private financing of long-term care, several elements are important for the future. First, the system must address the long-term care needs of all age groups, recognizing services must be tailored to meet each person's needs. Second, the system should be sensitive to family needs as well. Although formal care cannot and should not replace family and friends, the array of services should include family needs, preferences, and supports. The future system also should recognize the options possible to meet residential and care needs. It should be flexible enough to address fluctuating needs that may be acute, chronic, or nonmedical (e.g., transportation, housekeeping). People who want to make their own choices should have that option, although it is important that they know the tradeoffs involved in managing their own risk.

In an ideal world, the money would follow the person, rather than the provider. People and their families would be able to make choices that include preferences

and values, with financial constraints set by public programs and their private resources. This type of system requires major changes in our current public programs so funding streams become seamless.

Long-term care will be one of the major challenges of the next century. We can wait for a crisis, or be proactive in developing a financing and delivery system that learns from past successes and failures, that balances public and private resources, and that puts long-term care clients and their families in the driver's seat.

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