* Medicaid long term care

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NOVEMBER 1999

LONG-TERM CARE*

Over 12 million people in the United States need help with basic activities of daily living requiring long-term care services—that is, personal, social and medical supports provided at home, in the community, or in institutional settings. The long-term care population is diverse, reflecting a broad age spectrum, a variety of service needs, and differing abilities to satisfy them. The elderly are the primary users of long-term care services and, among the elderly, the most vulnerable are the very old and those who live alone.

Spending on long-term care came to $115 billion in 1997. Over 40 percent of that spending was financed by the Medicaid program, including half the costs of nursing home care. Medicaid is the nation's long-term care safety net—financing care not only for the poor but for the middle class as well. However, Medicaid pays for care for those with middle incomes *only* once they have exhausted their own financial resources; consequently, many of the elderly are at considerable risk of catastrophic long-term care expenditures. More than a third of the elderly who entered nursing homes—and more than 70 percent of those who were in nursing homes for at least a year—had catastrophic long-term care costs (with expenditures exceeding 40 percent of their annual income and non-housing financial assets). Because of their greater likelihood of needing long-term care and their limited ability to pay, the low-income elderly are especially at-risk.

The elderly pay for a substantial portion of long-term care costs out-of-pocket (nearly 30 percent in 1997). Medicare provides nearly universal coverage for the elderly for health care, but Medicare does not pay for most long-term care, paying only for limited amounts of skilled nursing care in nursing homes and for some home health care. Private insurance plays only a small role in long-term care. With eligibility for public programs limited and the costs of service high, the current system fails to meet all of the long-term care needs of persons with disabilities. For example, a significant proportion (about 20 percent) of elderly and nonelderly adults with long-term care needs report an inability to fully address these needs, with sometimes serious consequences for their health and quality of life.

The number of people likely to need long-term care, and national expenditures on long-term care for the elderly, will increase significantly with the aging of the baby-

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boom population. Exacerbating the problem of serving the growing long-term care population appropriately is the fact that long-term care costs are expected to grow faster than inflation. Inflation-adjusted long-term care expenditures are expected to triple to $346 billion by 2040, placing large burdens on both Medicaid and private resources. Assuming current policies continue, more resources will likely be required to address gaps in the current system, varied inputs across states, limited access to care in the community, and concerns about quality of care.

What is Long-Term Care?

Long-term care services provide the help required by individuals with physical or mental disabilities to perform basic "activities of daily living" (ADLs) such as eating, bathing, dressing, getting in and out of bed, and using the bathroom. Long-term care also includes services that are designed to assist individuals with "instrumental activities of daily living" (IADLs) that are necessary to remain independent, such as housework, laundry, grocery shopping, taking medication, and transportation. Long-term care is the care needed to cope when physical or mental disabilities interfere with an individual's ability to perform these basic tasks on their own.

Who Needs Long-Term Care?

Chronic conditions that create a need for long-term care are physical or mental in nature and their onset time ranges from before birth to late in life. Alzheimer's disease, heart disease, multiple sclerosis, cerebral palsy, spinal cord injury, and stroke are just a few of the diseases that may cause chronic disability. Unlike acute illness, chronic conditions are essentially permanent. Regimens of medical and personal care can sometimes control but rarely cure them.

Disability is a condition that often creates a need for a variety of services and supports on a continuing basis. The presence of disability, however, is not synonymous with the need for long-term care. Over forty million Americans have a physical or mental disability. Of these, more than twelve million (30 percent) need long-term care, defined as a need for assistance with activities of daily living, and about a third of those with long-term care needs (approximately 4 million people in the community and in institutions) have substantial needs—that is, they need help with 3 or more activities of daily living.[1]

The elderly are much more likely than younger age groups to suffer from disabling conditions and to require long-term care. Almost a quarter of the elderly (6.4 million individuals) have some long-term care need. However, individuals with long-term care may be young or old. Only 3 percent of adults ages 18 to 64 had some long-term care need, but this translates into a significant number of nonelderly adults needing long-term care (5.3 million); 400,000 children also have long-term care needs [Figure 1].

The prevalence of disability among children and non-elderly adults has been increasing as a result of improved trauma care and medical technologies that have extended the lives of those with life-threatening or debilitating illnesses. Recent advances in the treatment of AIDS has also fueled changes in the composition of the long-term care population. Improved treatments for those infected with HIV have

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Medicare

Although Medicare provides nearly universal coverage to the elderly for their acute care needs, it is not designed to cover the majority of their long-term care costs. Medicare covers short-term skilled nursing facility care and plays a limited role in financing home and community-based services. Although no prior hospitalization is required to receive home health care under Medicare, benefits are limited to people who are homebound, require skilled nursing, physical therapy or speech therapy on a part-time or intermittent basis, and are under the care of a physician.

In the past several years, increasing attention has been paid to the rapid growth in the use and costs of Medicare's post-acute care benefits, with many observers suggesting that this represents an inappropriate expansion of Medicare into long-term care. A rapid expansion in home health has been of special concern. Home health spending increased at an average annual rate of 29 percent between 1990 and 1996, rising from $3.9 billion to $18.3 billion and from 3.6 percent to 9.2 percent of Medicare spending. Medicare's payment policies have been revised in an attempt to constrain this growth, and there is continuing attention to additional reforms that would help to limit the use of home health benefits.

Even with the recent expansion of home health services, however, survey and program data suggest significant limits to its reach among people with long-term care needs. One survey found that only 10 percent of the community-dwelling elderly with chronic disabilities and long-term care needs received Medicare-financed home care in the week prior to the survey in 1994.[11] A large proportion of Medicare home health care expenditures (46 percent in 1997) are consumed by very small proportion (10 percent) of Medicare beneficiaries with high home health use (200 home health visits or more per year).[12] These home health users typically have both acute and long-term care needs and are disproportionately older, in poorer health, more disabled and have lower incomes than other home health care users.

Many observers have suggested that recent changes in treatment patterns under Medicare home health reflect a shift from a narrow post-acute benefit toward a long-term care benefit. Medicare beneficiaries using home health care are using care long after a hospitalization, they are receiving more visits, and as episodes of care have lengthened, they are receiving a higher proportion of aide visits and correspondingly fewer skilled visits.[13] But despite the rapid growth in home health utilization and expenditures, Medicare's benefit does not cover long-term care for people who need such care exclusively. However, for people who qualify, the type of care it covers overlaps substantially with long-term care: the home health benefit covers some personal assistance with basic daily activities—the long-term care services—along with skilled services for beneficiaries who need both. As Medicare tries to limit its home health care coverage, it remains to be seen if Medicaid's expansion into home and community-based services will sufficiently cover the long-term care population with severe disabilities.

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Private Long-Term Care Insurance

Most individuals with long-term care needs rely on their own resources to pay for long-term care, but private insurance plays a very limited role in the financing of long-term care. Most private health insurance policies pay for very little long-term care and only 7 percent of the elderly own a long-term care insurance policy that explicitly covers these services.[14] Less than one percent of long-term care expenditures are financed by private long-term care insurance.[15]

Sales of private insurance policies have increased over the past decade, but long-term care remains unaffordable for many of the elderly—with one recent study suggesting that only 10 to 20 percent of the elderly could afford to purchase a comprehensive long-term care policy.[16] The cost of private insurance coverage increases with age and with essential coverage provisions, such as inflation protection (which increases benefit levels as nursing home costs rise) and nonforfeiture benefits (which allow an individual to recover some of the cost of the policy if that person cannot pay the premium or thinks he/she will not need the coverage). The average annual premium for policies covering four years of nursing home and home care with inflation protection and nonforfeiture benefits in 1996 was $1,200 per year if purchased at age 50, $2,432 per year if purchased at age 65, and $7,440 a year if purchased at age 75.[17]

The people who are able to buy good quality policies at the prices offered are often middle to upper income individuals who generally would not qualify for Medicaid (and offset public expenditures for long-term care). Further, many of those who might purchase private insurance may not be able to buy it. One study has estimated that even if everyone applied for long-term care insurance at age 65, a significant proportion—perhaps as many as a quarter—would be rejected under current underwriting criteria.[5]

Medicaid

Medicaid is the only public program that provides substantial coverage for long-term care. Medicaid spending on long-term care was $44 billion in 1997, financing nearly 40 percent of all long-term care, 50 percent of the costs of nursing home care, and financing the care of nearly 70 percent of nursing home residents. Nationally, Medicaid spends an average of about $7,800 on long-term care per elderly Medicaid enrollee and $3,700 per disabled enrollee.[18]

Medicaid is the nation's safety net provider of long-term care services not only for the poor, but for the middle class as well. Unlike other insurance, however, which provides protection against catastrophic losses, Medicaid helps only after catastrophe strikes. Middle income Americans with catastrophic long-term care costs may become eligible for Medicaid benefits once they have "spent down" their income and assets—they must impoverish themselves before Medicaid assistance is available. Although some policymakers have expressed concern that Medicaid's spend down provisions encourage attempts to unfairly manipulate the system by those who could otherwise afford long-term care, there is little evidence of widespread abuse [See Box 2].

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BOX 2

Medicaid "Spend Down"

In 35 states and in the District of Columbia, people whose assets are less than a specified level ($2,000 for individuals, $3,000 for couples) can qualify for Medicaid if the cost of nursing home care exceeds their incomes—that is, they qualify for Medicaid as "medically needy." Individuals must contribute all of their income toward the cost of care, except for a small personal care allowance (of no less than $30 per month). The rules for couples are more generous to prevent impoverishment of a spouse who remains in the community. Protected income for the community spouse ranged from $1,326 to $1,978 per month in 1997, and protected assets ranged from $15,804 to $79,020 depending on state eligibility rules.[19]

Despite concerns about abuse of the system, only about 20 percent of current residents spend down at some point during their stays. However, those who stay in the nursing home for a long period of time are more likely to eventually spend down to Medicaid. About one-third of nursing home residents who used long-term care services for one to three years spent down and about half of those with nursing home stays of more than three years spent down their income and assets to Medicaid.[20]

Concern has been expressed that, despite prohibitions, elderly people are transferring assets to avoid spend down. However, the asset levels of elderly people likely to need nursing home care are typically low to begin with and federal legislation (OBRA 1993) has placed greater restrictions on asset transfers.[21] Recent research also suggests that there is little need for policy efforts to limit the use of trusts to avoid spend down, since very few of the elderly have a trust. Although the study found that 4 in 10 elderly community dwellers could potentially qualify for Medicaid by using a trust, fewer than 10 percent had a trust.[22]

Long-term care accounts for about 35 percent of Medicaid spending nationwide, but states vary greatly in their inputs to long-term care. The average Medicaid long-term care expenditure per elderly beneficiary ranges from over $15,000 in Connecticut, New York, and the District of Columbia, to less than $5,000 in South Carolina, Mississippi, and Oklahoma.[23] In most states, the large proportion of long-term care spending is for nursing home care. All states provide home and community-based long-term care services: Medicaid requires states to cover home health services for any individual eligible for nursing home care, states have the option (used by 31 states) to cover personal care and, under waivers, all states have developed programs designed to target a specific mix of home and community-based services to distinct population groups or in distinct geographic areas. Nevertheless, few states rely on Medicaid to provide substantial long-term care to people living at home. Nationally, less than 20 percent of Medicaid long-term care spending is for home and community-based care services, personal care, and home health care services.[24] Payments for home and community-based waiver services per person age 65 or over vary from $1,180 in New York to $29 in Mississippi, and in some states, such as Oregon and New York, there are

relatively balanced systems that devote a significant share (40 to 50 percent) of long-term care spending to home and community-based services.[25]

Initially, home and community-based services were conceived as a less expensive alternative to nursing home care. (Eligibility for these community-based benefits is typically extended to people who are eligible for nursing home or other institutional care and meet state income and asset criteria). However, there is little evidence that home-based services reduce nursing home use and expenditures, largely because individuals who would not otherwise use nursing home care will use home and community-based services if they are available. Because of concerns about these "woodwork effects," the law allows states to limit these services with respect to the number, type, and location of people served as well as the volume of services provided. Home and community-based care can expand service options without increasing state long-term care expenditures only if nursing home use is explicitly restricted—by diverting the least disabled prospective nursing home clients to available home care options.

Although some states expect to control overall long-term care expenditures by expanding home care options, most fear increasing costs (at least initially). However, legal requirements will likely create pressures to increase the amount and share of resources devoted to community-based long-term care. The recent Supreme Court decision in *Olmstead vs L.C.* may encourage or require states to expand access to community-based services for individuals with physical and mental disabilities.[28]

Long-Term Care Policy Issues

Growth in the number of people likely to need long-term care means that increased financing for long-term care is needed. Medicaid is the only significant source of public financing, but states devote varying resources to long-term care and access to care in both nursing homes and community settings has been limited. Medicaid also fails to protect middle income individuals from catastrophic long-term care costs. Concerns about the quality of care also persist. A range of strategies for expanding long-term care coverage exist, but regardless of which policy options are used, additional resources will be needed to help reduce the burdens of disability on elderly individuals and their families, to increase financial protections, and to address gaps in the current long-term care system.

Access to care

Although most long-term care spending in Medicaid is for nursing home care and Medicaid programs typically place limits on home and community-based care, there have been problems of access in both settings.

Access to care has always been limited by the availability of providers willing to deliver services at Medicaid's relatively low rates—despite Medicaid's entitlement to coverage of long-term care services. The recent repeal of the Boren Amendment—which established federal standards requiring that states' nursing home payments be "reasonable and adequate to meet the cost incurred by efficiently and economically operated facilities"—may result in a reduction in the rates paid for publicly financed residents and may reduce access to (and the quality of) care for Medicaid patients.

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What the repeal of these federal standards will actually mean is not yet known and depends on whether states alter payments to nursing homes.

In addition to the effect of relatively low payments, access to nursing home care may also be limited due to restrictions on the number of nursing homes and nursing home beds. States regulate the supply of nursing home beds through certificate-of-need programs (which require state approval for the establishment or expansion of health facilities or services) or moratoria on the construction of new nursing home beds. The number of nursing home beds per elderly has fallen substantially in many states—the number of nursing home beds per 1,000 elderly ages 85 and above fell by 18 percent between 1978 and 1994, and although nationwide declines in nursing home occupancy rates suggest that access may not be a problem, access problems remain in some areas, especially rural communities.[27]

Access to community-based alternatives to institutional long-term care has historically been limited in most states. Individuals with disabilities and their advocates—especially advocates for persons with mental disabilities—have long argued that Medicaid's "institutional bias" interferes with their rights under the Americans with Disabilities Act to receive care in the "least restrictive setting." Medicaid home and community-based waiver programs have grown significantly in the past decade. National expenditures were $8.1 billion in 1997—a more than six-fold increase over 1990 expenditures of $1.3 billion. However, many individuals with physical and mental disabilities continue to receive care in nursing homes rather than in the community, partly because nursing home care is needed or desired but partly because of limited funding, long waiting lists and limited eligibility for waiver services in many states. The recent Supreme Court decision in *Olmstead vs. L.C.* may encourage states to do more. In addition, states are expected to shift a greater share of spending for long-term care toward community-based settings—such as board and care homes and assisted living facilities as alternatives to costly nursing home care—as they address the challenges of financing care for an aging population.[28]

Quality

The quality of care in nursing homes, especially for Medicaid beneficiaries, has been a long-standing concern. Although significant improvements in the quality of nursing home care followed from comprehensive nursing home reform in the early 1990s, serious problems persist in many facilities. The quality of home and community-based care has received less attention, but as care increasingly moves outside of institutions, there is growing interest in measuring and monitoring quality in the community.

Comprehensive nursing home reforms—passed in 1987 as part of the Omnibus Budget Reconciliation Act—established new nursing home quality standards, requirements for federal and state oversight, and enforcement tools. Since the implementation of these standards in 1990, research studies have documented significant improvements in the quality of care, including reductions in the use of physical and chemical restraints and hospitalization rates and increases in the use of behavior management programs, hearing aids, and antidepressants and psychological therapy for residents with symptoms of depression.

Each year, however, more than a quarter of all nursing homes are cited for violations of federal regulations for causing actual physical harm to residents (such as inadequate prevention of pressure sores or failure to prevent accidents) or failing to properly assess residents' needs and provide for their care. Further, even when homes were threatened with sanctions, the problems often returned in subsequent surveys. Nearly 40 percent of nursing homes cited for deficiencies in an initial survey were cited for related violations in subsequent surveys. As a result, many observers have concluded that existing standards, though adequate in theory, don't work well in practice because the ability to enforce them (to shut down bad homes) is limited. Enforcement needs to be strengthened to help improve compliance with federal standards and ensure the safety and welfare of nursing home residents.[29]

Quality concerns have also been raised for home and community-based services. Like nursing home residents, the elderly receiving long-term care services in their homes are vulnerable to abuse, but it is more difficult to monitor services received in the home. Although some individuals receiving care live with others, many live alone and are especially vulnerable to threats to their personal safety and well-being. Beyond actual harm to individuals, there are also important concerns over the quality and appropriateness of the long-term care services delivered. What is meant by "quality" and "appropriateness" varies across population groups and services received. Consumer choice and control are critical issues especially for many nonelderly individuals with physical disabilities who have significant needs for assistance with activities of daily living. For the elderly who may be receiving both acute and long-term care, quality of care concerns have been raised about the appropriate volume and mix of services. For those receiving such services, often paid by Medicare, there is growing interest in the development of standards for the amount and mix of services (acute, rehabilitative and personal care) that patients should receive, and to measuring and monitoring the outcomes of that care. The issues, however, are quite complex since there is considerable variation in both treatments and outcomes.

The Growing Demand for Long-Term Care

Despite recent declines in disability rates among the elderly, the aging of the baby boom generation will bring about a significant increase in the demand for long-term care. The number of elderly is projected to more than double over the next three decades, rising from 34 million in 1997 to more than 69 million in 2030. The growth in the over 85 population—the population most likely to use long-term care services—is projected to more than triple by 2030 [Figure 6].

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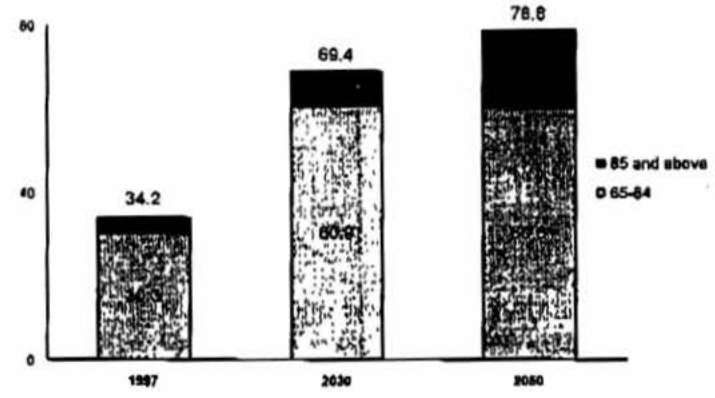
Figure 6

Projected Growth of the Elderly Population, 1997-2050
(Number in millions)



SOURCE: CBO, 1999.

If disability rates remain what they are today, the number of elderly needing long-term care is projected to rise dramatically. The hope is that medical advances and improvements in the economic status of the elderly will help people live both longer and healthier lives, and that the proportion of the elderly who are disabled will fall as the elderly population grows.[30] However, although the proportion of the elderly population needing long-term care may fall, the number of elderly individuals with long-term care needs will still grow significantly, rising from 8.8 million in 2000 to an estimated 12.1 million in 2040.[31] This increased demand will tend to cause the cost of long-term care to rise, placing the largest burdens on the low-income population not qualifying for public assistance.

Future Financing

The Congressional Budget Office projects that inflation-adjusted long-term care spending for the elderly will nearly triple in the next four decades, rising from $123 billion in 2000 to $346 billion (in constant 2000 dollars) in 2040 when the baby-boom generation reaches age 85 [Figure 7]. Public programs will continue to be liable for the largest proportion of these costs even assuming that the role of private long-term care insurance in the market will grow. In order to provide even the same level of long-term care service being provided today, Medicaid expenditures will have to rise to $75 billion dollars in 2020, or over one and a half times its liability in the year 2000 of $43 billion dollars. Combined public financing of long-term care—Medicaid and Medicare expenditures—will need to rise from $74 billion in 2000 to $126 billion in 2020, accounting for about 60 percent of all long-term care financing. Private out-of-pocket spending will remain high, but private long-term care insurance is expected to mitigate some of the pressure of out-of-pocket costs, rising from 4 percent of long-term care expenditures in 2000 to 17 percent in 2020 [Figure 8].

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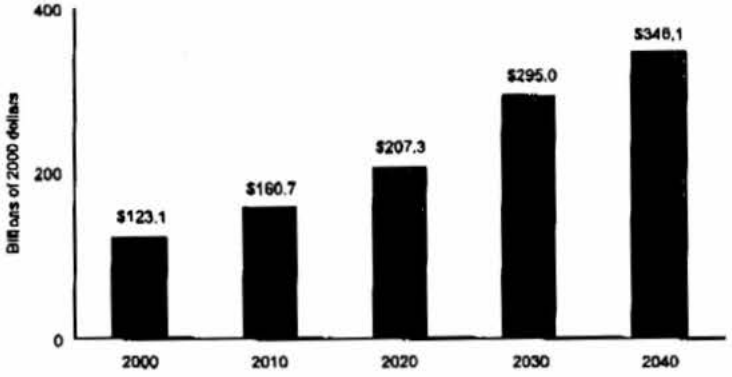
Figure 7

Projection of National Long-Term Care Expenditures, 2000-2040

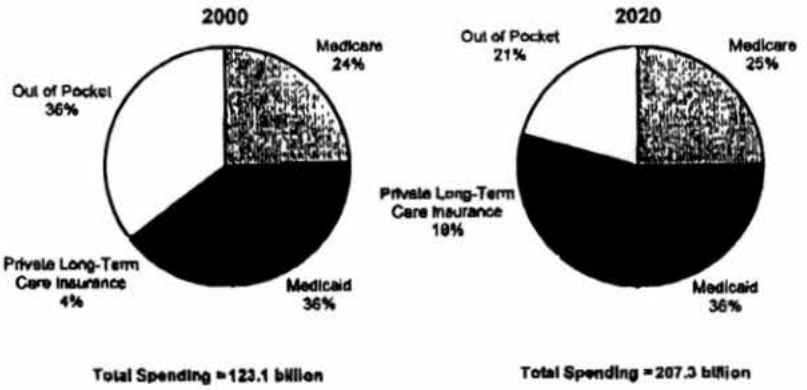
(In billions of 2000 dollars)



SOURCE: CBO, 1999.

Figure 8

Projection of the Distribution of National Long-Term Care Expenditures by Payer, 2000 and 2020



SOURCE: CBO, 1999.

There are a number of ways to pay for long-term care in the future—including both public and private sector approaches. Private sector approaches emphasize that individuals should be responsible for long-term care, paying for their own care out of savings or purchasing private long-term care insurance policies. Public sector approaches range from expansions of Medicaid, to protect modest income people against impoverishment, to a comprehensive social insurance option that would ensure care for all disabled persons regardless of financial need. In between are policies that combine private and public sector approaches.[32]

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A policy of increasing private savings—encouraging individuals to save for future long-term care needs much the way they put aside money for their children's education—seems unlikely to provide adequate protections for long-term care. The main difficulty rests with the fact that the need for long-term care is an unpredictable event. Although 40 percent of people who reach age 65 will use a nursing home at some point in their lives, people do not know in advance whether, or how much, they will need. A small proportion will have very high expenditures—spending more than one year in a nursing home or experiencing multiple episodes of care.[33] Depending on private savings concentrates the financial burden of severe impairment—an expensive and largely unpredictable event—on the few who experience it rather than spreading it among the many who are at risk of impairment.

Providing some financial assistance to those who need long-term care may help to mitigate these burdens. President Clinton has recently proposed a long-term care initiative along these lines. The President's proposal would give a $1,000 tax credit to individuals with significant long-term care needs, their caregivers, or families, that could be used to help pay for home care, adult day care and other long-term care services. Though limited in scope, the proposal has the advantage of targeting assistance to modest income people who are currently shouldering much of the burden on their own.[34]

Insurance, according to most observers, is a better approach to meeting the need for long-term care as the baby-boom generation reaches retirement age because it spreads risk. Those who favor a private sector approach advocate expanded tax preferences to encourage individuals to purchase long-term care policies. Some tax preferences are already in place—premiums for employer-sponsored long-term care insurance plans are excluded from taxable income and part of the cost of premiums for the self-employed is tax deductible—and recent proposals have called for expanded tax deductibility of individual premiums. However, tax preferred treatment of private insurance premiums is unlikely to significantly expand coverage, but is likely to deliver subsidies to those who already would have purchased private insurance.[35] Analysis suggests that even with favorable tax treatment, private long-term care insurance is likely to remain unaffordable for the modest and low-income elderly who are most at risk of needing long-term care.[36] A recent Congressional Budget Office analysis suggests that, even under very optimistic assumptions about the expansion of private long-term care insurance, Medicaid expenditures will need to nearly double by 2020 to provide the level of service being provided today.

Another option is to expand insurance for long-term care through new or existing public programs. For example, protected income and asset levels in Medicaid could be increased from their currently low levels, to give greater financial protection to modest income elderly who must now impoverish themselves in order to qualify for Medicaid. Including long-term care in Medicare is also an option. Creating a system of social insurance for long-term care would spread the costs of long-term care widely across the population to protect against potentially catastrophic financial losses for the minority at risk. In practice, however, the debate over the future of Medicare and Social Security raises questions about political commitments to existing entitlements, let alone new ones.

TAKING THE "AID" OUT OF MEDICAID

The Republicans propose to destroy Medicaid as we know it and replace it with a vastly underfunded block grant program.

The Republican Medicaid cuts put states in an untenable position: raise taxes, reduce Medicaid coverage, and/or cut services.

The result is that the Republican plan would destroy the social safety net in this country and could eliminate coverage for 8.8 million Americans by the year 2002 including:

- 4.4 million children
- 350,000 nursing home residents
- 330,000 people needing home care
- 1.4 million people with disabilities

The Republican Medicaid plan could leave families shouldering the full responsibility for the nursing home costs of elderly parents and grandparents.

The Medicaid safety net that covers two-thirds of nursing home patients and helps working families cope with the huge cost of nursing home care for their parents -- averaging $38,000 a year in the U.S. -- would be destroyed.

-- Elderly women could be forced to sell their homes to pay for their husbands' care;

-- Adult children of nursing home residents could be forced by the government to pay for the care of their parents;

-- Parents of mentally retarded children could be forced to pay the full cost of care for their children in an institution or at home.

The Republican Medicaid plans would wipe out quality standards for American nursing homes and institutions caring for the mentally retarded.

The Republican Medicaid plans would repeal the 1987 law -- signed by President Reagan -- creating tough standards for the quality of nursing homes caring for the elderly, disabled, and mentally retarded. These requirements include restrictions on the use of drugs and restraints to keep residents in their beds; requirements that nurses be on duty at least 8 hours a day; requirements that nurses' aides undergo training before caring for residents.

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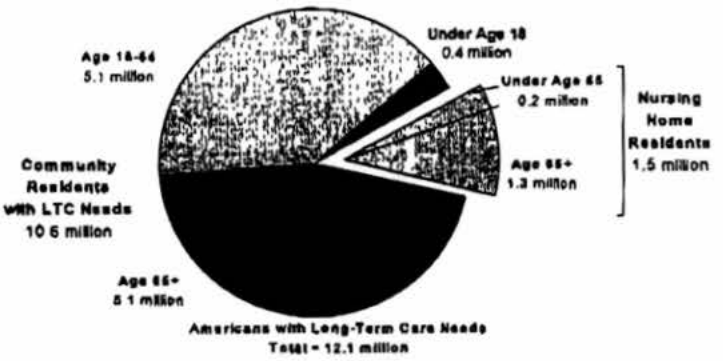
extended their quality of life and survival time, but many will continue to have chronic care needs.[2]

Figure 1

The Long-Term Care Population, 1995

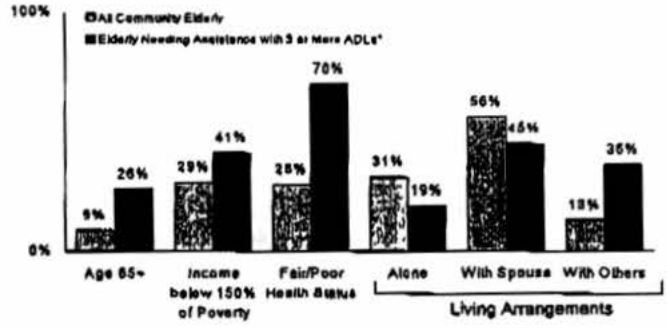


SOURCE: Georgetown University Institute for Health Care Research and Policy estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.; and The American Health Care Association, "The Nursing Facility Sourcebook: Facts and Trends, 1997;" data from the 1995 National Nursing Home Survey.

The 6.4 million elderly with long-term care needs have varying levels of impairment and receive care both in the community and in nursing homes. Nearly 1.5 million elderly live in nursing homes, and 4.9 million elderly individuals have some long-term care need and live in the community. Of the elderly 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 a quarter are age 85 and above, 40 percent are poor or near-poor (with incomes below 150 percent of the federal poverty level), and 70 percent report that they are in fair or poor health. Compared to the typical elderly person, they are less likely to live alone or with a spouse, and are substantially more likely to live with others—often an adult child [Figure 2]. Older women who live alone are particularly vulnerable; they are both more likely to need long-term care and to have fewer financial resources than the elderly population as a whole.

Figure 2

Characteristics of Community-Dwelling Elderly with Substantial Long-Term Care Needs



*Elderly individuals who need assistance with three or more "activities of daily living" (ADLs), including: bathing, dressing, eating, transferring, toileting, and walking.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview and National Health Interview Survey on Disability, Phase II.

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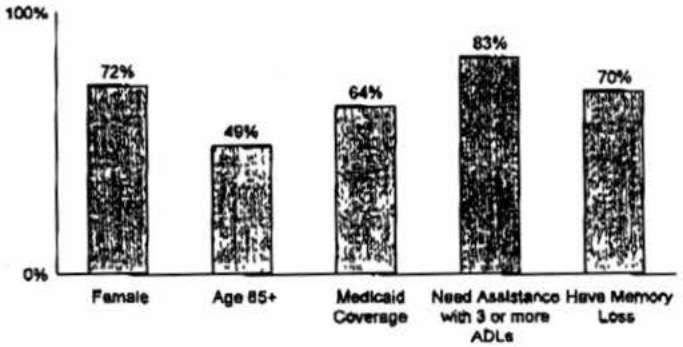
The 1.5 million elderly in nursing homes are typically older and more frail than the disabled elderly living in the community: nearly half are over age 85; more than 80 percent are severely disabled (requiring assistance with three or more ADLs); and 70 percent report cognitive impairments such as memory loss or orientation problems [Figure 3]. In addition, more than 70 percent are women, and almost two-thirds have Medicaid coverage.[3]

Figure 3

Characteristics of Nursing Home Residents, 1996



*Note: ADL = Activities of Daily Living
SOURCE: AHCPR 1998. Data from the National Medical Expenditures Panel Survey, 1996.

How do People Get Long-Term Care?

Most people who need long-term care (88 percent) receive that care at home (or in community-based settings, such as adult daycare facilities). Only 12 percent receive care in nursing homes or other institutional facilities, such as intermediate care facilities for people with mental retardation.

A number of factors determine whether individuals with long-term care receive care at home or in nursing homes or other institutional settings. The likelihood of nursing home admission increases with age and extent of disability; most nursing home residents (91 percent) are elderly and almost half are over the age of 85. Elderly individuals who are most likely to be at risk of nursing home placement include those with cognitive impairments, those who are incontinent, and those without caregivers at home or nearby.

For those with long-term care needs living in the community, care needs vary considerably. Many of the elderly with long-term care needs may have only limited needs for assistance with such activities as paying bills, grocery shopping and taking medication. Others are more severely disabled, with extensive care needs for which they require full-time nursing and personal care. The use of paid home care is greatest among the elderly with moderate to severe levels of disability and those who live alone.

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Among the elderly in the community, those with long-term care needs typically rely on assistance from family and friends. About two-thirds depend on informal (unpaid) caregiving as their only form of assistance, and one-third receive a combination of informal and formal care.[4] Even among the community elderly with chronic, severe limitations, about half rely solely on unpaid help, often placing considerable strain on the family members who care for them [See Box 1].

BOX 1

Burdens on Family Caregivers

Chronic illness and functional limitations create growing burdens for the elderly individuals themselves and for the family members—spouses, daughters, daughters-in-law— and others who help to care for them on a routine basis. Ironically, changes in medical care that have improved its effectiveness—such as shorter hospital stays, the increased use of outpatient procedures, and the substitution of home care for institutional care—have shifted responsibility from paid providers toward unpaid providers, increasing burdens on family caregivers. The difficulties are enhanced because many caregivers have competing career and family responsibilities, and many are elderly themselves. A substantial proportion of caregivers who work report conflicts between work and care-giving, resulting in rearranged work schedules, decreasing hours of work, and periods of unpaid leave.[5]

The current system fails to meet all the long-term care needs of all persons with disabilities. Of elderly and nonelderly adults with long-term care needs living in the community, a significant proportion (about 20 percent) report that they have experienced "unmet need" for long-term care. Those responding to a national survey in 1994-95 attributed these gaps to the high cost of services, difficulty finding help, and failure to qualify for assistance from a social service agency because they didn't meet eligibility criteria (that is, their incomes were too high or they didn't meet the medical criteria needed to receive assistance). A substantial proportion of community adults with "unmet needs" reported specific consequences from a lack of help: a third of people with unmet need for help in toileting reported that they wet or soiled themselves; twenty percent of people with unmet need for help eating said they experienced periods when they were unable to eat when hungry.[6]

Who Pays for Long-Term Care?

Long-term care can be quite costly and can drain private resources quickly. The average cost of a year of nursing home care was nearly $41,000 in 1995,[7] and even regular home care visits can quickly become expensive. Hiring a home care aide to visit four hours a day, five days a week, at $10 an hour would cost more than $10,000 a year, and could be more costly for individuals with extensive needs.[8] As a result of the high costs of care, more than a third of all elderly individuals admitted to nursing homes, and about 70 percent of those with lengths of stay at least one year, were estimated to have catastrophic long-term care costs in 1993—that is, their long-term care costs exceed 40 percent of their total income and non-housing financial assets.[9] Consequently, many of those with long-term care needs turn to Medicaid, the only public program providing significant financing for long-term care.

Health insurance coverage of persons with long-term care needs

Most, but not all, individuals with long-term care needs have health insurance of some kind—either publicly-financed or private health coverage. Their insurance plans, however, may or may not provide coverage for long-term care. For example, Medicare provides nearly universal coverage for the elderly but does not provide coverage for the extended personal care that is the bulk of long-term care, nor do most private health insurance plans cover long-term care.

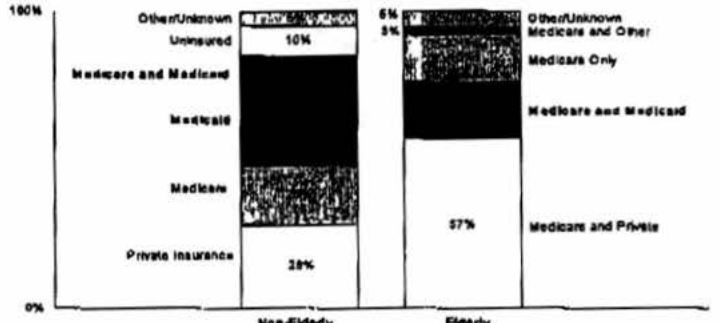
The elderly rely on Medicare for health insurance, and most have private or public supplemental coverage to help fill Medicare's gaps. Among the community-dwelling elderly with long-term care needs, 57 percent have private supplemental coverage in addition to Medicare, and 19 percent have Medicaid [Figure 4]. For those with private coverage, a very small proportion may have a private long-term care insurance policy, but most have only a Medigap policy, which does not typically provide substantial assistance with long-term care. For those with Medicaid, the extent of Medicaid protections varies, but the substantial majority of these Medicare and Medicaid "dual eligibles" receive the full range of benefits that Medicaid provides, including long-term care. A substantial minority (16 percent) of elderly people with long-term care needs only receive Medicare benefits, relying on their own income and assets to pay for prescription drugs, Medicare cost sharing, and any long-term care services they might need.

For nonelderly adults with long-term care needs, insurance coverage is more varied and Medicare plays a smaller role. About 30 percent (of the community-dwelling nonelderly disabled) rely on private health insurance, almost 60 percent have public coverage through Medicare and/or Medicaid; 20 percent have Medicare as their primary source of coverage, 25 percent have Medicaid, and 12 percent are covered by both Medicare and Medicaid. About 10 percent of the nonelderly disabled in the community are uninsured.

Figure 4

Health Insurance Coverage of Elderly and Non-Elderly Individuals with Long-Term Care Needs

(Community-dwelling individuals only)



Note: The "Medicare" and "Medicaid" categories for the nonelderly and the "Medicare and private" category for the elderly may include sources of public coverage other than Medicaid. "Other" includes Indian Health Care, Veterans' health care and other public insurance programs.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.

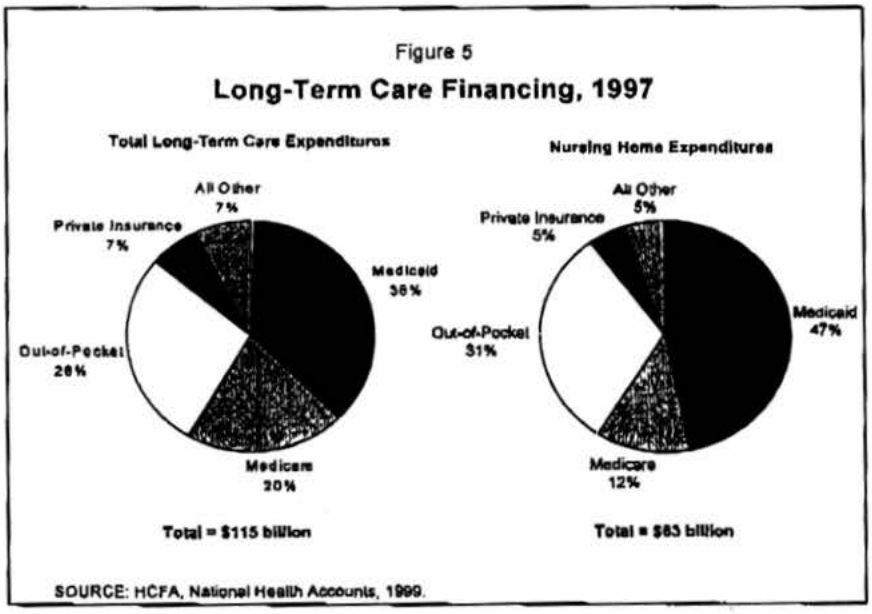
For the elderly and nonelderly poor who need long-term care, Medicaid is especially important. Of community residents with long-term care needs and incomes below the poverty line, 44 percent of the elderly and 64 percent of the nonelderly are covered by Medicaid. By comparison, only 9 percent of disabled elderly and 16 percent of the nonelderly disabled with incomes above 200 percent of the federal poverty level have Medicaid coverage.[10] Rates of Medicaid coverage are even higher among poor and low-income facility residents.

Although both private health insurance and Medicare are important sources of coverage for persons with long-term care needs, they play only limited roles in financing long-term care expenditures, but pay primarily for the acute health care needs of persons with disabilities. It is Medicaid that is the primary source of insurance coverage for long-term care, and thus Medicaid and out-of-pocket expenditures that account for the bulk of expenditures on long-term care.

More than $115 billion was spent on long-term care in the United States in 1997—12 percent of national health spending. Most long-term care is financed by the Medicaid program and by individuals with long-term care needs and their families (together accounting for 66 percent of long-term care expenditures). Medicare plays a more limited role (accounting for 20 percent of spending) and the role of private insurance is very limited (7 percent of long-term care expenditures are paid by private health care or long-term care insurance) [Figure 5]. In addition, a substantial amount of long-term care is unpaid—provided informally by family and friends—and is not reflected in these cost estimates.

Figure 5

Long-Term Care Financing, 1997



SOURCE: HCFA, National Health Accounts, 1999.

* Medicaid long term care

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NOVEMBER 1999

LONG-TERM CARE*

Over 12 million people in the United States need help with basic activities of daily living requiring long-term care services—that is, personal, social and medical supports provided at home, in the community, or in institutional settings. The long-term care population is diverse, reflecting a broad age spectrum, a variety of service needs, and differing abilities to satisfy them. The elderly are the primary users of long-term care services and, among the elderly, the most vulnerable are the very old and those who live alone.

Spending on long-term care came to $115 billion in 1997. Over 40 percent of that spending was financed by the Medicaid program, including half the costs of nursing home care. Medicaid is the nation's long-term care safety net—financing care not only for the poor but for the middle class as well. However, Medicaid pays for care for those with middle incomes *only* once they have exhausted their own financial resources; consequently, many of the elderly are at considerable risk of catastrophic long-term care expenditures. More than a third of the elderly who entered nursing homes—and more than 70 percent of those who were in nursing homes for at least a year—had catastrophic long-term care costs (with expenditures exceeding 40 percent of their annual income and non-housing financial assets). Because of their greater likelihood of needing long-term care and their limited ability to pay, the low-income elderly are especially at-risk.

The elderly pay for a substantial portion of long-term care costs out-of-pocket (nearly 30 percent in 1997). Medicare provides nearly universal coverage for the elderly for health care, but Medicare does not pay for most long-term care, paying only for limited amounts of skilled nursing care in nursing homes and for some home health care. Private insurance plays only a small role in long-term care. With eligibility for public programs limited and the costs of service high, the current system fails to meet all of the long-term care needs of persons with disabilities. For example, a significant proportion (about 20 percent) of elderly and nonelderly adults with long-term care needs report an inability to fully address these needs, with sometimes serious consequences for their health and quality of life.

The number of people likely to need long-term care, and national expenditures on long-term care for the elderly, will increase significantly with the aging of the baby-

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boom population. Exacerbating the problem of serving the growing long-term care population appropriately is the fact that long-term care costs are expected to grow faster than inflation. Inflation-adjusted long-term care expenditures are expected to triple to $346 billion by 2040, placing large burdens on both Medicaid and private resources. Assuming current policies continue, more resources will likely be required to address gaps in the current system, varied inputs across states, limited access to care in the community, and concerns about quality of care.

What is Long-Term Care?

Long-term care services provide the help required by individuals with physical or mental disabilities to perform basic "activities of daily living" (ADLs) such as eating, bathing, dressing, getting in and out of bed, and using the bathroom. Long-term care also includes services that are designed to assist individuals with "instrumental activities of daily living" (IADLs) that are necessary to remain independent, such as housework, laundry, grocery shopping, taking medication, and transportation. Long-term care is the care needed to cope when physical or mental disabilities interfere with an individual's ability to perform these basic tasks on their own.

Who Needs Long-Term Care?

Chronic conditions that create a need for long-term care are physical or mental in nature and their onset time ranges from before birth to late in life. Alzheimer's disease, heart disease, multiple sclerosis, cerebral palsy, spinal cord injury, and stroke are just a few of the diseases that may cause chronic disability. Unlike acute illness, chronic conditions are essentially permanent. Regimens of medical and personal care can sometimes control but rarely cure them.

Disability is a condition that often creates a need for a variety of services and supports on a continuing basis. The presence of disability, however, is not synonymous with the need for long-term care. Over forty million Americans have a physical or mental disability. Of these, more than twelve million (30 percent) need long-term care, defined as a need for assistance with activities of daily living, and about a third of those with long-term care needs (approximately 4 million people in the community and in institutions) have substantial needs—that is, they need help with 3 or more activities of daily living.[1]

The elderly are much more likely than younger age groups to suffer from disabling conditions and to require long-term care. Almost a quarter of the elderly (6.4 million individuals) have some long-term care need. However, individuals with long-term care may be young or old. Only 3 percent of adults ages 18 to 64 had some long-term care need, but this translates into a significant number of nonelderly adults needing long-term care (5.3 million); 400,000 children also have long-term care needs [Figure 1].

The prevalence of disability among children and non-elderly adults has been increasing as a result of improved trauma care and medical technologies that have extended the lives of those with life-threatening or debilitating illnesses. Recent advances in the treatment of AIDS has also fueled changes in the composition of the long-term care population. Improved treatments for those infected with HIV have

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Medicare

Although Medicare provides nearly universal coverage to the elderly for their acute care needs, it is not designed to cover the majority of their long-term care costs. Medicare covers short-term skilled nursing facility care and plays a limited role in financing home and community-based services. Although no prior hospitalization is required to receive home health care under Medicare, benefits are limited to people who are homebound, require skilled nursing, physical therapy or speech therapy on a part-time or intermittent basis, and are under the care of a physician.

In the past several years, increasing attention has been paid to the rapid growth in the use and costs of Medicare's post-acute care benefits, with many observers suggesting that this represents an inappropriate expansion of Medicare into long-term care. A rapid expansion in home health has been of special concern. Home health spending increased at an average annual rate of 29 percent between 1990 and 1996, rising from $3.9 billion to $18.3 billion and from 3.6 percent to 9.2 percent of Medicare spending. Medicare's payment policies have been revised in an attempt to constrain this growth, and there is continuing attention to additional reforms that would help to limit the use of home health benefits.

Even with the recent expansion of home health services, however, survey and program data suggest significant limits to its reach among people with long-term care needs. One survey found that only 10 percent of the community-dwelling elderly with chronic disabilities and long-term care needs received Medicare-financed home care in the week prior to the survey in 1994.[11] A large proportion of Medicare home health care expenditures (46 percent in 1997) are consumed by very small proportion (10 percent) of Medicare beneficiaries with high home health use (200 home health visits or more per year).[12] These home health users typically have both acute and long-term care needs and are disproportionately older, in poorer health, more disabled and have lower incomes than other home health care users.

Many observers have suggested that recent changes in treatment patterns under Medicare home health reflect a shift from a narrow post-acute benefit toward a long-term care benefit. Medicare beneficiaries using home health care are using care long after a hospitalization, they are receiving more visits, and as episodes of care have lengthened, they are receiving a higher proportion of aide visits and correspondingly fewer skilled visits.[13] But despite the rapid growth in home health utilization and expenditures, Medicare's benefit does not cover long-term care for people who need such care exclusively. However, for people who qualify, the type of care it covers overlaps substantially with long-term care: the home health benefit covers some personal assistance with basic daily activities—the long-term care services—along with skilled services for beneficiaries who need both. As Medicare tries to limit its home health care coverage, it remains to be seen if Medicaid's expansion into home and community-based services will sufficiently cover the long-term care population with severe disabilities.

Private Long-Term Care Insurance

Most individuals with long-term care needs rely on their own resources to pay for long-term care, but private insurance plays a very limited role in the financing of long-term care. Most private health insurance policies pay for very little long-term care and only 7 percent of the elderly own a long-term care insurance policy that explicitly covers these services.[14] Less than one percent of long-term care expenditures are financed by private long-term care insurance.[15]

Sales of private insurance policies have increased over the past decade, but long-term care remains unaffordable for many of the elderly—with one recent study suggesting that only 10 to 20 percent of the elderly could afford to purchase a comprehensive long-term care policy.[16] The cost of private insurance coverage increases with age and with essential coverage provisions, such as inflation protection (which increases benefit levels as nursing home costs rise) and nonforfeiture benefits (which allow an individual to recover some of the cost of the policy if that person cannot pay the premium or thinks he/she will not need the coverage). The average annual premium for policies covering four years of nursing home and home care with inflation protection and nonforfeiture benefits in 1996 was $1,200 per year if purchased at age 50, $2,432 per year if purchased at age 65, and $7,440 a year if purchased at age 75.[17]

The people who are able to buy good quality policies at the prices offered are often middle to upper income individuals who generally would not qualify for Medicaid (and offset public expenditures for long-term care). Further, many of those who might purchase private insurance may not be able to buy it. One study has estimated that even if everyone applied for long-term care insurance at age 65, a significant proportion—perhaps as many as a quarter—would be rejected under current underwriting criteria.[5]

Medicaid

Medicaid is the only public program that provides substantial coverage for long-term care. Medicaid spending on long-term care was $44 billion in 1997, financing nearly 40 percent of all long-term care, 50 percent of the costs of nursing home care, and financing the care of nearly 70 percent of nursing home residents. Nationally, Medicaid spends an average of about $7,800 on long-term care per elderly Medicaid enrollee and $3,700 per disabled enrollee.[18]

Medicaid is the nation's safety net provider of long-term care services not only for the poor, but for the middle class as well. Unlike other insurance, however, which provides protection against catastrophic losses, Medicaid helps only after catastrophe strikes. Middle income Americans with catastrophic long-term care costs may become eligible for Medicaid benefits once they have "spent down" their income and assets—they must impoverish themselves before Medicaid assistance is available. Although some policymakers have expressed concern that Medicaid's spend down provisions encourage attempts to unfairly manipulate the system by those who could otherwise afford long-term care, there is little evidence of widespread abuse [See Box 2].

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BOX 2

Medicaid "Spend Down"

In 35 states and in the District of Columbia, people whose assets are less than a specified level ($2,000 for individuals, $3,000 for couples) can qualify for Medicaid if the cost of nursing home care exceeds their incomes—that is, they qualify for Medicaid as "medically needy." Individuals must contribute all of their income toward the cost of care, except for a small personal care allowance (of no less than $30 per month). The rules for couples are more generous to prevent impoverishment of a spouse who remains in the community. Protected income for the community spouse ranged from $1,326 to $1,978 per month in 1997, and protected assets ranged from $15,804 to $79,020 depending on state eligibility rules.[19]

Despite concerns about abuse of the system, only about 20 percent of current residents spend down at some point during their stays. However, those who stay in the nursing home for a long period of time are more likely to eventually spend down to Medicaid. About one-third of nursing home residents who used long-term care services for one to three years spent down and about half of those with nursing home stays of more than three years spent down their income and assets to Medicaid.[20]

Concern has been expressed that, despite prohibitions, elderly people are transferring assets to avoid spend down. However, the asset levels of elderly people likely to need nursing home care are typically low to begin with and federal legislation (OBRA 1993) has placed greater restrictions on asset transfers.[21] Recent research also suggests that there is little need for policy efforts to limit the use of trusts to avoid spend down, since very few of the elderly have a trust. Although the study found that 4 in 10 elderly community dwellers could potentially qualify for Medicaid by using a trust, fewer than 10 percent had a trust.[22]

Long-term care accounts for about 35 percent of Medicaid spending nationwide, but states vary greatly in their inputs to long-term care. The average Medicaid long-term care expenditure per elderly beneficiary ranges from over $15,000 in Connecticut, New York, and the District of Columbia, to less than $5,000 in South Carolina, Mississippi, and Oklahoma.[23] In most states, the large proportion of long-term care spending is for nursing home care. All states provide home and community-based long-term care services: Medicaid requires states to cover home health services for any individual eligible for nursing home care, states have the option (used by 31 states) to cover personal care and, under waivers, all states have developed programs designed to target a specific mix of home and community-based services to distinct population groups or in distinct geographic areas. Nevertheless, few states rely on Medicaid to provide substantial long-term care to people living at home. Nationally, less than 20 percent of Medicaid long-term care spending is for home and community-based care services, personal care, and home health care services.[24] Payments for home and community-based waiver services per person age 65 or over vary from $1,180 in New York to $29 in Mississippi, and in some states, such as Oregon and New York, there are

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relatively balanced systems that devote a significant share (40 to 50 percent) of long-term care spending to home and community-based services.[25]

Initially, home and community-based services were conceived as a less expensive alternative to nursing home care. (Eligibility for these community-based benefits is typically extended to people who are eligible for nursing home or other institutional care and meet state income and asset criteria). However, there is little evidence that home-based services reduce nursing home use and expenditures, largely because individuals who would not otherwise use nursing home care will use home and community-based services if they are available. Because of concerns about these "woodwork effects," the law allows states to limit these services with respect to the number, type, and location of people served as well as the volume of services provided. Home and community-based care can expand service options without increasing state long-term care expenditures only if nursing home use is explicitly restricted—by diverting the least disabled prospective nursing home clients to available home care options.

Although some states expect to control overall long-term care expenditures by expanding home care options, most fear increasing costs (at least initially). However, legal requirements will likely create pressures to increase the amount and share of resources devoted to community-based long-term care. The recent Supreme Court decision in *Olmstead vs L.C.* may encourage or require states to expand access to community-based services for individuals with physical and mental disabilities.[26]

Long-Term Care Policy Issues

Growth in the number of people likely to need long-term care means that increased financing for long-term care is needed. Medicaid is the only significant source of public financing, but states devote varying resources to long-term care and access to care in both nursing homes and community settings has been limited. Medicaid also fails to protect middle income individuals from catastrophic long-term care costs. Concerns about the quality of care also persist. A range of strategies for expanding long-term care coverage exist, but regardless of which policy options are used, additional resources will be needed to help reduce the burdens of disability on elderly individuals and their families, to increase financial protections, and to address gaps in the current long-term care system.

Access to care

Although most long-term care spending in Medicaid is for nursing home care and Medicaid programs typically place limits on home and community-based care, there have been problems of access in both settings.

Access to care has always been limited by the availability of providers willing to deliver services at Medicaid's relatively low rates—despite Medicaid's entitlement to coverage of long-term care services. The recent repeal of the Boren Amendment—which established federal standards requiring that states' nursing home payments be "reasonable and adequate to meet the cost incurred by efficiently and economically operated facilities"—may result in a reduction in the rates paid for publicly financed residents and may reduce access to (and the quality of) care for Medicaid patients.

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What the repeal of these federal standards will actually mean is not yet known and depends on whether states alter payments to nursing homes.

In addition to the effect of relatively low payments, access to nursing home care may also be limited due to restrictions on the number of nursing homes and nursing home beds. States regulate the supply of nursing home beds through certificate-of-need programs (which require state approval for the establishment or expansion of health facilities or services) or moratoria on the construction of new nursing home beds. The number of nursing home beds per elderly has fallen substantially in many states—the number of nursing home beds per 1,000 elderly ages 85 and above fell by 18 percent between 1978 and 1994, and although nationwide declines in nursing home occupancy rates suggest that access may not be a problem, access problems remain in some areas, especially rural communities.[27]

Access to community-based alternatives to institutional long-term care has historically been limited in most states. Individuals with disabilities and their advocates—especially advocates for persons with mental disabilities—have long argued that Medicaid's "institutional bias" interferes with their rights under the Americans with Disabilities Act to receive care in the "least restrictive setting." Medicaid home and community-based waiver programs have grown significantly in the past decade. National expenditures were $8.1 billion in 1997—a more than six-fold increase over 1990 expenditures of $1.3 billion. However, many individuals with physical and mental disabilities continue to receive care in nursing homes rather than in the community, partly because nursing home care is needed or desired but partly because of limited funding, long waiting lists and limited eligibility for waiver services in many states. The recent Supreme Court decision in *Olmstead vs. L.C.* may encourage states to do more. In addition, states are expected to shift a greater share of spending for long-term care toward community-based settings—such as board and care homes and assisted living facilities as alternatives to costly nursing home care—as they address the challenges of financing care for an aging population.[28]

Quality

The quality of care in nursing homes, especially for Medicaid beneficiaries, has been a long-standing concern. Although significant improvements in the quality of nursing home care followed from comprehensive nursing home reform in the early 1990s, serious problems persist in many facilities. The quality of home and community-based care has received less attention, but as care increasingly moves outside of institutions, there is growing interest in measuring and monitoring quality in the community.

Comprehensive nursing home reforms—passed in 1987 as part of the Omnibus Budget Reconciliation Act—established new nursing home quality standards, requirements for federal and state oversight, and enforcement tools. Since the implementation of these standards in 1990, research studies have documented significant improvements in the quality of care, including reductions in the use of physical and chemical restraints and hospitalization rates and increases in the use of behavior management programs, hearing aids, and antidepressants and psychological therapy for residents with symptoms of depression.

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Each year, however, more than a quarter of all nursing homes are cited for violations of federal regulations for causing actual physical harm to residents (such as inadequate prevention of pressure sores or failure to prevent accidents) or failing to properly assess residents' needs and provide for their care. Further, even when homes were threatened with sanctions, the problems often returned in subsequent surveys. Nearly 40 percent of nursing homes cited for deficiencies in an initial survey were cited for related violations in subsequent surveys. As a result, many observers have concluded that existing standards, though adequate in theory, don't work well in practice because the ability to enforce them (to shut down bad homes) is limited. Enforcement needs to be strengthened to help improve compliance with federal standards and ensure the safety and welfare of nursing home residents.[20]

Quality concerns have also been raised for home and community-based services. Like nursing home residents, the elderly receiving long-term care services in their homes are vulnerable to abuse, but it is more difficult to monitor services received in the home. Although some individuals receiving care live with others, many live alone and are especially vulnerable to threats to their personal safety and well-being. Beyond actual harm to individuals, there are also important concerns over the quality and appropriateness of the long-term care services delivered. What is meant by "quality" and "appropriateness" varies across population groups and services received. Consumer choice and control are critical issues especially for many nonelderly individuals with physical disabilities who have significant needs for assistance with activities of daily living. For the elderly who may be receiving both acute and long-term care, quality of care concerns have been raised about the appropriate volume and mix of services. For those receiving such services, often paid by Medicare, there is growing interest in the development of standards for the amount and mix of services (acute, rehabilitative and personal care) that patients should receive, and to measuring and monitoring the outcomes of that care. The issues, however, are quite complex since there is considerable variation in both treatments and outcomes.

The Growing Demand for Long-Term Care

Despite recent declines in disability rates among the elderly, the aging of the baby boom generation will bring about a significant increase in the demand for long-term care. The number of elderly is projected to more than double over the next three decades, rising from 34 million in 1997 to more than 69 million in 2030. The growth in the over 85 population—the population most likely to use long-term care services—is projected to more than triple by 2030 [Figure 6].

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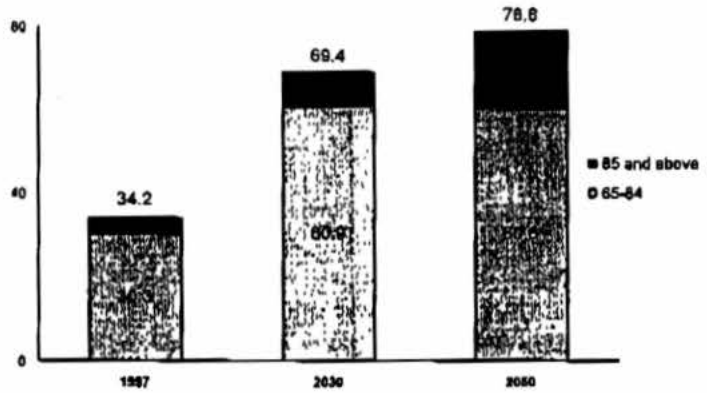
Figure 6

Projected Growth of the Elderly Population, 1997-2050
(Number in millions)



SOURCE: CBO, 1999.

If disability rates remain what they are today, the number of elderly needing long-term care is projected to rise dramatically. The hope is that medical advances and improvements in the economic status of the elderly will help people live both longer and healthier lives, and that the proportion of the elderly who are disabled will fall as the elderly population grows.[30] However, although the proportion of the elderly population needing long-term care may fall, the number of elderly individuals with long-term care needs will still grow significantly, rising from 8.8 million in 2000 to an estimated 12.1 million in 2040.[31] This increased demand will tend to cause the cost of long-term care to rise, placing the largest burdens on the low-income population not qualifying for public assistance.

Future Financing

The Congressional Budget Office projects that inflation-adjusted long-term care spending for the elderly will nearly triple in the next four decades, rising from $123 billion in 2000 to $346 billion (in constant 2000 dollars) in 2040 when the baby-boom generation reaches age 85 [Figure 7]. Public programs will continue to be liable for the largest proportion of these costs even assuming that the role of private long-term care insurance in the market will grow. In order to provide even the same level of long-term care service being provided today, Medicaid expenditures will have to rise to $75 billion dollars in 2020, or over one and a half times its liability in the year 2000 of $43 billion dollars. Combined public financing of long-term care—Medicaid and Medicare expenditures—will need to rise from $74 billion in 2000 to $126 billion in 2020, accounting for about 60 percent of all long-term care financing. Private out-of-pocket spending will remain high, but private long-term care insurance is expected to mitigate some of the pressure of out-of-pocket costs, rising from 4 percent of long-term care expenditures in 2000 to 17 percent in 2020 [Figure 8].

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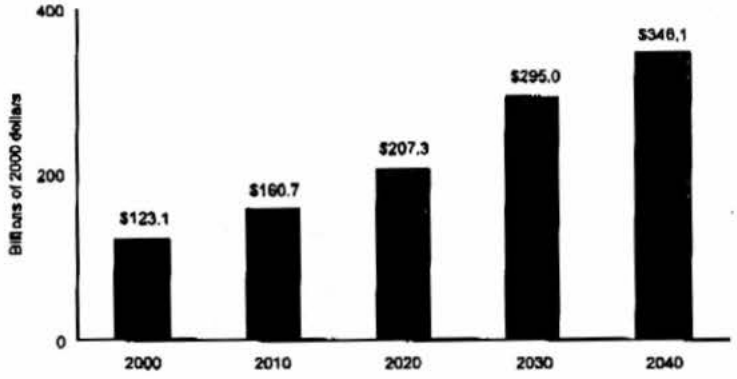
Figure 7

Projection of National Long-Term Care Expenditures, 2000-2040

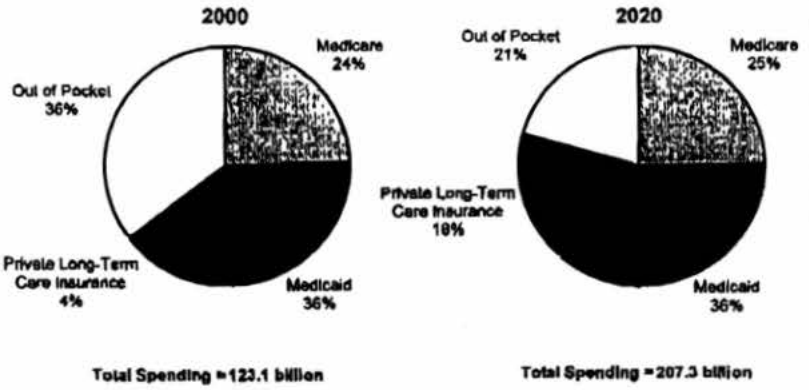
(In billions of 2000 dollars)



SOURCE: CBO, 1999.

Figure 8

Projection of the Distribution of National Long-Term Care Expenditures by Payer, 2000 and 2020



SOURCE: CBO, 1999.

There are a number of ways to pay for long-term care in the future—including both public and private sector approaches. Private sector approaches emphasize that individuals should be responsible for long-term care, paying for their own care out of savings or purchasing private long-term care insurance policies. Public sector approaches range from expansions of Medicaid, to protect modest income people against impoverishment, to a comprehensive social insurance option that would ensure care for all disabled persons regardless of financial need. In between are policies that combine private and public sector approaches.[32]

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A policy of increasing private savings—encouraging individuals to save for future long-term care needs much the way they put aside money for their children's education—seems unlikely to provide adequate protections for long-term care. The main difficulty rests with the fact that the need for long-term care is an unpredictable event. Although 40 percent of people who reach age 65 will use a nursing home at some point in their lives, people do not know in advance whether, or how much, they will need. A small proportion will have very high expenditures—spending more than one year in a nursing home or experiencing multiple episodes of care.[33] Depending on private savings concentrates the financial burden of severe impairment—an expensive and largely unpredictable event—on the few who experience it rather than spreading it among the many who are at risk of impairment.

Providing some financial assistance to those who need long-term care may help to mitigate these burdens. President Clinton has recently proposed a long-term care initiative along these lines. The President's proposal would give a $1,000 tax credit to individuals with significant long-term care needs, their caregivers, or families, that could be used to help pay for home care, adult day care and other long-term care services. Though limited in scope, the proposal has the advantage of targeting assistance to modest income people who are currently shouldering much of the burden on their own.[34]

Insurance, according to most observers, is a better approach to meeting the need for long-term care as the baby-boom generation reaches retirement age because it spreads risk. Those who favor a private sector approach advocate expanded tax preferences to encourage individuals to purchase long-term care policies. Some tax preferences are already in place—premiums for employer-sponsored long-term care insurance plans are excluded from taxable income and part of the cost of premiums for the self-employed is tax deductible—and recent proposals have called for expanded tax deductibility of individual premiums. However, tax preferred treatment of private insurance premiums is unlikely to significantly expand coverage, but is likely to deliver subsidies to those who already would have purchased private insurance.[35] Analysis suggests that even with favorable tax treatment, private long-term care insurance is likely to remain unaffordable for the modest and low-income elderly who are most at risk of needing long-term care.[36] A recent Congressional Budget Office analysis suggests that, even under very optimistic assumptions about the expansion of private long-term care insurance, Medicaid expenditures will need to nearly double by 2020 to provide the level of service being provided today.

Another option is to expand insurance for long-term care through new or existing public programs. For example, protected income and asset levels in Medicaid could be increased from their currently low levels, to give greater financial protection to modest income elderly who must now impoverish themselves in order to qualify for Medicaid. Including long-term care in Medicare is also an option. Creating a system of social insurance for long-term care would spread the costs of long-term care widely across the population to protect against potentially catastrophic financial losses for the minority at risk. In practice, however, the debate over the future of Medicare and Social Security raises questions about political commitments to existing entitlements, let alone new ones.

TAKING THE "AID" OUT OF MEDICAID

The Republicans propose to destroy Medicaid as we know it and replace it with a vastly underfunded block grant program.

The Republican Medicaid cuts put states in an untenable position: raise taxes, reduce Medicaid coverage, and/or cut services.

The result is that the Republican plan would destroy the social safety net in this country and could eliminate coverage for 8.8 million Americans by the year 2002 including:

- O 4.4 million children
- O 350,000 nursing home residents
- O 330,000 people needing home care
- O 1.4 million people with disabilities

The Republican Medicaid plan could leave families shouldering the full responsibility for the nursing home costs of elderly parents and grandparents.

The Medicaid safety net that covers two-thirds of nursing home patients and helps working families cope with the huge cost of nursing home care for their parents -- averaging $38,000 a year in the U.S. -- would be destroyed.

-- Elderly women could be forced to sell their homes to pay for their husbands' care;

-- Adult children of nursing home residents could be forced by the government to pay for the care of their parents;

-- Parents of mentally retarded children could be forced to pay the full cost of care for their children in an institution or at home.

The Republican Medicaid plans would wipe out quality standards for American nursing homes and institutions caring for the mentally retarded.

The Republican Medicaid plans would repeal the 1987 law -- signed by President Reagan -- creating tough standards for the quality of nursing homes caring for the elderly, disabled, and mentally retarded. These requirements include restrictions on the use of drugs and restraints to keep residents in their beds; requirements that nurses be on duty at least 8 hours a day; requirements that nurses' aides undergo training before caring for residents.

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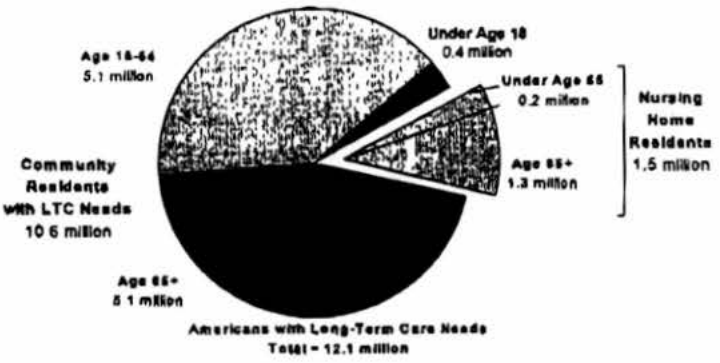
extended their quality of life and survival time, but many will continue to have chronic care needs.[2]

Figure 1

The Long-Term Care Population, 1995

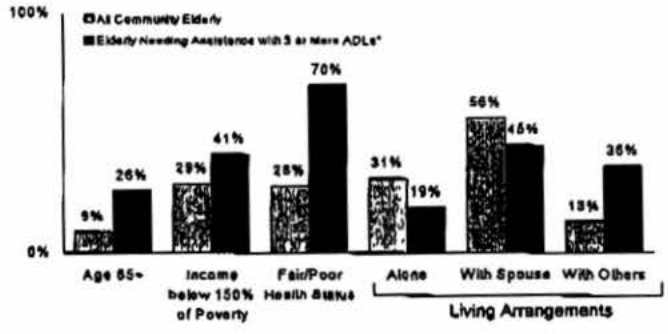


SOURCE: Georgetown University Institute for Health Care Research and Policy estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.; and The American Health Care Association, "The Nursing Facility Sourcebook: Facts and Trends, 1997;" data from the 1995 National Nursing Home Survey.

The 6.4 million elderly with long-term care needs have varying levels of impairment and receive care both in the community and in nursing homes. Nearly 1.5 million elderly live in nursing homes, and 4.9 million elderly individuals have some long-term care need and live in the community. Of the elderly 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 a quarter are age 85 and above, 40 percent are poor or near-poor (with incomes below 150 percent of the federal poverty level), and 70 percent report that they are in fair or poor health. Compared to the typical elderly person, they are less likely to live alone or with a spouse, and are substantially more likely to live with others—often an adult child [Figure 2]. Older women who live alone are particularly vulnerable; they are both more likely to need long-term care and to have fewer financial resources than the elderly population as a whole.

Figure 2

Characteristics of Community-Dwelling Elderly with Substantial Long-Term Care Needs



*Elderly individuals who need assistance with three or more "activities of daily living" (ADLs), including: bathing, dressing, eating, transferring, toileting, and walking.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview and National Health Interview Survey on Disability, Phase II.

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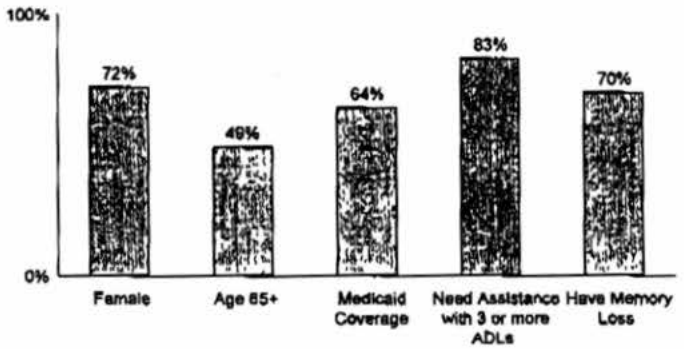
The 1.5 million elderly in nursing homes are typically older and more frail than the disabled elderly living in the community: nearly half are over age 85; more than 80 percent are severely disabled (requiring assistance with three or more ADLs); and 70 percent report cognitive impairments such as memory loss or orientation problems [Figure 3]. In addition, more than 70 percent are women, and almost two-thirds have Medicaid coverage.[3]

Figure 3

Characteristics of Nursing Home Residents, 1996



*Note: ADL = Activities of Daily Living
SOURCE: AHCPR 1996. Data from the National Medical Expenditures Panel Survey, 1996.

How do People Get Long-Term Care?

Most people who need long-term care (88 percent) receive that care at home (or in community-based settings, such as adult daycare facilities). Only 12 percent receive care in nursing homes or other institutional facilities, such as intermediate care facilities for people with mental retardation.

A number of factors determine whether individuals with long-term care receive care at home or in nursing homes or other institutional settings. The likelihood of nursing home admission increases with age and extent of disability; most nursing home residents (91 percent) are elderly and almost half are over the age of 85. Elderly individuals who are most likely to be at risk of nursing home placement include those with cognitive impairments, those who are incontinent, and those without caregivers at home or nearby.

For those with long-term care needs living in the community, care needs vary considerably. Many of the elderly with long-term care needs may have only limited needs for assistance with such activities as paying bills, grocery shopping and taking medication. Others are more severely disabled, with extensive care needs for which they require full-time nursing and personal care. The use of paid home care is greatest among the elderly with moderate to severe levels of disability and those who live alone.

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Among the elderly in the community, those with long-term care needs typically rely on assistance from family and friends. About two-thirds depend on informal (unpaid) caregiving as their only form of assistance, and one-third receive a combination of informal and formal care.[4] Even among the community elderly with chronic, severe limitations, about half rely solely on unpaid help, often placing considerable strain on the family members who care for them [See Box 1].

BOX 1

Burdens on Family Caregivers

Chronic illness and functional limitations create growing burdens for the elderly individuals themselves and for the family members—spouses, daughters, daughters-in-law— and others who help to care for them on a routine basis. Ironically, changes in medical care that have improved its effectiveness—such as shorter hospital stays, the increased use of outpatient procedures, and the substitution of home care for institutional care—have shifted responsibility from paid providers toward unpaid providers, increasing burdens on family caregivers. The difficulties are enhanced because many caregivers have competing career and family responsibilities, and many are elderly themselves. A substantial proportion of caregivers who work report conflicts between work and care-giving, resulting in rearranged work schedules, decreasing hours of work, and periods of unpaid leave.[5]

The current system fails to meet all the long-term care needs of all persons with disabilities. Of elderly and nonelderly adults with long-term care needs living in the community, a significant proportion (about 20 percent) report that they have experienced "unmet need" for long-term care. Those responding to a national survey in 1994-95 attributed these gaps to the high cost of services, difficulty finding help, and failure to qualify for assistance from a social service agency because they didn't meet eligibility criteria (that is, their incomes were too high or they didn't meet the medical criteria needed to receive assistance). A substantial proportion of community adults with "unmet needs" reported specific consequences from a lack of help: a third of people with unmet need for help in toileting reported that they wet or soiled themselves; twenty percent of people with unmet need for help eating said they experienced periods when they were unable to eat when hungry.[6]

Who Pays for Long-Term Care?

Long-term care can be quite costly and can drain private resources quickly. The average cost of a year of nursing home care was nearly $41,000 in 1995,[7] and even regular home care visits can quickly become expensive. Hiring a home care aide to visit four hours a day, five days a week, at $10 an hour would cost more than $10,000 a year, and could be more costly for individuals with extensive needs.[8] As a result of the high costs of care, more than a third of all elderly individuals admitted to nursing homes, and about 70 percent of those with lengths of stay at least one year, were estimated to have catastrophic long-term care costs in 1993—that is, their long-term care costs exceed 40 percent of their total income and non-housing financial assets.[9] Consequently, many of those with long-term care needs turn to Medicaid, the only public program providing significant financing for long-term care.

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Health insurance coverage of persons with long-term care needs

Most, but not all, individuals with long-term care needs have health insurance of some kind—either publicly-financed or private health coverage. Their insurance plans, however, may or may not provide coverage for long-term care. For example, Medicare provides nearly universal coverage for the elderly but does not provide coverage for the extended personal care that is the bulk of long-term care, nor do most private health insurance plans cover long-term care.

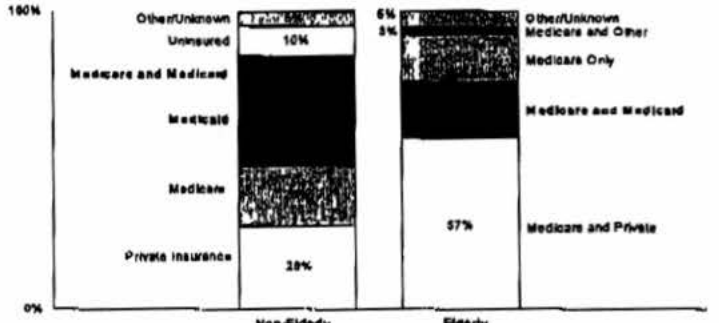
The elderly rely on Medicare for health insurance, and most have private or public supplemental coverage to help fill Medicare's gaps. Among the community-dwelling elderly with long-term care needs, 57 percent have private supplemental coverage in addition to Medicare, and 19 percent have Medicaid [Figure 4]. For those with private coverage, a very small proportion may have a private long-term care insurance policy, but most have only a Medigap policy, which does not typically provide substantial assistance with long-term care. For those with Medicaid, the extent of Medicaid protections varies, but the substantial majority of these Medicare and Medicaid "dual eligibles" receive the full range of benefits that Medicaid provides, including long-term care. A substantial minority (16 percent) of elderly people with long-term care needs only receive Medicare benefits, relying on their own income and assets to pay for prescription drugs, Medicare cost sharing, and any long-term care services they might need.

For nonelderly adults with long-term care needs, insurance coverage is more varied and Medicare plays a smaller role. About 30 percent (of the community-dwelling nonelderly disabled) rely on private health insurance, almost 60 percent have public coverage through Medicare and/or Medicaid; 20 percent have Medicare as their primary source of coverage, 25 percent have Medicaid, and 12 percent are covered by both Medicare and Medicaid. About 10 percent of the nonelderly disabled in the community are uninsured.

Figure 4

Health Insurance Coverage of Elderly and Non-Elderly Individuals with Long-Term Care Needs

(Community-dwelling individuals only)



Note: The "Medicare" and "Medicaid" categories for the nonelderly and the "Medicare and private" category for the elderly may include sources of public coverage other than Medicaid. "Other" includes Indian Health Care, Veterans' health care and other public insurance programs.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.

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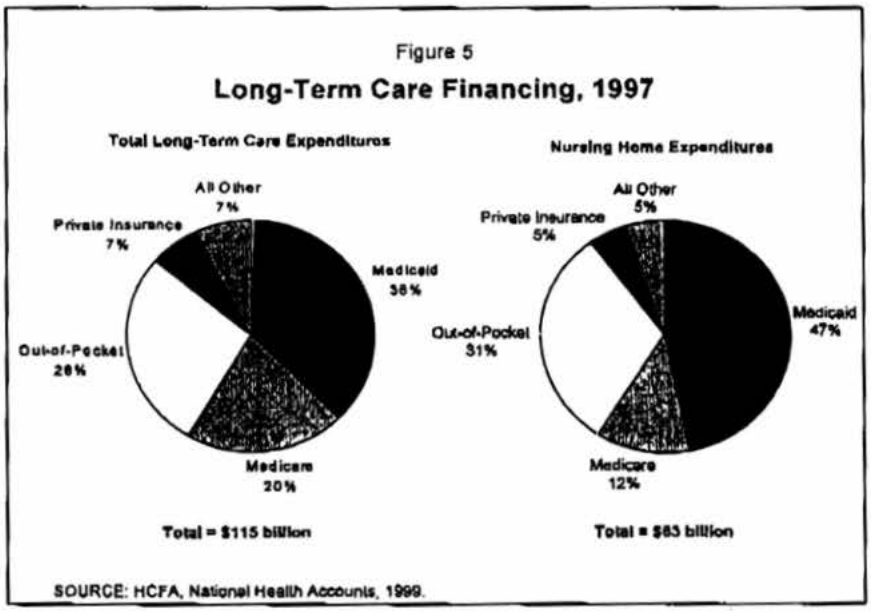
For the elderly and nonelderly poor who need long-term care, Medicaid is especially important. Of community residents with long-term care needs and incomes below the poverty line, 44 percent of the elderly and 64 percent of the nonelderly are covered by Medicaid. By comparison, only 9 percent of disabled elderly and 16 percent of the nonelderly disabled with incomes above 200 percent of the federal poverty level have Medicaid coverage.[10] Rates of Medicaid coverage are even higher among poor and low-income facility residents.

Although both private health insurance and Medicare are important sources of coverage for persons with long-term care needs, they play only limited roles in financing long-term care expenditures, but pay primarily for the acute health care needs of persons with disabilities. It is Medicaid that is the primary source of insurance coverage for long-term care, and thus Medicaid and out-of-pocket expenditures that account for the bulk of expenditures on long-term care.

More than $115 billion was spent on long-term care in the United States in 1997—12 percent of national health spending. Most long-term care is financed by the Medicaid program and by individuals with long-term care needs and their families (together accounting for 66 percent of long-term care expenditures). Medicare plays a more limited role (accounting for 20 percent of spending) and the role of private insurance is very limited (7 percent of long-term care expenditures are paid by private health care or long-term care insurance) [Figure 5]. In addition, a substantial amount of long-term care is unpaid—provided informally by family and friends—and is not reflected in these cost estimates.

Figure 5

Long-Term Care Financing, 1997



SOURCE: HCFA, National Health Accounts, 1999.

* Medicaid long term care

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NOVEMBER 1999

LONG-TERM CARE*

Over 12 million people in the United States need help with basic activities of daily living requiring long-term care services—that is, personal, social and medical supports provided at home, in the community, or in institutional settings. The long-term care population is diverse, reflecting a broad age spectrum, a variety of service needs, and differing abilities to satisfy them. The elderly are the primary users of long-term care services and, among the elderly, the most vulnerable are the very old and those who live alone.

Spending on long-term care came to $115 billion in 1997. Over 40 percent of that spending was financed by the Medicaid program, including half the costs of nursing home care. Medicaid is the nation's long-term care safety net—financing care not only for the poor but for the middle class as well. However, Medicaid pays for care for those with middle incomes *only* once they have exhausted their own financial resources; consequently, many of the elderly are at considerable risk of catastrophic long-term care expenditures. More than a third of the elderly who entered nursing homes—and more than 70 percent of those who were in nursing homes for at least a year—had catastrophic long-term care costs (with expenditures exceeding 40 percent of their annual income and non-housing financial assets). Because of their greater likelihood of needing long-term care and their limited ability to pay, the low-income elderly are especially at-risk.

The elderly pay for a substantial portion of long-term care costs out-of-pocket (nearly 30 percent in 1997). Medicare provides nearly universal coverage for the elderly for health care, but Medicare does not pay for most long-term care, paying only for limited amounts of skilled nursing care in nursing homes and for some home health care. Private insurance plays only a small role in long-term care. With eligibility for public programs limited and the costs of service high, the current system fails to meet all of the long-term care needs of persons with disabilities. For example, a significant proportion (about 20 percent) of elderly and nonelderly adults with long-term care needs report an inability to fully address these needs, with sometimes serious consequences for their health and quality of life.

The number of people likely to need long-term care, and national expenditures on long-term care for the elderly, will increase significantly with the aging of the baby-

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* Prepared for the Henry J. Kaiser Family Foundation and the Kaiser Commission on Medicaid and the Uninsured by Marlene Niefeld, Ellen O'Brien, and Judith Feder.

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boom population. Exacerbating the problem of serving the growing long-term care population appropriately is the fact that long-term care costs are expected to grow faster than inflation. Inflation-adjusted long-term care expenditures are expected to triple to $346 billion by 2040, placing large burdens on both Medicaid and private resources. Assuming current policies continue, more resources will likely be required to address gaps in the current system, varied inputs across states, limited access to care in the community, and concerns about quality of care.

What is Long-Term Care?

Long-term care services provide the help required by individuals with physical or mental disabilities to perform basic "activities of daily living" (ADLs) such as eating, bathing, dressing, getting in and out of bed, and using the bathroom. Long-term care also includes services that are designed to assist individuals with "instrumental activities of daily living" (IADLs) that are necessary to remain independent, such as housework, laundry, grocery shopping, taking medication, and transportation. Long-term care is the care needed to cope when physical or mental disabilities interfere with an individual's ability to perform these basic tasks on their own.

Who Needs Long-Term Care?

Chronic conditions that create a need for long-term care are physical or mental in nature and their onset time ranges from before birth to late in life. Alzheimer's disease, heart disease, multiple sclerosis, cerebral palsy, spinal cord injury, and stroke are just a few of the diseases that may cause chronic disability. Unlike acute illness, chronic conditions are essentially permanent. Regimens of medical and personal care can sometimes control but rarely cure them.

Disability is a condition that often creates a need for a variety of services and supports on a continuing basis. The presence of disability, however, is not synonymous with the need for long-term care. Over forty million Americans have a physical or mental disability. Of these, more than twelve million (30 percent) need long-term care, defined as a need for assistance with activities of daily living, and about a third of those with long-term care needs (approximately 4 million people in the community and in institutions) have substantial needs—that is, they need help with 3 or more activities of daily living.[1]

The elderly are much more likely than younger age groups to suffer from disabling conditions and to require long-term care. Almost a quarter of the elderly (6.4 million individuals) have some long-term care need. However, individuals with long-term care may be young or old. Only 3 percent of adults ages 18 to 64 had some long-term care need, but this translates into a significant number of nonelderly adults needing long-term care (5.3 million); 400,000 children also have long-term care needs [Figure 1].

The prevalence of disability among children and non-elderly adults has been increasing as a result of improved trauma care and medical technologies that have extended the lives of those with life-threatening or debilitating illnesses. Recent advances in the treatment of AIDS has also fueled changes in the composition of the long-term care population. Improved treatments for those infected with HIV have

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Medicare

Although Medicare provides nearly universal coverage to the elderly for their acute care needs, it is not designed to cover the majority of their long-term care costs. Medicare covers short-term skilled nursing facility care and plays a limited role in financing home and community-based services. Although no prior hospitalization is required to receive home health care under Medicare, benefits are limited to people who are homebound, require skilled nursing, physical therapy or speech therapy on a part-time or intermittent basis, and are under the care of a physician.

In the past several years, increasing attention has been paid to the rapid growth in the use and costs of Medicare's post-acute care benefits, with many observers suggesting that this represents an inappropriate expansion of Medicare into long-term care. A rapid expansion in home health has been of special concern. Home health spending increased at an average annual rate of 29 percent between 1990 and 1996, rising from $3.9 billion to $18.3 billion and from 3.6 percent to 9.2 percent of Medicare spending. Medicare's payment policies have been revised in an attempt to constrain this growth, and there is continuing attention to additional reforms that would help to limit the use of home health benefits.

Even with the recent expansion of home health services, however, survey and program data suggest significant limits to its reach among people with long-term care needs. One survey found that only 10 percent of the community-dwelling elderly with chronic disabilities and long-term care needs received Medicare-financed home care in the week prior to the survey in 1994.[11] A large proportion of Medicare home health care expenditures (46 percent in 1997) are consumed by very small proportion (10 percent) of Medicare beneficiaries with high home health use (200 home health visits or more per year).[12] These home health users typically have both acute and long-term care needs and are disproportionately older, in poorer health, more disabled and have lower incomes than other home health care users.

Many observers have suggested that recent changes in treatment patterns under Medicare home health reflect a shift from a narrow post-acute benefit toward a long-term care benefit. Medicare beneficiaries using home health care are using care long after a hospitalization, they are receiving more visits, and as episodes of care have lengthened, they are receiving a higher proportion of aide visits and correspondingly fewer skilled visits.[13] But despite the rapid growth in home health utilization and expenditures, Medicare's benefit does not cover long-term care for people who need such care exclusively. However, for people who qualify, the type of care it covers overlaps substantially with long-term care: the home health benefit covers some personal assistance with basic daily activities—the long-term care services—along with skilled services for beneficiaries who need both. As Medicare tries to limit its home health care coverage, it remains to be seen if Medicaid's expansion into home and community-based services will sufficiently cover the long-term care population with severe disabilities.

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Private Long-Term Care Insurance

Most individuals with long-term care needs rely on their own resources to pay for long-term care, but private insurance plays a very limited role in the financing of long-term care. Most private health insurance policies pay for very little long-term care and only 7 percent of the elderly own a long-term care insurance policy that explicitly covers these services.[14] Less than one percent of long-term care expenditures are financed by private long-term care insurance.[15]

Sales of private insurance policies have increased over the past decade, but long-term care remains unaffordable for many of the elderly—with one recent study suggesting that only 10 to 20 percent of the elderly could afford to purchase a comprehensive long-term care policy.[16] The cost of private insurance coverage increases with age and with essential coverage provisions, such as inflation protection (which increases benefit levels as nursing home costs rise) and nonforfeiture benefits (which allow an individual to recover some of the cost of the policy if that person cannot pay the premium or thinks he/she will not need the coverage). The average annual premium for policies covering four years of nursing home and home care with inflation protection and nonforfeiture benefits in 1996 was $1,200 per year if purchased at age 50, $2,432 per year if purchased at age 65, and $7,440 a year if purchased at age 75.[17]

The people who are able to buy good quality policies at the prices offered are often middle to upper income individuals who generally would not qualify for Medicaid (and offset public expenditures for long-term care). Further, many of those who might purchase private insurance may not be able to buy it. One study has estimated that even if everyone applied for long-term care insurance at age 65, a significant proportion—perhaps as many as a quarter—would be rejected under current underwriting criteria.[5]

Medicaid

Medicaid is the only public program that provides substantial coverage for long-term care. Medicaid spending on long-term care was $44 billion in 1997, financing nearly 40 percent of all long-term care, 50 percent of the costs of nursing home care, and financing the care of nearly 70 percent of nursing home residents. Nationally, Medicaid spends an average of about $7,800 on long-term care per elderly Medicaid enrollee and $3,700 per disabled enrollee.[18]

Medicaid is the nation's safety net provider of long-term care services not only for the poor, but for the middle class as well. Unlike other insurance, however, which provides protection against catastrophic losses, Medicaid helps only after catastrophe strikes. Middle income Americans with catastrophic long-term care costs may become eligible for Medicaid benefits once they have "spent down" their income and assets—they must impoverish themselves before Medicaid assistance is available. Although some policymakers have expressed concern that Medicaid's spend down provisions encourage attempts to unfairly manipulate the system by those who could otherwise afford long-term care, there is little evidence of widespread abuse [See Box 2].

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BOX 2

Medicaid "Spend Down"

In 35 states and in the District of Columbia, people whose assets are less than a specified level ($2,000 for individuals, $3,000 for couples) can qualify for Medicaid if the cost of nursing home care exceeds their incomes—that is, they qualify for Medicaid as "medically needy." Individuals must contribute all of their income toward the cost of care, except for a small personal care allowance (of no less than $30 per month). The rules for couples are more generous to prevent impoverishment of a spouse who remains in the community. Protected income for the community spouse ranged from $1,326 to $1,978 per month in 1997, and protected assets ranged from $15,804 to $79,020 depending on state eligibility rules.[19]

Despite concerns about abuse of the system, only about 20 percent of current residents spend down at some point during their stays. However, those who stay in the nursing home for a long period of time are more likely to eventually spend down to Medicaid. About one-third of nursing home residents who used long-term care services for one to three years spent down and about half of those with nursing home stays of more than three years spent down their income and assets to Medicaid.[20]

Concern has been expressed that, despite prohibitions, elderly people are transferring assets to avoid spend down. However, the asset levels of elderly people likely to need nursing home care are typically low to begin with and federal legislation (OBRA 1993) has placed greater restrictions on asset transfers.[21] Recent research also suggests that there is little need for policy efforts to limit the use of trusts to avoid spend down, since very few of the elderly have a trust. Although the study found that 4 in 10 elderly community dwellers could potentially qualify for Medicaid by using a trust, fewer than 10 percent had a trust.[22]

Long-term care accounts for about 35 percent of Medicaid spending nationwide, but states vary greatly in their inputs to long-term care. The average Medicaid long-term care expenditure per elderly beneficiary ranges from over $15,000 in Connecticut, New York, and the District of Columbia, to less than $5,000 in South Carolina, Mississippi, and Oklahoma.[23] In most states, the large proportion of long-term care spending is for nursing home care. All states provide home and community-based long-term care services: Medicaid requires states to cover home health services for any individual eligible for nursing home care, states have the option (used by 31 states) to cover personal care and, under waivers, all states have developed programs designed to target a specific mix of home and community-based services to distinct population groups or in distinct geographic areas. Nevertheless, few states rely on Medicaid to provide substantial long-term care to people living at home. Nationally, less than 20 percent of Medicaid long-term care spending is for home and community-based care services, personal care, and home health care services.[24] Payments for home and community-based waiver services per person age 65 or over vary from $1,180 in New York to $29 in Mississippi, and in some states, such as Oregon and New York, there are

relatively balanced systems that devote a significant share (40 to 50 percent) of long-term care spending to home and community-based services.[25]

Initially, home and community-based services were conceived as a less expensive alternative to nursing home care. (Eligibility for these community-based benefits is typically extended to people who are eligible for nursing home or other institutional care and meet state income and asset criteria). However, there is little evidence that home-based services reduce nursing home use and expenditures, largely because individuals who would not otherwise use nursing home care will use home and community-based services if they are available. Because of concerns about these "woodwork effects," the law allows states to limit these services with respect to the number, type, and location of people served as well as the volume of services provided. Home and community-based care can expand service options without increasing state long-term care expenditures only if nursing home use is explicitly restricted—by diverting the least disabled prospective nursing home clients to available home care options.

Although some states expect to control overall long-term care expenditures by expanding home care options, most fear increasing costs (at least initially). However, legal requirements will likely create pressures to increase the amount and share of resources devoted to community-based long-term care. The recent Supreme Court decision in *Olmstead vs L.C.* may encourage or require states to expand access to community-based services for individuals with physical and mental disabilities.[26]

Long-Term Care Policy Issues

Growth in the number of people likely to need long-term care means that increased financing for long-term care is needed. Medicaid is the only significant source of public financing, but states devote varying resources to long-term care and access to care in both nursing homes and community settings has been limited. Medicaid also fails to protect middle income individuals from catastrophic long-term care costs. Concerns about the quality of care also persist. A range of strategies for expanding long-term care coverage exist, but regardless of which policy options are used, additional resources will be needed to help reduce the burdens of disability on elderly individuals and their families, to increase financial protections, and to address gaps in the current long-term care system.

Access to care

Although most long-term care spending in Medicaid is for nursing home care and Medicaid programs typically place limits on home and community-based care, there have been problems of access in both settings.

Access to care has always been limited by the availability of providers willing to deliver services at Medicaid's relatively low rates—despite Medicaid's entitlement to coverage of long-term care services. The recent repeal of the Boren Amendment—which established federal standards requiring that states' nursing home payments be "reasonable and adequate to meet the cost incurred by efficiently and economically operated facilities"—may result in a reduction in the rates paid for publicly financed residents and may reduce access to (and the quality of) care for Medicaid patients.

What the repeal of these federal standards will actually mean is not yet known and depends on whether states alter payments to nursing homes.

In addition to the effect of relatively low payments, access to nursing home care may also be limited due to restrictions on the number of nursing homes and nursing home beds. States regulate the supply of nursing home beds through certificate-of-need programs (which require state approval for the establishment or expansion of health facilities or services) or moratoria on the construction of new nursing home beds. The number of nursing home beds per elderly has fallen substantially in many states—the number of nursing home beds per 1,000 elderly ages 85 and above fell by 18 percent between 1978 and 1994, and although nationwide declines in nursing home occupancy rates suggest that access may not be a problem, access problems remain in some areas, especially rural communities.[27]

Access to community-based alternatives to institutional long-term care has historically been limited in most states. Individuals with disabilities and their advocates—especially advocates for persons with mental disabilities—have long argued that Medicaid's "institutional bias" interferes with their rights under the Americans with Disabilities Act to receive care in the "least restrictive setting." Medicaid home and community-based waiver programs have grown significantly in the past decade. National expenditures were $8.1 billion in 1997—a more than six-fold increase over 1990 expenditures of $1.3 billion. However, many individuals with physical and mental disabilities continue to receive care in nursing homes rather than in the community, partly because nursing home care is needed or desired but partly because of limited funding, long waiting lists and limited eligibility for waiver services in many states. The recent Supreme Court decision in *Olmstead vs. L.C.* may encourage states to do more. In addition, states are expected to shift a greater share of spending for long-term care toward community-based settings—such as board and care homes and assisted living facilities as alternatives to costly nursing home care—as they address the challenges of financing care for an aging population.[28]

Quality

The quality of care in nursing homes, especially for Medicaid beneficiaries, has been a long-standing concern. Although significant improvements in the quality of nursing home care followed from comprehensive nursing home reform in the early 1990s, serious problems persist in many facilities. The quality of home and community-based care has received less attention, but as care increasingly moves outside of institutions, there is growing interest in measuring and monitoring quality in the community.

Comprehensive nursing home reforms—passed in 1987 as part of the Omnibus Budget Reconciliation Act—established new nursing home quality standards, requirements for federal and state oversight, and enforcement tools. Since the implementation of these standards in 1990, research studies have documented significant improvements in the quality of care, including reductions in the use of physical and chemical restraints and hospitalization rates and increases in the use of behavior management programs, hearing aids, and antidepressants and psychological therapy for residents with symptoms of depression.

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Each year, however, more than a quarter of all nursing homes are cited for violations of federal regulations for causing actual physical harm to residents (such as inadequate prevention of pressure sores or failure to prevent accidents) or failing to properly assess residents' needs and provide for their care. Further, even when homes were threatened with sanctions, the problems often returned in subsequent surveys. Nearly 40 percent of nursing homes cited for deficiencies in an initial survey were cited for related violations in subsequent surveys. As a result, many observers have concluded that existing standards, though adequate in theory, don't work well in practice because the ability to enforce them (to shut down bad homes) is limited. Enforcement needs to be strengthened to help improve compliance with federal standards and ensure the safety and welfare of nursing home residents.[29]

Quality concerns have also been raised for home and community-based services. Like nursing home residents, the elderly receiving long-term care services in their homes are vulnerable to abuse, but it is more difficult to monitor services received in the home. Although some individuals receiving care live with others, many live alone and are especially vulnerable to threats to their personal safety and well-being. Beyond actual harm to individuals, there are also important concerns over the quality and appropriateness of the long-term care services delivered. What is meant by "quality" and "appropriateness" varies across population groups and services received. Consumer choice and control are critical issues especially for many nonelderly individuals with physical disabilities who have significant needs for assistance with activities of daily living. For the elderly who may be receiving both acute and long-term care, quality of care concerns have been raised about the appropriate volume and mix of services. For those receiving such services, often paid by Medicare, there is growing interest in the development of standards for the amount and mix of services (acute, rehabilitative and personal care) that patients should receive, and to measuring and monitoring the outcomes of that care. The issues, however, are quite complex since there is considerable variation in both treatments and outcomes.

The Growing Demand for Long-Term Care

Despite recent declines in disability rates among the elderly, the aging of the baby boom generation will bring about a significant increase in the demand for long-term care. The number of elderly is projected to more than double over the next three decades, rising from 34 million in 1997 to more than 69 million in 2030. The growth in the over 85 population—the population most likely to use long-term care services—is projected to more than triple by 2030 [Figure 6].

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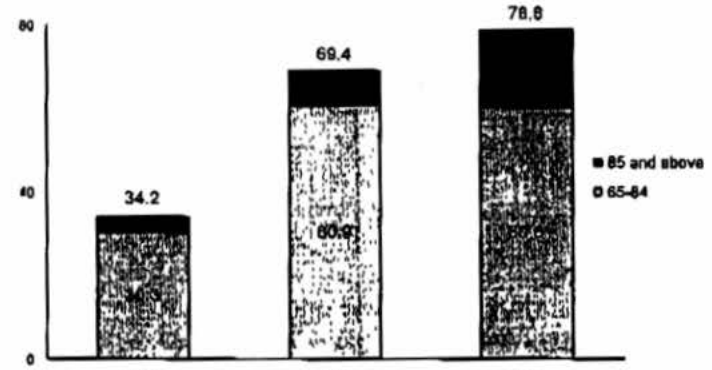
Figure 6

Projected Growth of the Elderly Population, 1997-2050
(Number in millions)



SOURCE: CBO, 1999.

If disability rates remain what they are today, the number of elderly needing long-term care is projected to rise dramatically. The hope is that medical advances and improvements in the economic status of the elderly will help people live both longer and healthier lives, and that the proportion of the elderly who are disabled will fall as the elderly population grows.[30] However, although the proportion of the elderly population needing long-term care may fall, the number of elderly individuals with long-term care needs will still grow significantly, rising from 8.8 million in 2000 to an estimated 12.1 million in 2040.[31] This increased demand will tend to cause the cost of long-term care to rise, placing the largest burdens on the low-income population not qualifying for public assistance.

Future Financing

The Congressional Budget Office projects that inflation-adjusted long-term care spending for the elderly will nearly triple in the next four decades, rising from $123 billion in 2000 to $346 billion (in constant 2000 dollars) in 2040 when the baby-boom generation reaches age 85 [Figure 7]. Public programs will continue to be liable for the largest proportion of these costs even assuming that the role of private long-term care insurance in the market will grow. In order to provide even the same level of long-term care service being provided today, Medicaid expenditures will have to rise to $75 billion dollars in 2020, or over one and a half times its liability in the year 2000 of $43 billion dollars. Combined public financing of long-term care—Medicaid and Medicare expenditures—will need to rise from $74 billion in 2000 to $126 billion in 2020, accounting for about 60 percent of all long-term care financing. Private out-of-pocket spending will remain high, but private long-term care insurance is expected to mitigate some of the pressure of out-of-pocket costs, rising from 4 percent of long-term care expenditures in 2000 to 17 percent in 2020 [Figure 8].

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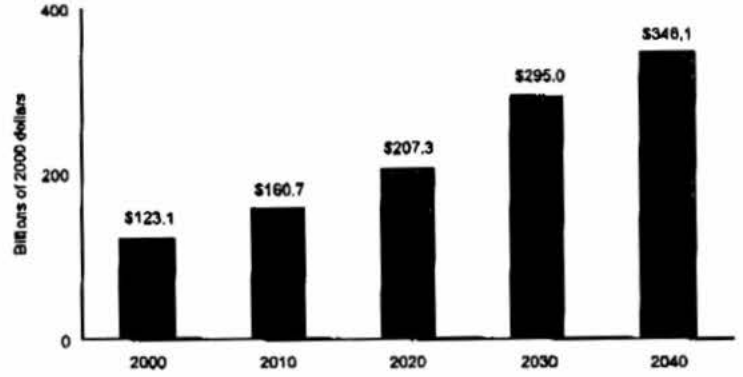
Figure 7

Projection of National Long-Term Care Expenditures, 2000-2040

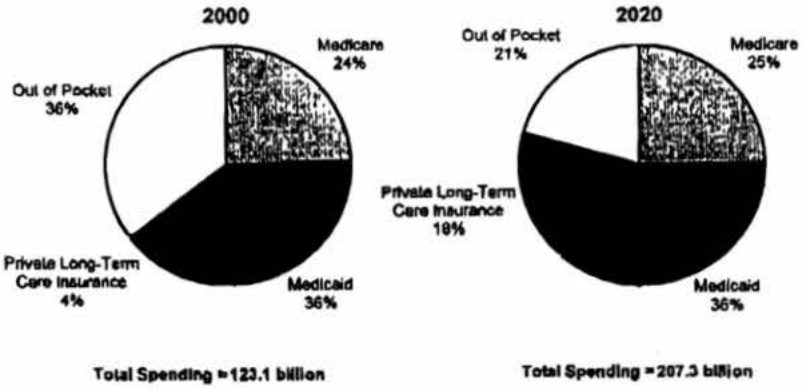
(In billions of 2000 dollars)



SOURCE: CBO, 1999.

Figure 8

Projection of the Distribution of National Long-Term Care Expenditures by Payer, 2000 and 2020



SOURCE: CBO, 1999.

There are a number of ways to pay for long-term care in the future—including both public and private sector approaches. Private sector approaches emphasize that individuals should be responsible for long-term care, paying for their own care out of savings or purchasing private long-term care insurance policies. Public sector approaches range from expansions of Medicaid, to protect modest income people against impoverishment, to a comprehensive social insurance option that would ensure care for all disabled persons regardless of financial need. In between are policies that combine private and public sector approaches.[32]

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A policy of increasing private savings—encouraging individuals to save for future long-term care needs much the way they put aside money for their children's education—seems unlikely to provide adequate protections for long-term care. The main difficulty rests with the fact that the need for long-term care is an unpredictable event. Although 40 percent of people who reach age 65 will use a nursing home at some point in their lives, people do not know in advance whether, or how much, they will need. A small proportion will have very high expenditures—spending more than one year in a nursing home or experiencing multiple episodes of care.[33] Depending on private savings concentrates the financial burden of severe impairment—an expensive and largely unpredictable event—on the few who experience it rather than spreading it among the many who are at risk of impairment.

Providing some financial assistance to those who need long-term care may help to mitigate these burdens. President Clinton has recently proposed a long-term care initiative along these lines. The President's proposal would give a $1,000 tax credit to individuals with significant long-term care needs, their caregivers, or families, that could be used to help pay for home care, adult day care and other long-term care services. Though limited in scope, the proposal has the advantage of targeting assistance to modest income people who are currently shouldering much of the burden on their own.[34]

Insurance, according to most observers, is a better approach to meeting the need for long-term care as the baby-boom generation reaches retirement age because it spreads risk. Those who favor a private sector approach advocate expanded tax preferences to encourage individuals to purchase long-term care policies. Some tax preferences are already in place—premiums for employer-sponsored long-term care insurance plans are excluded from taxable income and part of the cost of premiums for the self-employed is tax deductible—and recent proposals have called for expanded tax deductibility of individual premiums. However, tax preferred treatment of private insurance premiums is unlikely to significantly expand coverage, but is likely to deliver subsidies to those who already would have purchased private insurance.[35] Analysis suggests that even with favorable tax treatment, private long-term care insurance is likely to remain unaffordable for the modest and low-income elderly who are most at risk of needing long-term care.[36] A recent Congressional Budget Office analysis suggests that, even under very optimistic assumptions about the expansion of private long-term care insurance, Medicaid expenditures will need to nearly double by 2020 to provide the level of service being provided today.

Another option is to expand insurance for long-term care through new or existing public programs. For example, protected income and asset levels in Medicaid could be increased from their currently low levels, to give greater financial protection to modest income elderly who must now impoverish themselves in order to qualify for Medicaid. Including long-term care in Medicare is also an option. Creating a system of social insurance for long-term care would spread the costs of long-term care widely across the population to protect against potentially catastrophic financial losses for the minority at risk. In practice, however, the debate over the future of Medicare and Social Security raises questions about political commitments to existing entitlements, let alone new ones.

TAKING THE "AID" OUT OF MEDICAID

The Republicans propose to destroy Medicaid as we know it and replace it with a vastly underfunded block grant program.

The Republican Medicaid cuts put states in an untenable position: raise taxes, reduce Medicaid coverage, and/or cut services.

The result is that the Republican plan would destroy the social safety net in this country and could eliminate coverage for 8.8 million Americans by the year 2002 including:

- 4.4 million children
- 350,000 nursing home residents
- 330,000 people needing home care
- 1.4 million people with disabilities

The Republican Medicaid plan could leave families shouldering the full responsibility for the nursing home costs of elderly parents and grandparents.

The Medicaid safety net that covers two-thirds of nursing home patients and helps working families cope with the huge cost of nursing home care for their parents -- averaging $38,000 a year in the U.S. -- would be destroyed.

-- Elderly women could be forced to sell their homes to pay for their husbands' care;

-- Adult children of nursing home residents could be forced by the government to pay for the care of their parents;

-- Parents of mentally retarded children could be forced to pay the full cost of care for their children in an institution or at home.

The Republican Medicaid plans would wipe out quality standards for American nursing homes and institutions caring for the mentally retarded.

The Republican Medicaid plans would repeal the 1987 law -- signed by President Reagan -- creating tough standards for the quality of nursing homes caring for the elderly, disabled, and mentally retarded. These requirements include restrictions on the use of drugs and restraints to keep residents in their beds; requirements that nurses be on duty at least 8 hours a day; requirements that nurses' aides undergo training before caring for residents.

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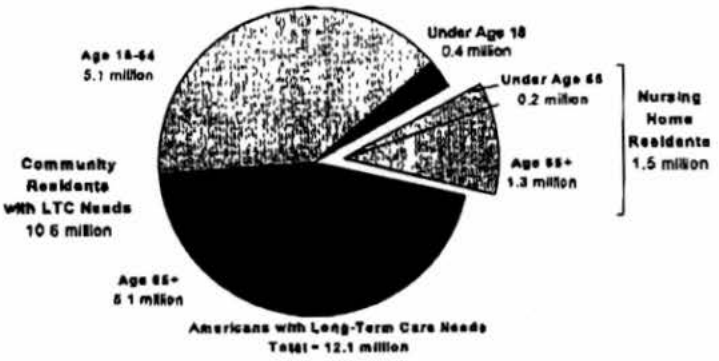
extended their quality of life and survival time, but many will continue to have chronic care needs.[2]

Figure 1

The Long-Term Care Population, 1995

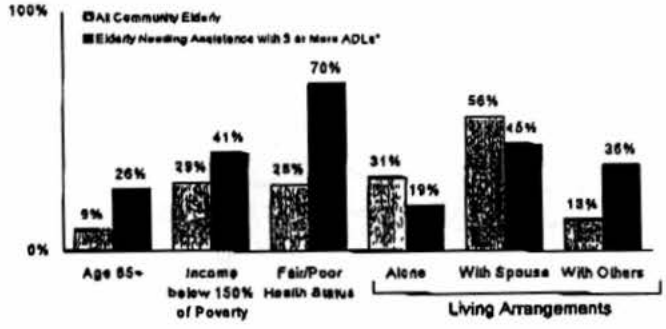


SOURCE: Georgetown University Institute for Health Care Research and Policy estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.; and The American Health Care Association, "The Nursing Facility Sourcebook: Facts and Trends, 1997;" data from the 1995 National Nursing Home Survey.

The 6.4 million elderly with long-term care needs have varying levels of impairment and receive care both in the community and in nursing homes. Nearly 1.5 million elderly live in nursing homes, and 4.9 million elderly individuals have some long-term care need and live in the community. Of the elderly 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 a quarter are age 85 and above, 40 percent are poor or near-poor (with incomes below 150 percent of the federal poverty level), and 70 percent report that they are in fair or poor health. Compared to the typical elderly person, they are less likely to live alone or with a spouse, and are substantially more likely to live with others—often an adult child [Figure 2]. Older women who live alone are particularly vulnerable; they are both more likely to need long-term care and to have fewer financial resources than the elderly population as a whole.

Figure 2

Characteristics of Community-Dwelling Elderly with Substantial Long-Term Care Needs



*Elderly individuals who need assistance with three or more "activities of daily living" (ADLs), including: bathing, dressing, eating, transferring, toileting, and walking.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview and National Health Interview Survey on Disability, Phase II.

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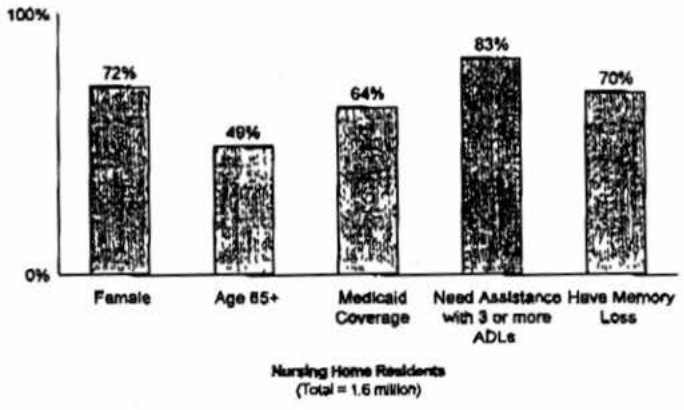
The 1.5 million elderly in nursing homes are typically older and more frail than the disabled elderly living in the community: nearly half are over age 85; more than 80 percent are severely disabled (requiring assistance with three or more ADLs); and 70 percent report cognitive impairments such as memory loss or orientation problems [Figure 3]. In addition, more than 70 percent are women, and almost two-thirds have Medicaid coverage.[3]

Figure 3

Characteristics of Nursing Home Residents, 1996



*Note: ADL = Activities of Daily Living
SOURCE: AHCPR 1998. Data from the National Medical Expenditures Panel Survey, 1996.

How do People Get Long-Term Care?

Most people who need long-term care (88 percent) receive that care at home (or in community-based settings, such as adult daycare facilities). Only 12 percent receive care in nursing homes or other institutional facilities, such as intermediate care facilities for people with mental retardation.

A number of factors determine whether individuals with long-term care receive care at home or in nursing homes or other institutional settings. The likelihood of nursing home admission increases with age and extent of disability; most nursing home residents (91 percent) are elderly and almost half are over the age of 85. Elderly individuals who are most likely to be at risk of nursing home placement include those with cognitive impairments, those who are incontinent, and those without caregivers at home or nearby.

For those with long-term care needs living in the community, care needs vary considerably. Many of the elderly with long-term care needs may have only limited needs for assistance with such activities as paying bills, grocery shopping and taking medication. Others are more severely disabled, with extensive care needs for which they require full-time nursing and personal care. The use of paid home care is greatest among the elderly with moderate to severe levels of disability and those who live alone.

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Among the elderly in the community, those with long-term care needs typically rely on assistance from family and friends. About two-thirds depend on informal (unpaid) caregiving as their only form of assistance, and one-third receive a combination of informal and formal care.[4] Even among the community elderly with chronic, severe limitations, about half rely solely on unpaid help, often placing considerable strain on the family members who care for them [See Box 1].

BOX 1

Burdens on Family Caregivers

Chronic illness and functional limitations create growing burdens for the elderly individuals themselves and for the family members—spouses, daughters, daughters-in-law— and others who help to care for them on a routine basis. Ironically, changes in medical care that have improved its effectiveness—such as shorter hospital stays, the increased use of outpatient procedures, and the substitution of home care for institutional care—have shifted responsibility from paid providers toward unpaid providers, increasing burdens on family caregivers. The difficulties are enhanced because many caregivers have competing career and family responsibilities, and many are elderly themselves. A substantial proportion of caregivers who work report conflicts between work and care-giving, resulting in rearranged work schedules, decreasing hours of work, and periods of unpaid leave.[5]

The current system fails to meet all the long-term care needs of all persons with disabilities. Of elderly and nonelderly adults with long-term care needs living in the community, a significant proportion (about 20 percent) report that they have experienced "unmet need" for long-term care. Those responding to a national survey in 1994-95 attributed these gaps to the high cost of services, difficulty finding help, and failure to qualify for assistance from a social service agency because they didn't meet eligibility criteria (that is, their incomes were too high or they didn't meet the medical criteria needed to receive assistance). A substantial proportion of community adults with "unmet needs" reported specific consequences from a lack of help: a third of people with unmet need for help in toileting reported that they wet or soiled themselves; twenty percent of people with unmet need for help eating said they experienced periods when they were unable to eat when hungry.[6]

Who Pays for Long-Term Care?

Long-term care can be quite costly and can drain private resources quickly. The average cost of a year of nursing home care was nearly $41,000 in 1995,[7] and even regular home care visits can quickly become expensive. Hiring a home care aide to visit four hours a day, five days a week, at $10 an hour would cost more than $10,000 a year, and could be more costly for individuals with extensive needs.[8] As a result of the high costs of care, more than a third of all elderly individuals admitted to nursing homes, and about 70 percent of those with lengths of stay at least one year, were estimated to have catastrophic long-term care costs in 1993—that is, their long-term care costs exceed 40 percent of their total income and non-housing financial assets.[9] Consequently, many of those with long-term care needs turn to Medicaid, the only public program providing significant financing for long-term care.

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Health insurance coverage of persons with long-term care needs

Most, but not all, individuals with long-term care needs have health insurance of some kind—either publicly-financed or private health coverage. Their insurance plans, however, may or may not provide coverage for long-term care. For example, Medicare provides nearly universal coverage for the elderly but does not provide coverage for the extended personal care that is the bulk of long-term care, nor do most private health insurance plans cover long-term care.

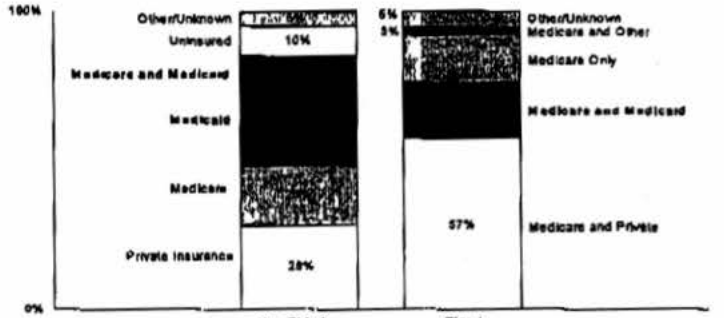
The elderly rely on Medicare for health insurance, and most have private or public supplemental coverage to help fill Medicare's gaps. Among the community-dwelling elderly with long-term care needs, 57 percent have private supplemental coverage in addition to Medicare, and 19 percent have Medicaid [Figure 4]. For those with private coverage, a very small proportion may have a private long-term care insurance policy, but most have only a Medigap policy, which does not typically provide substantial assistance with long-term care. For those with Medicaid, the extent of Medicaid protections varies, but the substantial majority of these Medicare and Medicaid "dual eligibles" receive the full range of benefits that Medicaid provides, including long-term care. A substantial minority (16 percent) of elderly people with long-term care needs only receive Medicare benefits, relying on their own income and assets to pay for prescription drugs, Medicare cost sharing, and any long-term care services they might need.

For nonelderly adults with long-term care needs, insurance coverage is more varied and Medicare plays a smaller role. About 30 percent (of the community-dwelling nonelderly disabled) rely on private health insurance, almost 60 percent have public coverage through Medicare and/or Medicaid; 20 percent have Medicare as their primary source of coverage, 25 percent have Medicaid, and 12 percent are covered by both Medicare and Medicaid. About 10 percent of the nonelderly disabled in the community are uninsured.

Figure 4

Health Insurance Coverage of Elderly and Non-Elderly Individuals with Long-Term Care Needs

(Community-dwelling individuals only)



Note: The "Medicare" and "Medicaid" categories for the nonelderly and the "Medicare and private" category for the elderly may include sources of public coverage other than Medicaid. "Other" includes Indian Health Care, Veterans' health care and other public insurance programs.

SOURCE: Georgetown University Institute for Health Care Research and Policy, estimates from the 1994-1995 National Health Interview Survey on Disability, Phase II.

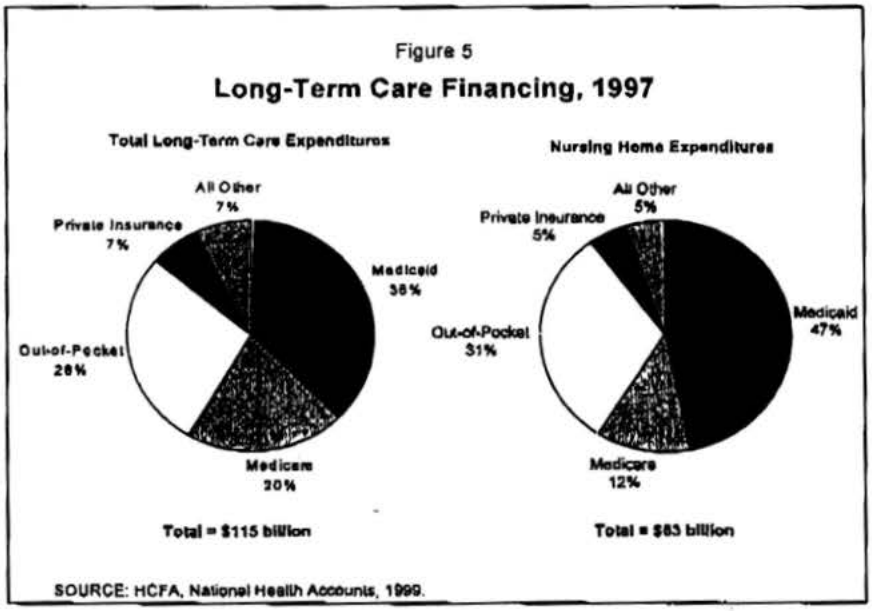
For the elderly and nonelderly poor who need long-term care, Medicaid is especially important. Of community residents with long-term care needs and incomes below the poverty line, 44 percent of the elderly and 64 percent of the nonelderly are covered by Medicaid. By comparison, only 9 percent of disabled elderly and 16 percent of the nonelderly disabled with incomes above 200 percent of the federal poverty level have Medicaid coverage.[10] Rates of Medicaid coverage are even higher among poor and low-income facility residents.

Although both private health insurance and Medicare are important sources of coverage for persons with long-term care needs, they play only limited roles in financing long-term care expenditures, but pay primarily for the acute health care needs of persons with disabilities. It is Medicaid that is the primary source of insurance coverage for long-term care, and thus Medicaid and out-of-pocket expenditures that account for the bulk of expenditures on long-term care.

More than $115 billion was spent on long-term care in the United States in 1997—12 percent of national health spending. Most long-term care is financed by the Medicaid program and by individuals with long-term care needs and their families (together accounting for 66 percent of long-term care expenditures). Medicare plays a more limited role (accounting for 20 percent of spending) and the role of private insurance is very limited (7 percent of long-term care expenditures are paid by private health care or long-term care insurance) [Figure 5]. In addition, a substantial amount of long-term care is unpaid—provided informally by family and friends—and is not reflected in these cost estimates.

Figure 5

Long-Term Care Financing, 1997



SOURCE: HCFA, National Health Accounts, 1999.