United States General Accounting Office

GAO

Report to the Chairman, Special Committee on Aging, U.S. Senate

April 1995

LONG-TERM CARE

Current Issues and Future Directions

GAO/HEHS-95-109

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-260713

April 13, 1995

The Honorable William S. Cohen
Chairman, Special Committee on Aging
United States Senate

Dear Senator Cohen:

Today, an increasing number of Americans need long-term care. Unprecedented growth in the elderly population is projected for the 21st century, and the population age 85 and older—those most in need of long-term care services—is expected to outpace the rate of growth for the entire elderly population. In addition to the dramatic increase in the elderly population, a substantial portion of the long-term care population consists of younger people with disabilities.

For all ages, most people who need long-term care receive their care at home or in a community setting, rather than in an institution. Yet, most public and private spending for long-term care still pays for institutional care, primarily for the elderly. Because expenditures for long-term care are substantial and growing, long-term care issues have been highlighted at both the state and national levels of government, with policymakers deliberating how best to respond given budget constraints.

In addition to long-term care purchased with public and private funds, a significant burden falls on family members who provide unpaid long-term care to spouses, children, parents, and other relatives. Congressional deliberations on health care reform last year and, more recently, the "Contract with America" underscored the importance of long-term care through proposing assistance such as tax deductions for long-term care insurance and tax credits for family caregiving.

You asked us to provide information on long term-care. As requested, this report addresses

- what is meant by "long-term care," the conditions that give rise to long-term care need, and how such need is measured;
- which groups, young and old, need long-term care;
- what long-term care costs are for the federal and state governments as well as for families;
- what strategies some states and other countries are pursuing to contain public long-term care costs; and

- what experts predict about the future demand for long-term care.

To develop this information, we drew upon our existing body of work on long-term care, updated the information on private long-term care insurance, and developed long-term care cost information using data from the Health Care Financing Administration (HCFA) and the Assistant Secretary for Planning and Evaluation (ASPE), both of the Department of Health and Human Services (HHS). A list of selected GAO products issued over the past 2 years appears in appendix I.

Results in Brief

Long-term care consists of many different services aimed at helping people with chronic conditions compensate for limitations in their ability to function independently. Many different physical and mental conditions can give rise to a need for long-term care. However, this need cannot easily be determined on the basis of a diagnosis or illness alone. Thus, other measures of a person's ability to function independently, such as activities of daily living (ADLs), have been developed.

More than 12 million Americans—young and old—report some long-term care need, and more than 5 million are estimated to be severely disabled. While most of the 12 million are elderly, 40 percent are not, and, regardless of age, most of the care that they need is nonmedical assistance with the routines of daily living.

Expenditures for long-term care, particularly institutional care, are high. In 1993, of nearly $108 billion spent, about 70 percent paid for institutional care. Government—both federal and states—provides most of the money for long-term care through dozens of categorical funding streams. Medicaid is the largest government payer for long-term care services—with the federal government spending $24.7 billion and states spending $19.0 billion in 1993—predominately for nursing home care. Home health services reimbursed by Medicare have experienced rapid growth over recent years—from $2.3 billion in 1989 to $9.5 billion in 1993.

The financial burden on families, who pay over a third of the long-term care bill out of pocket, is also high. To guard against financial loss, a small but growing number of individuals are purchasing private long-term care insurance policies. Families also bear a considerable nonmonetary burden by caring for relatives. Recognizing this, some employers have begun to offer more flexible schedules and other assistance to help employees balance work and caregiving.

Faced with rising expenditures for long-term care, some states and other countries are experimenting with new ways to control costs, including service delivery models that increasingly emphasize home and community-based care rather than institutional care. Other strategies involve capping budgets and provider fees, consolidating program administration, and using case management more often. Whether these approaches will contain costs remains to be seen.

The number of people needing long-term care is expected to increase. However, the extent of the nation's future long-term care needs is clouded by uncertainty about medical and technological advances. For example, breakthroughs could result in longer, healthier lives for baby boomers as well as an increase in the number of younger disabled people who survive low birth weight or accidents. Further developments in the private long-term care insurance market and the availability of unpaid caregivers are also likely to affect future demand for publicly funded long-term care. Continued experimentation in public program administration and continued evolution of long-term care service delivery models will be important in determining if more flexible, cost-effective responses to providing public and private assistance may be achieved both now and in the future.

Long-Term Care Helps People With Chronic Conditions Function as Independently as Possible

Long-term care essentially involves many diverse services for people with chronic conditions. These conditions include both physical and mental disabilities requiring different types of care. Various measures are used to identify an individual's need for long-term care.

Most Long-Term Care Is Assistance With the Routines of Daily Living

Long-term care is not one service but many different services aimed at helping people with chronic conditions compensate for limitations in their ability to function independently. People needing long-term care have many different types of physical and mental disabilities that require different kinds of care. Typically, long-term care does not involve high-tech medical care but basic assistance from others. For example, people with physical disabilities are likely to need hands-on assistance, and those with mental disabilities need supervision, protection, or verbal reminders to accomplish everyday activities. A person with a physical condition like quadriplegia might need hands-on help to get in and out of bed. In contrast, someone with a mental condition, such as Alzheimer's

disease, might need constant supervision for his or her own safety. Types of long-term care services therefore vary widely—from helping a frail elderly person dress, eat, and use the bathroom to skills training and medication management for a mentally ill person to technology and nursing care for a ventilator-dependent child.

The largest proportion of elderly persons with severe disabilities need nonmedical services, according to a recent survey that we conducted of directors of state agencies on aging and Medicaid.[1] The directors most often cited (1) personal care; (2) housekeeping, meal preparation, and other home chore services; and (3) case/care management as the services needed by the largest proportion of elderly persons with severe disabilities. (See table 1.)

Table 1: Examples of Home and Community-Based Services

Service	Description
Case management	Assists beneficiaries in getting medical, social, educational, and other services.
Personal care	Includes bathing, dressing, ambulation, feeding, grooming, and some household services such as meal preparation and shopping.
Adult day care	Includes personal care and supervision and may include physical, occupational, and speech therapies. Also provides socialization and recreational activities adapted to compensate for any physical or mental impairments.
Respite care	Provides relief to the primary caregiver of a chronically ill or disabled beneficiary. By providing services in the beneficiary's or provider's home or in other settings, respite care allows the primary caregiver to be absent for a time.
Homemaker	Assists beneficiaries with general household activities and may include cleaning, laundry, meal planning, grocery shopping, meal preparation, transportation to medical services, and bill paying.

Both Physical and Mental Conditions Can Cause Long-Term Care Need

Many different types of physical and mental conditions can give rise to a need for long-term care. Physical conditions include paraplegia, heart disease, asthma, arthritis, and many others. Mental conditions include severe and persistent mental illness, dementia, traumatic brain injuries, and mental retardation and other developmental disabilities. Among the elderly, arthritis and heart disease are the two most common causes of long-term care for individuals. For nonelderly adults, the most common causes of long-term care need are arthritis, heart disease, and mental retardation. In children, the most common chronic conditions limiting

[1]We received responses to our survey from all 51 state agencies on aging and from 50 of 51 state Medicaid agencies. For additional information, see Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly (GAO/HEHS-94-227, Sept. 6, 1994).

activity are respiratory disorders, such as asthma; mental retardation; and other mental or nervous system conditions, such as cerebral palsy.

Long-Term Care Need Is Difficult to Measure

The need for long-term care cannot easily be determined on the basis of a diagnosis or illness alone. For example, a person who has arthritis or mental retardation does not necessarily need long-term care. Furthermore, not all those with the same impairment need the same type and level of assistance, and a single individual's needs can vary over time.

Because a person's long-term care needs cannot be simply determined from his or her medical diagnosis, other ways to measure a person's ability to function independently have been developed. One set of measures gauges a person's ability to perform basic self-care tasks such as eating, bathing, dressing, getting to and using the bathroom, and getting in or out of a bed or chair. These measures are known as activities of daily living or ADLs. (See fig. 1.) ADLs, however, do not describe all types of functional limitations. Many people with Alzheimer's disease and other mental impairments, for example, may not have serious ADL limitations.

Figure 1: Definitions for ADL and IADL

ADL	Activities of Daily Living	Generally include eating, bathing, dressing, getting to and using the bathroom, getting in or out of a bed or chair, and mobility.
IADL	Instrumental Activities of Daily Living	Generally include going outside the home, keeping track of money or bills, preparing meals, doing light housework, using the telephone, and taking medicine.

Another measure of impairment examines other functional abilities that involve performing household chores and social tasks. These are known as instrumental activities of daily living or IADLs. They include the ability to

keep track of money, prepare meals, do light housework, take medicine, and go outside the home. In addition, other criteria—such as the ability to attend school or to behave in an age-appropriate manner—are sometimes used for children or adults with mental illness whose age or condition means that ADLs and IADLs may not be adequate to assess need.

Directors of state agencies on aging and Medicaid agencies reported to us that an elderly person's ability to perform ADLs was the best indicator to determine need for publicly funded home and community-based services.[2] They did not, however, have a uniform definition of ADLs. And most of the state agencies' assessment instruments used ADLs in combination with other indicators to determine need.

Long-Term Care Is Not Just for the Elderly or the Institutionalized

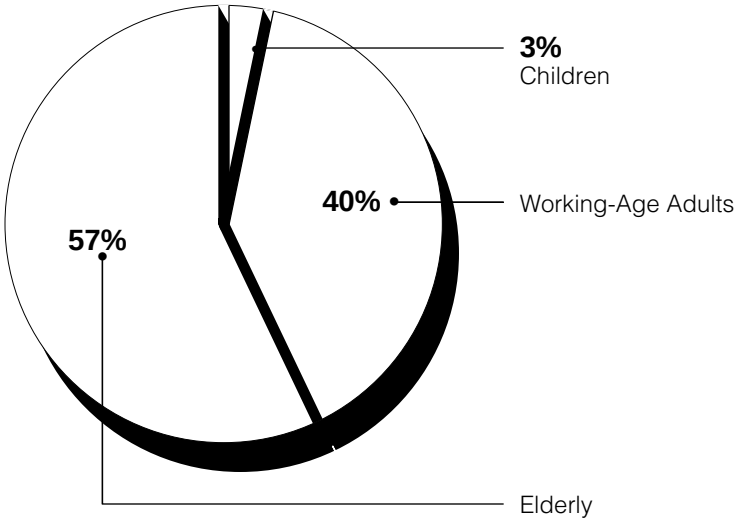
While the phrase "long-term care" may evoke images of the elderly in nursing homes, many Americans today who say they need long-term care services are not elderly. Moreover, across all ages, most people with long-term care needs live in the community, not an institution.

More Than 12 Million People Report Some Long-Term Care Need

More than 12 million Americans say they need assistance with everyday activities. Of these, about 60 percent are elderly; however, about 5 million are working-age adults, and approximately 400,000 are children under age 18. (See fig. 2.)

[2]Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly.

Figure 2: Both Young and Old Report Long-Term Care Need



Note: Includes people needing long-term care in institutions or in the community. Children are those under 18 years old, working-age adults are those 18 to 64 years old, and the elderly are those 65 years old and older.

Source: Based on our analysis of information from HHS and the Institute for Health Policy Studies at the University of California, San Francisco.

We estimate that about 5.1 million people of the more than 12 million needing long-term care are severely disabled due to a mental or physical impairment. That is, about 5.1 million people need substantial assistance from others in basic self-care activities or significant supervision for their own protection.

While most of those needing long-term care are elderly, 40 percent are not, and the number of nonelderly disabled has grown consistently in recent years. Possible explanations for the growth in the nonelderly disabled population include better medical technology and improved access to acute care, both of which may enable people to survive previously fatal conditions while sustaining permanent disabilities.

Most People Reporting Long-Term Care Need Are Not Institutionalized

In contrast to the traditional notions of long-term care, the vast majority of all those who say they need long-term care services do not live in nursing homes or other institutions. About 2.4 million people live in institutions, and most of these individuals are over 65 years old. The remaining 10.4 million individuals live at home or in small community residential settings, such as group homes or supervised apartments.[3] (See table 2.)

Table 2: Most Needing Long-Term Care Are Not Institutionalized

Numbers in thousands

Age group	In institutions	At home or in community settings	Total population
Children	90	330	420
Working-age adults	710	4,380	5,090
Elderly	1,640	5,690	7,330
Total	2,440	10,400	12,840

Sources: Based on our analysis of information from HHS and the Institute for Health Policy Studies at the University of California, San Francisco.

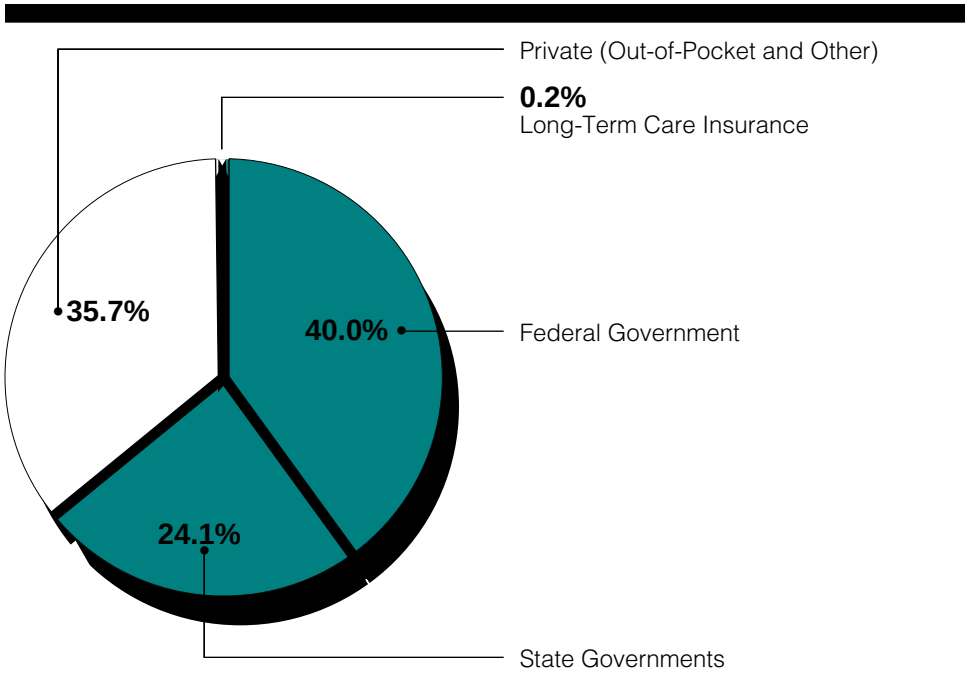
Government Is the Primary Payer of Long-Term Care

Long term-care is expensive. Nationwide, an estimated $107.8 billion was spent on long-term care in 1993.[4] The bulk of these costs—$69.1 billion—were paid for with public dollars, $43.1 billion from the federal government and $26 billion from state governments. Private sources paid the rest—about $38.5 billion—mostly as out-of-pocket spending by individuals and families. Private long-term care insurance contributed $200 million to this total. (See fig. 3.) In addition, family and friends, mostly women, provide the overwhelming majority of care for disabled persons on an unpaid basis.

[3]These statistics are explained in more detail in Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages (GAO/HEHS-95-26, Nov. 7, 1994).

[4]The HHS Assistant Secretary for Planning and Evaluation (ASPE) estimate for 1993 spending on long-term care. This estimate includes most long-term care spending by Medicare, Medicaid, the Older Americans Act, and the Department of Veterans Affairs. However, it does not include long-term care spending from such programs as the Social Services Block Grant, the Rehabilitation Act, state vocational rehabilitation, or the Maternal and Child Health Block Grant.

Figure 3: Government Pays the Largest Share of Long-Term Care Costs, 1993



Source: Office of the Assistant Secretary for Planning and Evaluation, HHS.

Dozens of Government Programs Provide Most of the Long-Term Care Dollars

Literally dozens of categorical funding streams provide long-term care to specific populations such as chronically ill children, persons with developmental disabilities, and the frail elderly. The National Academy for State Health Policy estimates that more than 100 federal programs—including Medicaid and Medicare—specifically target people with disabilities of all ages.[5] Other federal programs that provide significant support for long-term care include the Social Services Block Grant, the Older Americans Act, and the Rehabilitation Act. (See table 3.) Each program has its own unique rules governing eligibility and what services it will provide. Nearly three-fourths of state long-term care spending consists of the state share of Medicaid. The rest of state spending is for the state share of other federal matching programs or programs funded solely by state dollars.

[5]A Guide to Federal Programs for People With Disabilities, National Academy for State Health Policy (Portland, Me.: Dec. 1994).

Table 3: Major Federal Programs Supporting Long-Term Care Services for the Elderly and Persons With Disabilities

Program	Objectives	Fiscal year 1993 federal spending (billions)[a]	Administration	Long-term care services
Medicaid/Title XIX of the Social Security Act	To pay for medical assistance for certain low-income persons	Total: $77.4 Long-term care: $24.7 (estimated)	Federal: HCFA/HHS State: State Medicaid Agency	Nursing home care, home and community-based health and social services, facilities for persons with mental retardation, chronic care hospitals
Medicare/Title XVIII of the Social Security Act	To pay for acute medical care for the aged and selected disabled	Total: $138.8 Long-term care: $15.8 (estimated)	Federal: HCFA/HHS State: none	Home health visits, limited skilled nursing facility care
Older Americans Act	To foster development of a comprehensive and coordinated service system to serve the elderly	Total: $1.4 Long-term care: $.8	Federal: Administration on Aging/Office of Human Development, HHS State: State Agency on Aging	Nutrition services, home and community-based social services, protective services, and long-term care ombudsman
Rehabilitation Act	To promote and support vocational rehabilitation and independent living services for the disabled	Total: $2.2 Long-term care: $.1	Federal: Office of Special Education and Rehabilitative Services/Department of Education State: State Vocational Rehabilitation Agencies	Rehabilitation services, attendant and personal care, centers for independent living
Social Services Block Grant/Title XX of the Social Security Act	To assist families and individuals in maintaining self-sufficiency and independence	Total: $2.8 Long-term care: (not available)	Federal: Office of Human Development Services, HHS State: State Social Services or Human Resources Agency; other state agencies may administer part of Title XX funds for certain groups; for example, State Agency on Aging	Services provided at the states' discretion, may include long-term care

[a]Data represent total fiscal year 1993 obligations as reported in the Budget of the United States Government, Appendix, Fiscal Year 1995, except for estimates of Medicare and Medicaid long-term care spending. These figures are estimates for 1993 from the Assistant Secretary for Planning and Evaluation, HHS. Under the Medicaid program, states contributed an estimated $19.0 billion in support of long-term care in addition to the federal share of $24.7 billion.

Medicaid, a federal-state health program for people with certain low income and limited assets, is the largest government payer for long-term care services. In 1993, federal and state Medicaid spending accounted for a total of $43.7 billion in long-term care expenditures with $36.3 billion for institutional care and $7.4 billion for home and community-based services.[6]

Medicare, a federal health insurance program for those age 65 and older and certain persons with disabilities, is the second largest government payer of long-term care costs.[7] In 1993, Medicare accounted for an estimated $15.8 billion in long-term care expenditures, with $5.7 billion for institutional care and $10.1 billion for home health services.[8]

Private Long-Term Care Burden Is Also Substantial

The remainder of long-term care costs—both dollars spent and in-kind services—is borne privately, mostly by families and individuals. Despite the high cost of long-term care, most long-term care services are provided on an unpaid basis. In 1993, an estimated $38.7 billion, or nearly 36 percent of all long-term care expenditures, was paid privately, mostly as out-of-pocket expenditures by families and individuals for nursing home and home care. Much of the nonfinancial burden of long-term caregiving falls on families and individuals as well, often on women and—increasingly—on family members who are employed. Currently, about 2 million working Americans provide significant levels of unpaid care to elderly relatives living in the community who need assistance with everyday activities.

In response to the needs of employees who care for elderly relatives, some private companies and public-sector employers provide assistance—known as "elder care"—to help resolve conflicts between work and caregiving. Among other things, this assistance may include providing information about long-term care services and aging or allowing flexible work schedules to accommodate employees' family responsibilities. In a recent survey of private companies, we found that at least 23 million Americans work for medium and large companies that

[6]Estimates from the Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, March 1994.

[7]Medicare Part A Home Health Services include post-hospital services and long-term care services for persons with qualifying chronic conditions. Medicare Part A Skilled Nursing Facility Services are post-hospital services but have often been counted as long-term care because they are provided primarily by nursing homes, traditional long-term care providers.

[8]Estimates from the Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, March 1994.

offer at least one flexible schedule option.[9] In another recent study, we found that the federal government, state governments, and city governments with the largest work forces offer flexible schedule options and elder care information.[10]

Private Insurance for Future Long-Term Care Costs Holds Potential

Only a small share of long-term care costs—0.2 percent—is currently paid for by private long-term care insurance. (See fig. 3.) However, long-term care insurance may play a larger role in the future. In response to a 1994 GAO survey, directors of state Medicaid agencies and state agencies on aging most often cited long-term care insurance as one private-sector approach whose increased use they believed could be effective in reducing government spending.[11] The insurance industry has approached this market with caution, though, concerned that only those more likely to need care would purchase insurance. Insurance companies must compete in this complex and evolving market with limited experience in estimating the number of policyholders who will claim benefits.

Long-term care insurance can help people defray the considerable costs of long-term care. Further, the general quality of policies and the standards that govern them have improved significantly since the first generation of policies sold in the 1980s. Yet, some problems remain that consumers should be aware of to help ensure that they purchase policies that meet their needs. In particular, states and insurance companies have adopted to varying degrees minimum standards for long-term care insurance suggested by the National Association of Insurance Commissioners (NAIC).[12] These standards include such key consumer protection features as inflation protection against the increasing costs of long-term care and disclosure standards that protect consumers from unfair or deceptive marketing practices. Analysts of long-term care policies continue to emphasize that potential purchasers of long-term care insurance should carefully examine and compare policies, considering the differences

[9]Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (GAO/HEHS-94-60, Jan. 31, 1994).

[10]Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (GAO/HEHS-94-64, Mar. 4, 1994).

[11]Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly.

[12]Legislation introduced in the 104th Congress, including the Private Long-Term Care Family Protection Act of 1995, promotes national standards for long-term care insurance based on standards developed by NAIC.

among policies in premium costs, benefits, definitions, and eligibility requirements.[13]

The continued upward spiral of public and private long-term care costs has renewed interest in private long-term care insurance. Some people purchase such insurance to protect their assets against possible future long-term care expenses. Other people purchase it because they are uncertain about the quality and availability of long-term care funded by Medicaid. However, whether long-term care insurance will play a greater role in financing long-term care costs depends greatly on the extent to which people consider such insurance a viable and attractive option relative to their needs.

Institutional Bias Still Drives Long-Term Care Spending, but Medicare Home Health Now Increasing Rapidly

Despite people's preference for home and community-based services, long-term care dollars are overwhelmingly spent on institutional care. In 1993, total public and private expenditures were an estimated $75.2 billion for institutional care and $32.6 billion for home and community-based care. Overall, about 70 percent of all public and private long-term care dollars are currently spent for institutional care.

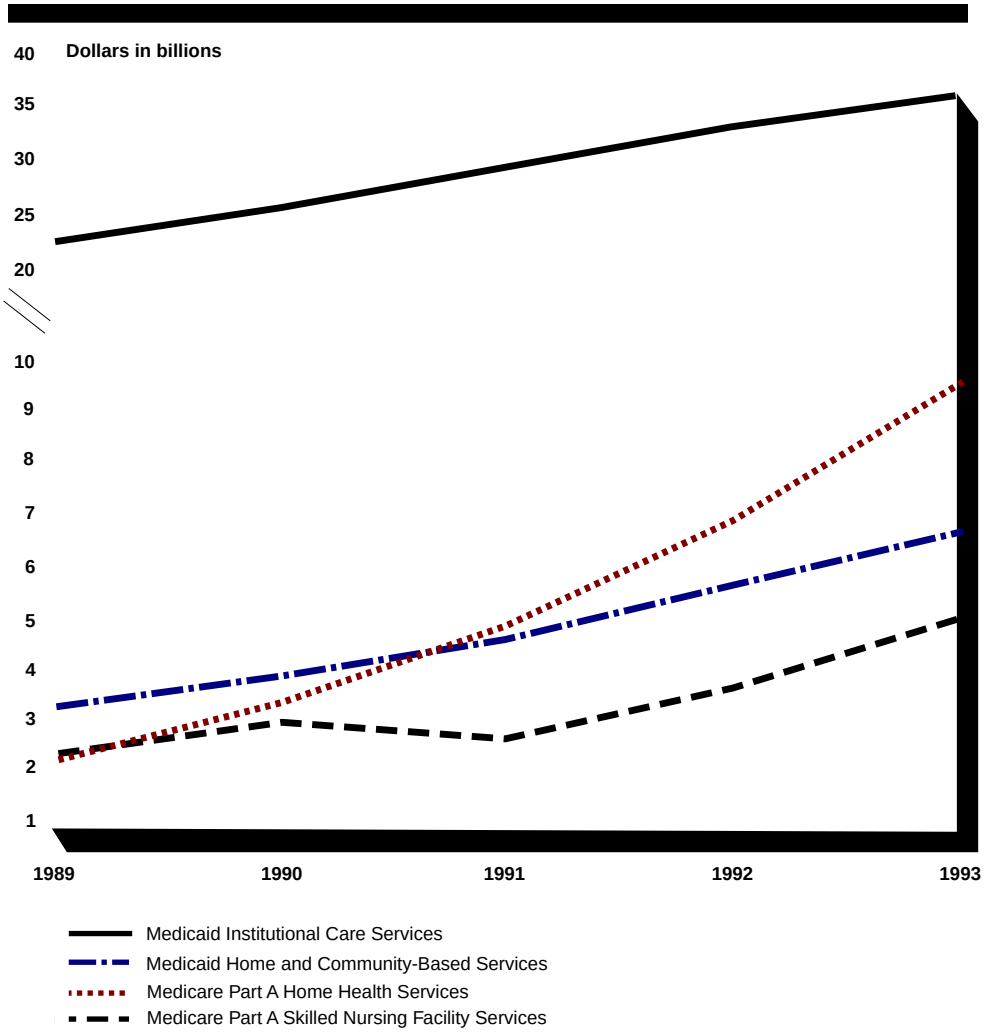
In recent years, long-term care spending in both the Medicaid and Medicare programs has grown dramatically. Long-term care spending under Medicaid grew at an average rate of 13.2 percent per year from fiscal years 1989 to 1993, with expenditures for home and community-based services growing faster than expenditures for persons in institutions.[14] And Medicare long-term care spending has been growing at a rate of 33.8 percent per year during the same period, although it represents a smaller share of total public long-term care spending than Medicaid.[15] (See fig. 4.)

[13]GAO's 1991 review of long-term care policies found that they often did not meet existing NAIC standards and contained inconsistent and vague policy terms, definitions, and eligibility requirements. We also found that policies that offered similar benefits could differ substantially in price. Long-Term Care Insurance: Risks to Consumers Should Be Reduced (GAO/HRD-92-14, Dec. 26, 1991).

[14]Systemetrics (MEDSTAT, using data from HCFA-64).

[15]1994 Green Book, Overview of Entitlement Programs, Committee on Ways and Means, U.S. House of Representatives (Washington, D.C., July 15, 1994).

Figure 4: Medicaid and Medicare Long-Term Care Expenditures, Fiscal Years 1989-1993



Note: Medicare Part A Home Health Services include post-hospital services and long-term care services for persons with qualifying chronic conditions. Medicare Part A Skilled Nursing Facility Services are post-hospital services but have often been counted as long-term care because they are provided primarily by nursing homes, traditional long-term care providers.

Sources: Medicare Expenditure Data from 1994 Green Book, Overview of Entitlement Programs. Medicaid Expenditure Data from Systemetrics (MEDSTAT, using data from HCFA-64).

Medicaid long-term care spending, while growing less rapidly than Medicare's, is still increasing at about twice the rate of inflation. Interest in

controlling this growth and aligning services more with citizens' preferences has led states to experiment more with innovative approaches to long-term care delivery. Certain states are increasingly emphasizing home and community-based services and constraining costly institutional care as they seek more efficient or cost-effective ways to organize and prioritize services.

Growing especially quickly are Medicare home health care expenditures, which have grown from $2.3 billion in 1989 to $9.5 billion in 1993 and are estimated to increase to $15.1 billion in 1995.[16] Part of this growth is attributed to a 1989 revision of the Medicare home health coverage guidelines in response to litigation.[17] The development of complex medical technologies that can be provided in the home, the implementation of Medicare hospital prospective payment in 1984, and the aging of the population have also contributed to this growth.

States and Other Countries Are Experimenting With Cost-Control Strategies, but Impact Yet to Be Determined

In the United States and some other countries, concerns about costs are a key factor driving changes in long-term care financing and service delivery. The attempted substitution of home and community-based services for institutional care is the most visible response to cost concerns. Other cost-control strategies include limits on nursing home beds, "capping" budgets, controls on provider fees, and case management. States are taking the lead in this shift, hoping to contain costs while responding to the desire of disabled people to avoid institutionalization. Other countries faced with high and rising public demand and costs for long-term care are pursuing similar strategies. Whether increased reliance on home and community-based services and limitations on institutional care will reduce the rate of spending growth, however, is not yet clear. Experimentation in controlling costs and using different long-term care service delivery models will likely continue.

[16] 1994 Green Book, Overview of Entitlement Programs.

[17] Interim Analysis of Payment Reform for Home Health Services, Prospective Payment Assessment Commission, Congressional Report C-94-02 (Mar. 1, 1994).

States Are Trying Budget Caps and More Reliance on Home and Community-Based Services but Cost Impact of Changes Unclear

The emerging models of long-term care service delivery now being developed emphasize (1) greater reliance on home and community-based services, (2) consolidation and decentralization of administrative responsibility for long-term care, and (3) stronger limits on the supply of institutional care. Together, these changes constitute a paradigm shift that emphasizes different models of home care, rather than care provided in an institution. Many of these models aim to incorporate individualized planning to provide services that consider a person's specific needs, preferences, and availability of community supports, including informal, unpaid caregiving rather than a standard package of services. In so doing, the models reflect the desire of many disabled people to be as independent as possible in their homes and communities.

While the bulk of public long-term care funding is from federal sources, state governments have taken the lead in developing and administering public long-term care programs. Some of the state innovations were pioneered under the Medicaid waiver program.[18] Since 1981, states have had the option of applying for Medicaid waivers to fund home and community-based services for people who meet Medicaid eligibility requirements and would otherwise require expensive institutional care. All states now provide some home and community-based services in their Medicaid programs, primarily to elderly persons and persons with physical disabilities.

In 1994, we reported on the experience of three states with long-standing Medicaid waiver programs—Oregon, Washington, and Wisconsin.[19] Although these states used various strategies to control program growth, all three placed additional restrictions beyond federal limits on program size, prompted in part by state budget limitations. These restrictions involve financial eligibility criteria; functional eligibility criteria; and a variety of program management techniques. These techniques include (1) controls on provider fees, (2) capped individual service budgets, (3) case management, and (4) limits on new nursing home beds. Some states also set up a consolidated administrative authority within the state over both institutional and community-based services to help shift

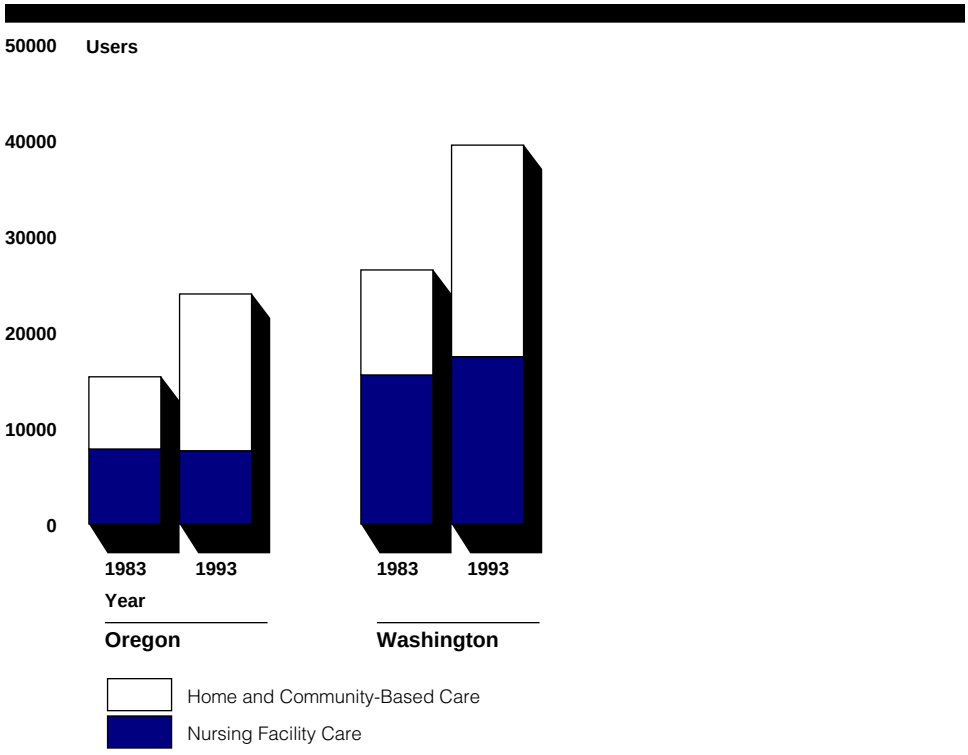
[18]The changes made by the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) authorize the Secretary of HHS through HCFA, the federal agency in charge of Medicaid, to approve exceptions or waivers to Medicaid program rules. These waivers allow the states to offer packages of services, including nonmedical services, that may not be covered by the states' regular Medicaid programs. Moreover, the states may choose to provide specific services only to defined groups, instead of to all eligible beneficiaries, as would be required under Medicaid absent a waiver.

[19]Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11, 1994).

individuals from institutional care and to home and community-based care. State officials singled out case management as especially useful in controlling costs by authorizing and monitoring services and by ensuring that beneficiaries receive the support services that they need to stay out of institutions. State Medicaid directors as well as directors of state agencies on aging surveyed by us also cited case management as an important technique for cost control.

As a result of the shift from institutional care to home and community-based care, the states we studied—Oregon, Washington, and Wisconsin—have been able to provide services to more people with available funds. (See fig. 5.) In addition, the states have accommodated all or most of the growth in their long-term care programs in home and community-based care. Some state officials believe that their ability to provide home and community-based care through state-funded and Medicaid waiver programs has allowed their states to successfully contain growth in overall state long-term care spending. In these states, the combined number of nursing facility beds declined 1.3 percent between 1982 and 1992 while the total number of nursing facility beds operated in the United States in the same period increased by 20.5 percent. Controls on program growth, however, have at times resulted in waiting lists for some programs, particularly the state-funded ones.

Figure 5: Aged and Physically Disabled Users of Nursing Facility and Home and Community-Based Care in Oregon and Washington, 1983 and 1993



Note: Wisconsin is not included in the figure because comparable data were not available.

Sources: Senior and Disabled Services Division, Oregon Department of Human Resources; and Aging and Adult Services Administration, Washington Department of Social and Health Services.

Accordingly, the success of the new service delivery models in containing costs nationwide is not yet clear. The passage of Medicaid waivers was based in part on the theory that providing certain nonmedical services (such as housekeeping, personal care, and adult day care) in the home or community could delay or eliminate institutionalization. Research has shown that while home and community-based programs were less costly on a per person basis, they generally raised total long-term care costs. Limited reductions in institutional use were more than offset by increased demand for home and community-based care—often referred to as "the woodwork effect." However, states are no longer relying on the availability of home and community-based services to reduce demand for nursing home care. Rather, savings are expected to result from restricting the

numbers of nursing home beds, thereby preventing additional nursing home use.

Other Countries Also Implementing Long-Term Care Cost-Control Strategies, but Impact Not Yet Known

In 1994, we reported that some other countries—Germany, Sweden, the United Kingdom, and several Canadian provinces —are establishing similar initiatives to contain long-term care costs, though it is too early to tell what effect the changes will have.[20] (See table 4.) While their health care systems differ significantly from ours, they face similar pressures associated with aging populations and rising government spending for long-term care. To contain spending growth, these countries are applying global or capped budgets to long-term care expenditures and have strengthened other controls, such as cost sharing, fee negotiation and rate setting, and management of nursing home bed supply. For example, Germany is in the process of developing a budget expressly for long-term care spending, while certain Canadian provinces, the United Kingdom, and Sweden have recently given local governments fixed budgets to fund nursing home care or home and community-based services.

Table 4: Key Long-Term Care Reform, by Country

Country	Reform
Canada	1978 to present: Most provinces, using incremental reforms, have developed long-term care as a universal benefit program.
Germany	1995-96: Reforms will make long-term care services standard benefits to be provided through national health insurance.
Sweden	1992 Adel Reform: The legislation shifts resources and taxing authority to municipalities, making them fully responsible for administering long-term care services.
United Kingdom	1990 Community Care Act: Implemented in 1993, the act grants local authorities strict global budgets for long-term care services.

The United Kingdom, Sweden, and certain Canadian provinces' reforms have sought to simplify access to care and target public resources more efficiently by consolidating the administration of services into single agencies and locating these agencies within local governments. As a result, an individual can obtain initial access to services at a single local public agency. Agencies in other countries are also increasingly relying on case management to assess needs, coordinate health and social services' components of care, and allocate resources. Last, to encourage informal caregiving, several countries are providing various financial incentives, such as cash payments and credits toward public pensions for caregivers.

[20]Long-Term Care: Other Countries Tighten Budgets While Seeking Better Access (GAO/HEHS-94-154, Aug. 30, 1994).

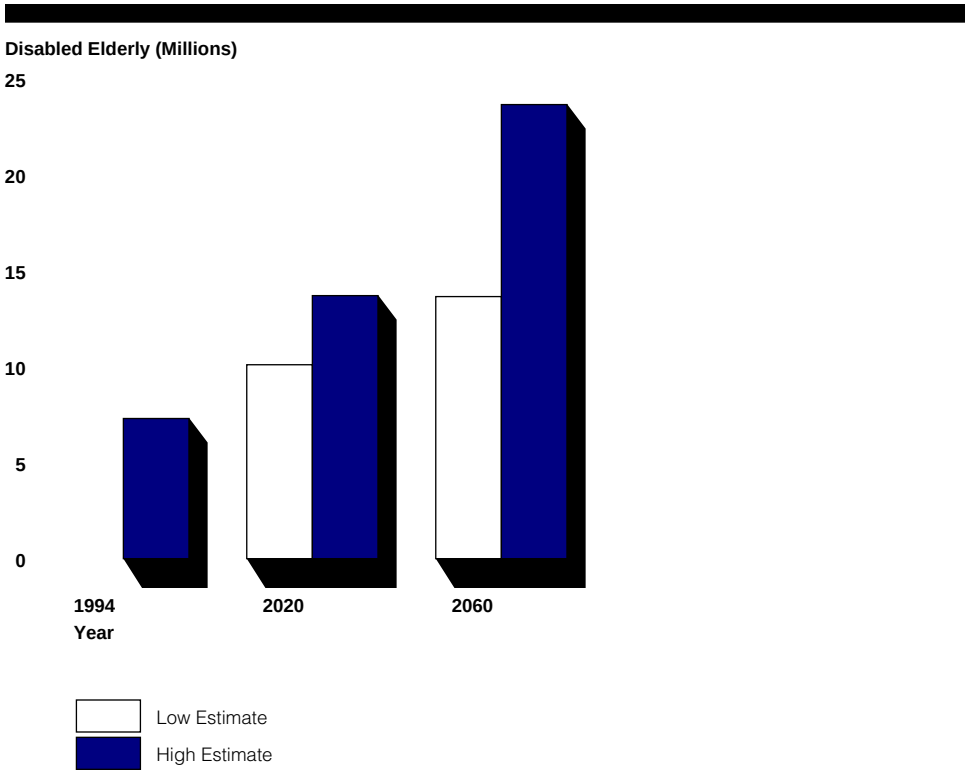
Demand for Long-Term Care Expected to Increase

The number of Americans needing long-term care will continue to grow, but predicting the magnitude and composition of that growth is complicated by several factors. Experts agree that population aging will increase the number of disabled elderly needing long-term care in the next several decades, but no consensus exists on the size of that increase. In addition, estimates of future long-term care need among the nonelderly disabled are difficult to project. Several factors, such as medical advances or changes in death rates, could increase or decrease need among elderly and nonelderly persons alike. Finally, the availability of informal, unpaid caregivers and workplace policies will also affect future demand for public long-term care services.

Number of People Needing Long-Term Care Will Increase, but Extent of Size Is Uncertain

Because long-term care need increases with age, especially after age 85, we can expect significant demand for long-term care well into the next century as the baby boom generation ages. (See fig. 6.) Current predictions of the numbers of disabled elderly vary widely, with predictions at the upper end of the range estimating that the number of elderly needing long-term care may as much as double in the next 25 years. Some researchers argue that medical advances that yield longer life expectancies may actually increase long-term care need as more people live longer and develop age-related disabilities, such as Alzheimer's disease, or live longer with disabilities they already have. Other researchers maintain that better treatments for common problems among the elderly, such as strokes and heart disease, or the prevention of disabilities could mitigate long-term care need.

Figure 6: Population Aging Will Increase Long-Term Care Need



Source: These projections are from K. Manton, "Epidemiological, Demographic, and Social Correlates of Disability among the Elderly," The Milbank Quarterly, Vol. 67 (1989), tables 1, 3, and 4.

Even more controversial are estimates of the future numbers of nonelderly disabled people who will need long-term care. Less information is available on which to base predictions about disability among the nonelderly, and small changes in how frequently certain disabling conditions, such as cerebral palsy, occur among the nonelderly can significantly affect the numbers needing long-term care. But most researchers believe that the increase in recent years in the nonelderly disabled population is likely to continue.

Demand for Publicly Funded Long-Term Care Subject to Several Factors

While limitations in the ability to function independently affect a person's need for long-term care, the demand for publicly funded long-term care services is influenced by several other factors. For example, some people

with severe disabilities may not want assistance from others. Among those who want assistance, many people receive most of their care for free from family or friends and may prefer this kind of care to a public program. Some people may be able to afford private long-term care insurance or services. Also, community resources, such as public transportation, can make it easier for a person with a disability to function without help from others.

The availability of informal, unpaid caregivers will also affect future demand for public long-term care services. Greater geographic dispersion of families, smaller family sizes, and the large percentage of women who work outside the home may continue to strain the capacity of informal caregiving. In the short term, large numbers of potential caregivers in the baby boom generation may ease the strain. But as baby boomers grow old, they may have fewer family members to care for them.

The capacity of families to provide care in the future may also be influenced by workplace policies. Workplace support for informal caregiving, for example, through elder care policies, could help employed caregivers in providing unpaid care. However, growth in elder care options among private companies is unclear. Many companies have concerns about the perceived costs of offering elder care assistance as well as about maintaining equitable benefits for employees who do not have elder care responsibilities. In the public sector, the federal government, as well as some state and city governments, plan to make additional support available to their employees or to expand availability of existing elder care programs. Many of these employers, however, are uncertain of their future plans.

Because our work was a summary of previous GAO reports, we did not obtain agency comments.

As arranged with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days after its issue date. At that time, we will send copies of this report to other congressional committees and members with an interest in this matter; the Secretary of Health and Human Services; the Assistant Secretary for Aging; the Administrator, Health Care Financing Administration; the Assistant Secretary for Planning and Evaluation; and others upon request.

This work was done under the direction of Cynthia A. Bascetta, Assistant Director. If you or your staff have any questions about this report, please call me on (202) 512-7215 or Cynthia Bascetta on (202) 512-7207. Other major contributors are listed in appendix II.

Sincerely yours,

Jane L. Ross
Director, Income Security Issues

Contents

Abbreviations

ADL	activities of daily living
ASPE	Assistant Secretary for Planning and Evaluation
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
IADL	instrumental activities of daily living
NAIC	National Association of Insurance Commissioners

Selected GAO Products on Long-Term Care

Aging Issues: Related GAO Reports and Activities in Fiscal Year 1994 (GAO/HEHS-95-44, Dec. 29, 1994). This report compiles GAO's fiscal year 1994 products and ongoing work on older Americans and their families. Because the elderly are one of the fastest growing segments of today's society, the Congress faces a host of issues—ranging from demographic changes in the structure and role of the family to financing and providing health care, Social Security, and pensions—in which the federal government will play an important role. This report summarizes 30 issued reports on policies and programs directed mainly at older Americans. Included are reviews of health, income security, social services, and other topics. We also summarize 59 reports in which older Americans were one of several groups targeted by federal policies. For example, Medicaid finances nursing homes and other types of long-term care, along with medical care for poor persons of all ages. In addition, this report describes testimonies delivered in fiscal year 1994 on subjects affecting older Americans and lists 55 ongoing GAO jobs on older Americans.

Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages (GAO/HEHS-95-26, Nov. 7, 1994). Contrary to popular perception, not all Americans needing long-term care are elderly or institutionalized. Of the 12 million Americans requiring such care, 5 million are working-age adults and about half a million are children; the vast majority—10 million—live at home or in community residential facilities. The long-term care needs of this population vary considerably, from around-the-clock nursing care to occasional assistance with household chores, such as cooking and housecleaning. The aging of the baby boom generation means that long-term care needs will increase well into the next century, as much as doubling among the elderly population in the next 25 years. Meaningful projections of the nation's future long-term care needs, however, are clouded by uncertainty about whether baby boomers will live longer, healthier lives than preceding generations and by a lack of reliable estimates on the future size of the nonelderly disabled population. Further, researchers believe that the number of younger disabled has grown in recent decades and will continue to do so, in part as a result of changing medical technology and other factors that may allow more low birth weight infants to reach childhood, for example, or more young adults to survive disabling accidents. The diverse ages, needs, and conditions of the long-term care population mean that greater flexibility is needed in the design and administration of programs to match the range of individual needs.

Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly (GAO/HEHS-94-227, Sept. 6, 1994). The state agencies agree widely on the key components of well-designed programs for the elderly. State agencies believe that an elderly person's ability to perform activities of daily living is the best way to identify persons with the greatest need for services, although states do not uniformly define such activities. To determine service needs, state agencies generally agree that case/care management, a standard assessment instrument, and involvement of the elderly person in the process are most useful. State agencies report that the largest number of severely disabled elderly persons need nonmedical services, such as personal care. State agencies agree that a variety of cost control methods are effective, although less consensus exists about which specific methods work best. Regarding the private-sector role in long-term care, state agencies believe that the private-sector role could probably reduce government costs, and government interventions might spur private-sector activity.

Long-Term Care: Other Countries Tighten Budgets While Seeking Better Access (GAO/HEHS-94-154, Aug. 30, 1994). In the United States, the number of people age 65 and older will exceed 20 percent of the total population by the year 2030, up from 12.5 percent in 1990. Public and private spending for long-term care has risen dramatically during the past decade—exceeding $100 billion in fiscal year 1993—and is projected to continue this upward trend. At the same time, considerable consumer dissatisfaction exists with the cost of and access to this care. To varying degrees, other countries also face aging populations, cost pressures, and service delivery problems. This report reviews the provision of long-term care in Canada, Germany, Sweden, and the United Kingdom. It examines (1) the financing and cost-containment measures these countries use to control public spending for long-term care and (2) administrative and delivery approaches the countries use to expand the range of and access to services.

Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11, 1994). Because nearly one-third of the nation's Medicaid expenditures are now spent on long-term care ($42 billion in 1993), we were asked to review the experience of states in expanding government-funded home and community-based services. Our review focused on Oregon, Washington, and Wisconsin. These three states have expanded home and community-based long-term care in part as a strategy to help control rapidly increasing Medicaid expenditures for institutional care. As they

expanded home and community-based care, the three states restricted how large most of the programs could grow. Some restrictions were mandated by the federal government, which approves capacity limits on programs operated under Medicaid waivers. Other restrictions result from constrained state budgets. Despite these deliberate limits on program size, one impact of the shift to home and community-based care is that the three states have been able to provide services to more people with the dollars available, primarily because home and community-based care is less expensive per person than institutional care.

Long-Term Care: The Need for Geriatric Assessment in Publicly Funded Home and Community-Based Programs (GAO/T-PEMD-94-20, Apr. 14, 1994). Because of advances in medicine and public health, Americans are living longer than ever before. Nearly 1 in every 8 Americans was 65 years of age or older in 1990; by 2020, this ratio is expected to rise to 1 in 5. To maintain their independence, many elderly people need daily help with routine activities, such as bathing, dressing, shopping, and meal preparation. Home and community-based long-term care for the elderly is today financed and run through a host of federal and state programs. This fragmentation can result in elderly persons being reevaluated every time they apply for a new program or pass a particular milestone, such as being discharged from a hospital. Despite this potential for redundancy, geriatric assessment is a potentially useful part of any program with frail elderly clients seeking home and community-based long-term care. This testimony discusses (1) what geriatric evaluation is and how it is used, (2) the extent to which it is available in public programs, (3) the professional requirements for persons who administer it, and (4) the pros and cons of standardizing the evaluation process.

Long-Term Care Reform: Program Eligibility, States' Service Capacity, and Federal Role in Reform Need More Consideration (GAO/T-HEHS-94-144, Apr. 14, 1994). Passage of any long-term care reform legislation is merely the first step in a long journey toward meeting the nation's long-term care needs. Knowledge about determining long-term care needs and services, derived largely from the experience of innovative states, suggests that state flexibility is the best way to meet the diverse needs of individuals and communities. This flexibility requires a new, different federal role, largely one of partnership with the states in the design and management of programs. The administration's proposal would give states $38 billion in federal funding each year for a new federal-state program of home and community-based services to be phased in from 1996 to 2003. States will be given wide latitude to design and run programs to serve persons of all

income ranges. The proposal would also liberalize Medicaid nursing home eligibility, provide tax credits to defray the costs of personal assistance for working persons with disabilities, and encourage and regulate private long-term care insurance. If the administration's proposal is to be the blueprint for long-term care reform, the new federal role should be defined more clearly. More thought should also be given to developing state guidance on determining eligibility and to helping states with less capacity to use program funds wisely.

Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform (GAO/T-HEHS, 94-140, Apr. 12, 1994). The long-term care system has evolved in a patchwork fashion and today comprises multiple programs that individuals find hard to access. Despite millions of dollars in outlays, the system often fails to meet the diverse needs of the disabled, and many believe that access to services could be improved with the same level of funding. This testimony focuses on three trends underlying the quest for reform. First, demographic changes make rising demand for long-term care inevitable across all ages, not just for the elderly. Second, spending will escalate sharply across all ages, not just for the elderly. Third, despite high costs, disabled persons are increasingly unhappy with available services and their ability to obtain them.

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (GAO/HEHS-94-64, Mar. 4, 1994). Today, about six million older Americans living at home need help with day-to-day activities, such as eating, bathing, shopping, and housecleaning. Most disabled elderly get all their care informally, from family members and friends, mainly women. Greater geographic dispersion of families, small families, and more women working outside the home are straining the ability of informal caregiving. Some private- and public-sector employers are now providing assistance known as "elder care" to alleviate work and caregiving conflicts. This assistance may include leave policies, alternative work schedules, and referral services to help employees care for their elderly relatives. Little is known nationwide about the extent and content of elder care generally—and even less is known about elder care in government, which employs 18 million people or 15 percent of the workforce. This report evaluates (1) the extent and nature of government practices facilitating elder care; (2) planned changes in these practices; and (3) their potential to further support informal caregivers.

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (GAO/HEHS-94-60, Jan. 31, 1994). Today, about 6 million older Americans need

help living at home because of their disabilities. The demand for this kind of assistance is expected to increase significantly in the future, with upwards of 10 million persons needing help by 2020. Most disabled elderly receive this care from family members and friends, primarily women. Yet greater geographic dispersion of families, smaller family size, and the large number of women who work outside the home are straining the ability of caregivers. Some companies are responding to the needs of their workers with policies and programs, known as "elder care," to help ease work and caregiving conflicts. This report evaluates (1) the extent and nature of company practices now offered to help employees who look after the elderly, (2) planned changes in these practices, and (3) the potential of company practices to further support informal caregivers.

Health Care Reform: Supplemental and Long-Term Care Insurance (GAO/T-HRD-94-58, Nov. 9, 1993). Provisions of the Clinton administration's Health Security Act that deal with private long-term care insurance and supplemental health insurance address many of the problems that we have pointed out in the past. The act has detailed sections governing the content and marketing of such insurance, including disclosure standards that protect consumers from deceptive marketing practices, grievance procedures that allow policyholders to contest insurance company decisions, and sales commission standards that discourage questionable sales practices. In general, we believe that the administration's proposal contains the kinds of consumer protections that we have long advocated. Some problems, however, are not addressed. Specifically, the act will not protect consumers from the sale of duplicate policies or high-pressure sales techniques. It also does not address other kinds of supplemental insurance that cover specific diseases or conditions requiring hospitalization. Because of their limited, narrow coverage, such insurance may be unnecessary for many consumers.

Long-Term Care Insurance: High Percentage of Policyholders Drop Policies (GAO/HRD-93-129, Aug. 25, 1993). From 1988 until the early 1990s, sales of long-term care insurance grew at about 32 percent annually. Although greater consumer protections are built into the long-term care policies being sold today, many Members of Congress are concerned about continuing abuses in this area and the need for more protections. This report provides information on (1) the percentage of policyholders that are expected to allow their policies to lapse and (2) the percentage of policyholders' premiums that are paid as sales commissions. It also discusses the adoption of consumer protection standards, such as benefits

that provide a return of a portion of premiums paid on long-term care insurance policies that are terminated.

Medicaid Estate Planning (GAO/HRD-93-29R, July 20, 1993). Pursuant to congressional requests, we determined the (1) prevalence of Medicaid estate planning for becoming Medicaid-eligible, (2) value of assets sheltered through Medicaid estate planning, and (3) extent to which states are enforcing Medicaid requirements concerning Medicaid estate planning. We found that (1) half of the Medicaid applicants converted assets from one form to another or transferred assets to another party, (2) asset conversions averaged $5,600 and typically involved setting aside money for burial arrangements, (3) other types of conversions included home repairs and automobile purchases, (4) asset transfers were far less frequent but involved larger amounts of money, and (5) half of the applicants that transferred assets were denied eligibility.

Long-Term Care Forum: Rethinking Service Delivery, Accountability, and Cost Control (GAO/HRD-93-1SP, July 13, 1993). Public dissatisfaction with the long-term care system is mounting. Long-term care is seen widely as both expensive and failing to meet the needs of the disabled of all ages. In particular, many people take issue with long-term care's bias in favor of institutional rather than home- and community-based services. This discussion paper was prepared for a GAO forum on long-term care issues. The views presented, although not necessarily the official position of GAO, are an attempt to pull together a wide variety of evidence and expert opinion on the key issues in long-term care reform. The paper touches on the key elements of innovative long-term care programs in the United States and abroad that have developed a wider range of home- and community-based services for the elderly as well as younger disabled persons. These key elements include (1) service flexibility to meet the unique needs of individuals, (2) high standards of organizational accountability to taxpayers for money spent and the quality of services delivered, and (3) effective cost controls to stay within the budgets decided upon by elected officials.

Long-Term Care Case Management: State Experiences and Implications for Federal Policy (GAO/HRD-93-52, Apr. 6, 1993). The number of Americans age 65 and older is rising steadily and could exceed 52 million by 2020. Older people require more health and social services but are often confused about how to obtain them. Case management helps people define their service needs, locates and arranges for services, and coordinates the services of multiple providers. The Congress has recently

considered several bills dealing with long-term care; some of this legislation has proposed establishing a network of case managers to integrate long-term care services and ensure that beneficiaries receive necessary care and support. This report discusses (1) what, in practice, constitutes case management; what roles case managers play; and what barriers they face in doing their jobs and (2) whether standards for case managers would best be defined in terms of professional qualifications, the functions of case management, or performance measures based on the experience of state officials and outstanding case managers.

Long-Term Care: Projected Needs of the Aging Baby Boom Generation (GAO/HRD-91-86, June 14, 1991). By virtue of its numbers, the baby boom generation—about 76 million people born between 1946 and 1964—has already had a profound impact on the American education system and, in more recent years, the workforce. As the baby boom generation ages, rapid growth in the number of elderly people who need nursing home care or care at home will increase long-term care resource requirements. This report provides information on projections of (1) the disabled elderly population and its use of long-term care services, (2) the number of home health aides required, (3) the costs of future long-term care services, and (4) the base of taxpayers or employed workforce available to pay for the elderly needing care.

GAO Contacts and Staff Acknowledgments

GAO Contacts

Cynthia Bascetta, Assistant Director, (202) 512-7207
Linda Baker
Connie Peebles

Acknowledgments

The following staff also contributed to this report: Eric Anderson, George Bogart, Patricia Davis, Joel Hamilton, Richard Jensen, James Musselwhite, and William Scanlon.

Ordering Information

The first copy of each GAO report and testimony is free. Additional copies are $2 each. Orders should be sent to the following address, accompanied by a check or money order made out to the Superintendent of Documents, when necessary. Orders for 100 or more copies to be mailed to a single address are discounted 25 percent.

Orders by mail:

U.S. General Accounting Office
P.O. Box 6015
Gaithersburg, MD 20884-6015

or visit:

Room 1100
700 4th St. NW (corner of 4th and G Sts. NW)
U.S. General Accounting Office
Washington, DC

Orders may also be placed by calling (202) 512-6000 or by using fax number (301) 258-4066, or TDD (301) 413-0006.

Each day, GAO issues a list of newly available reports and testimony. To receive facsimile copies of the daily list or any list from the past 30 days, please call (301) 258-4097 using a touchtone phone. A recorded menu will provide information on how to obtain these lists.

PRINTED ON  RECYCLED PAPER

United States
General Accounting Office
Washington, D.C. 20548-0001

Bulk Mail
Postage & Fees Paid
GAO
Permit No. G100

Official Business
Penalty for Private Use $300

Address Correction Requested