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Report to Congressional Requesters

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LONG-TERM CARE

Diverse, Growing Population Includes Millions of Americans of All Ages

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Health, Education, and
Human Services Division

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The Honorable David Pryor
Chairman
The Honorable William Cohen
Ranking Minority Member
Special Committee on Aging
United States Senate

The Honorable Dave Durenberger
Ranking Minority Member
Subcommittee on Disability Policy
Committee on Labor and Human Resources
United States Senate

Last year, individuals and their families, as well as federal, state, and local government programs, spent more than $100 billion on long-term care. Both the demand for and expenditures on these services are projected to escalate rapidly. Long-term care has been evolving in recent years, both in terms of who receives services and where those services are delivered. Families, the traditional providers of long-term care, are less able to maintain caregiving responsibilities as they cope with competing demands. Furthermore, many program recipients currently are dissatisfied with the accessibility and type of public services they receive.[1]

Government at all levels, the private sector, and those who need long-term care, as well as their families, are struggling with their roles in the face of these trends. State governments and other entities have been experimenting with alternatives to current programs to better meet individual needs. As all players rethink long-term care strategies, more information is needed about the size and scope of the population needing long-term care.

At your joint request, this report addresses this issue by providing estimates of the current and future number of people needing long-term care, as well as characteristics of this population. These estimates include those who currently receive family care or paid services, as well as those who do not. Our review objectives for this effort were to (1) estimate the prevalence of current long-term care need; (2) report on the future prevalence of need, including the factors that may influence it; and

[1]For more discussion of dissatisfaction with current long-term care services, see Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform (GAO/T-HEHS-94-140, Apr. 12, 1994).

(3) describe the diversity of needs among different groups. To address these objectives, we reviewed key literature; interviewed researchers, practitioners, experts, and long-term care consumers; and visited state and local programs providing long-term care services. A full description of our methodology appears in appendix I.

Results in Brief

The long-term care population today includes more than 12 million people who say they need assistance with everyday activities as a result of chronic conditions such as heart disease, mental retardation, or acquired immunodeficiency syndrome (AIDS). Contrary to popular perception, millions of these individuals are not elderly. About 5 million are working-age adults and about half a million are children under age 18. And, in contrast to traditional notions of long-term care, the vast majority of these people do not live in nursing homes or other institutions. Nearly 10 million live at home or in other small community residences. Furthermore, most people needing long-term care assistance receive their care unpaid from family members or friends, while a much smaller number receive government services.

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 house cleaning. We estimate that about 5.1 million people are so severely disabled that they need substantial assistance from others with basic self-care activities like eating and going to the bathroom or significant supervision for their own protection. About half of this severely disabled group, or 2.4 million people, live in institutions like nursing homes; the remaining 2.7 million live at home or in community settings.

The aging of the large baby boom generation means that long-term care need 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 good estimates on the future size of the nonelderly disabled population. The rising demand for long-term care services could be especially acute in future years if longevity increases and with it the number of elderly who are disabled. Long-term care needs could be mitigated, on the other hand, by medical breakthroughs that reduce disability and enhance the quality of life.

Less is known about the future long-term care needs of the nonelderly, and projections of this population are difficult. Researchers nevertheless 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 enable 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. Many different conditions, both physical and mental, can cause disability and necessitate different types of assistance. An individual with a physical condition like quadriplegia, for example, may need hands-on help to get in and out of bed, while someone with a mental condition, such as Alzheimer's disease, might instead require constant supervision for their own safety. In addition, age can affect the type of assistance needed, because expectations of what is an everyday activity change across the lifespan. Children and nonelderly adults, who constitute about 40 percent of the long-term care population, often have different long-term care needs than the disabled elderly, such as assistance attending school or working.

Background

Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to perform independently activities essential to maintaining themselves or their households, or puts them at risk of behavior that may harm themselves or others. Different definitions of long-term care yield different estimates of the number of people who need long-term care services. In this report, we define a need for long-term care as needing assistance from another person to perform certain everyday activities or as residing in an institution such as a nursing home.

Both physical and mental limitations can create a long-term care need. "Long-term care" is shorthand for the wide array of services provided to help compensate for these limitations.[2] Most of the support needed is not complex medical care, but assistance from others with the routines of daily living. As such, long-term care often involves the most intimate aspects of people's lives—what and when they eat, personal hygiene, getting dressed, using the bathroom. Services vary widely in their intensity and cost, depending on individuals' conditions, the severity of their needs,

[2]Some people with disabilities prefer to use the term "services" rather than "care" and think of themselves as "consumers" rather than "clients" or "care recipients." They prefer a more active role for themselves in their use of services.

and their environment. Long-term care assistance can range 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.

Need for long-term care is generally defined, irrespective of age and diagnosis, by long-lasting limitations in the ability to undertake basic activities and routines of daily living independently. One common way to assess these limitations is to measure an individual's ability to perform basic self-care tasks, often called the activities of daily living (ADL). These include eating, bathing, dressing, getting to and using the bathroom, and getting in or out of a bed or chair. Less severe impairments are often measured through the ability to perform household chores and social tasks, known as instrumental activities of daily living (IADL). These include going outside the home, keeping track of money or bills, preparing meals, doing light housework, and using the telephone.[3] In addition, other criteria—such as the ability to attend school or behavioral problems—are sometimes used for children or people with mental illness, whose age or condition means that limitations in self-care and household tasks may not be as valid for assessing need.

Families and friends provide the bulk of long-term care services to people who need them. Nonetheless, public and private spending on long-term care services was estimated to exceed $108 billion in 1993. About $70 billion of this money was federal and state government spending, primarily through the Medicaid program. Almost all the remaining $38 billion was paid by individuals and their families. Assuming the continuation of current spending patterns under current law, expenditures for long-term care are projected to more than double in the next 25 years.

Long-Term Care Population Not All in Nursing Homes or Elderly

The long-term care population today includes an estimated more than 12 million Americans of all ages, in many different settings, who need assistance from others to carry out everyday activities as a result of physical and mental impairments. Contrary to popular perception, most people within this population live at home or in community residential settings, not in institutions such as nursing homes. The largest group is elderly, but approximately 40 percent are working-age adults or children. Of those receiving assistance from others, most are helped by family

[3]These are the ADLs and IADLs measured in the data reported here. In other analyses, continence (bladder or bowel control or both) and the ability to get around inside the home are sometimes considered ADLs, and laundry, grocery shopping, heavy work, and taking medications may be included as IADLs.

members and friends, while a much smaller number receive assistance from government programs.

Most people who need long-term care do not live in institutions. Of the more than 12 million Americans estimated to need long-term care assistance, only about 2.4 million live in institutions, such as nursing homes, chronic care hospitals, or other facilities. (See table 1.) The remaining 10 million individuals live at home or in small community residential settings, such as group homes or supervised apartments.

Table 1: Most Needing Long-Term Care Are Not in Institutions

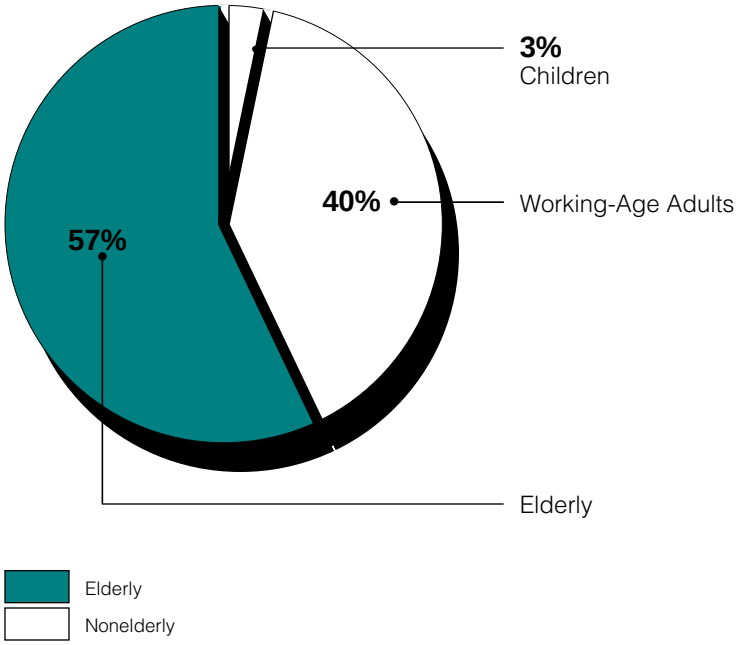
Numbers in thousands

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 information from the U.S. Department of Health and Human Services, and the Institute for Health Policy Studies at the University of California, San Francisco. For more detail, see appendix II.

Most people needing long-term care are elderly, a total of about 7.3 million. Overall, approximately three-fifths of the long-term care population are elderly. (See fig. 1.) Nonetheless, a sizable proportion of people needing long-term care is under age 65—about 5.1 million working-age adults and 400,000 children with long-term care needs either reside in institutions or live in the community.

Figure 1: Most People Needing Long-Term Care Are Elderly



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

Source: Based on data shown in table 1.

Level of Need Varies; Smaller Group Has Severe Disabilities

Among the more than 12 million people with limitations in everyday activities, there is a considerable range in the intensity and severity of their need for long-term care. Some people need assistance only with household tasks, like preparing meals or doing housework, while others cannot even undertake basic self-care, such as eating and bathing, without help from others. Still others may have a long-term care need for supervision or guidance, because of their mental impairments, regardless of their ability to care for themselves.

One common way to identify people with more severe needs is to focus only on those individuals needing assistance with self-care and to exclude those who only need assistance with less intense household tasks. This smaller group of 6.2 million people includes about 3.8 million adults outside of institutions who require another person's help with at least one

of the basic self-care tasks—eating, dressing, bathing, or using the bathroom—which are more essential to independent personal functioning, and 2.4 million people in institutions.

The most severely disabled population—those who need substantial assistance—comprises approximately 5.1 million individuals. About 2.4 million of these people live in institutions because of their disabilities. Another 1.3 million adults live in the community and need assistance from others with three or more self-care tasks, for example, people with advanced multiple sclerosis who cannot eat, dress, use the bathroom, or get out of bed without help. Finally, researchers in the Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services estimate an additional 1.4 million people require significant assistance because of mental disabilities, even if they do not report needing help with three or more self-care activities. People with mental impairments—such as mental retardation or schizophrenia—may be physically capable of performing everyday activities without assistance, but may be unlikely to do them in a safe, consistent, or appropriate manner. Even with no limitations in self-care, they may engage in other inappropriate behaviors that are a danger to themselves or others and require substantial supervision. It is important to note that the actual number of people who ultimately participate in any program may differ from these estimates, depending on how need for assistance is measured and the level of demand for program services.

Limitations in a number of self-care tasks are a good indicator of severity of need because the amount and intensity of long-term care assistance a person needs increase appreciably with the number of his or her impairments. Recent data confirm that the average number of hours of care received—both from family and paid sources—rises with the number of basic self-care activities with which an individual needs assistance. This increase is especially dramatic between limitations in two or fewer and three or more self-care tasks.

In addition to the elderly and working-aged adults, children are an important component of the long-term care population and often have distinct care needs. Among young children, need for long-term care is harder to assess because their age makes the traditional measures of self-care and household maintenance inappropriate measures of their abilities. Infants and toddlers, for example, are not expected to dress themselves or prepare their own food, whether or not they are disabled. Instead, children's long-term care needs may be assessed by other criteria,

such as limitations in activities more typical for their age group. About 330,000 children living at home are unable to engage in major play or school activities because of disabilities such as epilepsy, asthma, or cystic fibrosis. A smaller population of approximately 170,000 children are severely disabled with conditions such as cerebral palsy or mental retardation and need assistance with self-care if they are 6 years and older or if they are under that age and have a similar level of impairment. An additional 90,000 children live in settings away from their families, such as a facility for those with mental illness or mental retardation, or homes for the physically handicapped.[4]

Future Long-Term Care Need Will Grow, but Extent Is Uncertain

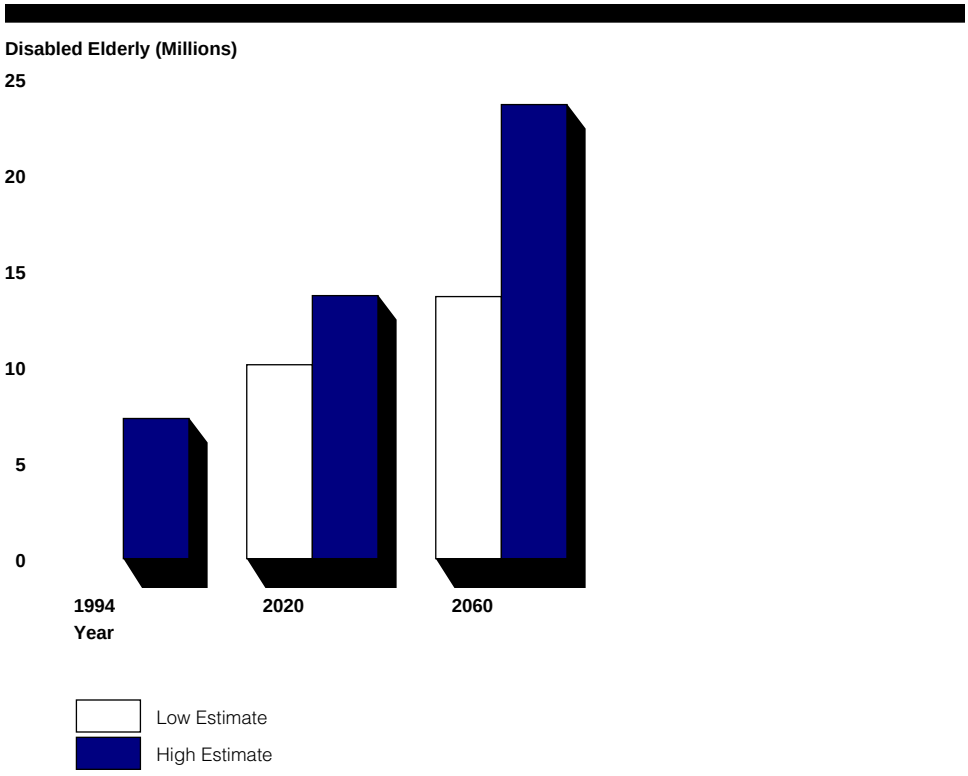
In the future, long-term care need will grow, but predicting the magnitude and composition of that growth is complicated by several factors. Experts agree that population aging will increase the number of disabled elderly needing long-term care over the next several decades, but no consensus exists on the size of that increase. In addition, estimates of future long-term care need among the nonelderly disabled are difficult to project. Finally, several factors, such as medical advances or changes in death rates, could increase or decrease need among elderly and nonelderly persons alike.

Population Aging Will Increase Need

The 21st century will be marked by a dramatic increase in the size of the elderly population as the large baby boom generation ages. While most elderly people are not disabled, the elderly as a whole have the greatest likelihood of needing long-term care. As a result of this population aging, researchers predict that the number of elderly needing long-term care may as much as double in the next 25 years. Figure 2 shows that recent projections of elderly needing long-term care reach between 10 million and 14 million by 2020, and 14 million to 24 million in 2060, compared with about 7 million today.

[4]This statistic includes children living in a range of settings outside their homes, such as foster care placements and nursing homes. Not all are large institutions, some may only have a few beds. See app. II for details.

Figure 2: Population Aging Will Increase Long-Term Care Need



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

While the sheer number of future elderly is expected to drive up demand for long-term care services, projections of the number of elderly needing long-term care in the next century vary because of different assumptions about the future prevalence of disability. Changes in death and disease rates among the nation's older population, for example, will affect the need for long-term care. Long-term care need intensifies significantly with age, especially after age 85. It is this subpopulation, the elderly aged 85 and older, that is projected to grow most rapidly. Some researchers argue that medical advances have increased life expectancy but have not changed the onset of illness. They predict that declining death rates may actually increase long-term care need if, for example, more people live to develop age-related disabling conditions such as Alzheimer's disease or live longer with existing disabilities. Others argue that disability is becoming

increasingly compressed into a shorter portion of the lifespan, decreasing the number of years long-term care is needed. Improved treatments or prevention of common disabling conditions among the elderly, such as strokes and heart disease, could lessen long-term care need, independent of death rates.

Furthermore, according to the Bureau of the Census, future generations of elderly are likely to be different from the elderly of today—better educated and more culturally diverse—in ways that could affect their ultimate health and economic status. Higher levels of both education and income are often associated with lower levels of disability. At the same time, the economic resources available in old age vary significantly with race and ethnicity. Increasing cultural diversity among the elderly may increase the number of disabled elderly with few resources who need publicly subsidized long-term care.

Estimates of Future Need Among Nonelderly Difficult

Estimates of future long-term care need among the nonelderly are difficult for a variety of reasons. There are fewer data on disability among the nonelderly with which to project future disability. Relative to the elderly, severe disability among those under 65 is less common. 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. These factors make it difficult to predict future disability trends and subsequent long-term care need.

Researchers agree that the number of nonelderly people with long-term care needs has grown in recent decades and that this increase is likely to continue. Some of the reasons suggested for past growth include better technology and improved access to acute care, both of which may make it possible for people to survive previously fatal conditions while sustaining permanent disabilities. Furthermore, survival of many low-birth-weight babies to childhood or children with developmental disabilities into adulthood may also be increasing the numbers of nonelderly needing long-term care.

Other Factors Could Affect Future Disability

Future disability and long-term care need among people of all ages will be affected by several factors. Changes in health behaviors can have an impact on the prevalence of common disabling conditions. For example, the percentage of Americans who smoke cigarettes dropped nearly 40 percent—from 42 to 26 percent—between 1965 and 1991. Smoking is

strongly related to future heart disease, one of the most common causes of functional impairments that necessitate long-term care. Research also suggests many traumatic brain injuries, which can cause both mental and physical disabilities, could be prevented by improved motor vehicle safety or by use of protective head gear by bicyclists and motorcyclists. Greater use of these safety devices may decrease the incidence of such injuries and subsequent long-term care need.

We do not know now how future medical advances will affect long-term care need. Improved treatments and technology may result in the prevention of certain chronic conditions, or simply in incremental or marginal improvements in the management of their symptoms. Improved management of AIDS complications has and could continue to result in the need for long-term care over longer periods. Lower death rates from two common causes of functional limitation, heart disease and stroke, may actually result in a larger number of people living with disabilities.

Population Includes Diverse Disabilities and Needs

The long-term care population is very diverse and includes people of all ages with a wide array of disabling conditions and assistance needs. Long-term care need can stem from a variety of limitations in mental or physical abilities, or both. While the type of long-term care assistance needed is often related to the disabling condition, needs are also affected by an individual's age. Need for publicly funded long-term care is a function of several additional factors, including the availability of family caregivers and financial resources.

Many Different Physical, Mental Conditions Can Create Long-Term Care Need

Individuals of all ages need long-term care as a result of many different physical and mental conditions. Physical disabilities, such as difficulty walking, are caused by a range of conditions, such as paraplegia, heart disease, asthma, arthritis, and many others. Mental disabilities, such as a limited ability to reason or inappropriate and dangerous behavior, result from conditions that include severe and persistent mental illness, dementia, traumatic brain injuries, mental retardation, and other developmental disabilities. Some people can have both types of disabilities resulting, for example, from Alzheimer's disease and a stroke or from a traumatic brain injury.

There are both similarities and differences between the elderly and nonelderly population in the conditions most often causing a need for assistance. Among both the elderly and the nonelderly, arthritis and heart

disease are two of the most common causes of long-term care need. Among the nonelderly, mental retardation is the third most frequent condition necessitating long-term care. About 670,000 nonelderly adults need assistance with household tasks or self-care because of mental retardation or a related developmental disability. An additional 140,000 individuals under 65 live in institutions, primarily facilities for those with mental retardation, and 180,000 more live in small residential facilities. Mental retardation is less common among the elderly; however, dementia, generally stemming from Alzheimer's disease, is especially prevalent and a frequent cause of long-term care need. More than half a million elderly living at home or in community settings report needing assistance with everyday activities as a result of Alzheimer's disease or other dementias. Many fewer adults under 65 have Alzheimer's; however, about 750,000 people aged 18 to 64 need long-term care because of a mental or emotional illness or condition, such as schizophrenia or bipolar disorder. The most common chronic conditions limiting activity in children are respiratory disorders, such as asthma; mental retardation; and other mental or nervous system conditions, such as cerebral palsy.

Disability, Age Affect Type of Assistance Needed

The range of disabilities and ages in the long-term care population creates significant diversity in the types of support needed—both between and within population groups. The long-term care assistance an individual needs is often related to the type of impairment—mental or physical—causing his or her disability. People with mental disabilities are more likely to need supervision, protection, or verbal reminders to accomplish everyday activities, rather than the hands-on assistance people with physical disabilities frequently need. However, not everyone with the same disabling condition needs the same type of care. Long-term care need can even vary for the same person over time as conditions, such as AIDS, change and symptoms worsen or abate.

Age can also influence the type of assistance required, and long-term care needs and goals often vary among the elderly, working-age adults, and children. These differences are related to the expectations and everyday activities typical for each stage of life. Severely disabled children frequently need services to support their families in continuing the care they already provide as well as assistance with learning basic life skills and attending school. In contrast, nonelderly adults more often require services to help them establish their own households or regain lost skills. They may want assistance to enable them to work and participate in related activities. Elderly people, who often no longer work, may instead

need long-term care services that let them maintain their independence and stay in their own homes and communities despite a decline in their abilities.

Need for Publicly Funded Care Affected by Additional Factors

While a person's need for long-term care begins with functional limitations, the need and demand for publicly subsidized services are influenced by several additional factors. Many people needing long-term care already receive unpaid help from family or friends, and may prefer this informal care to a public program. Currently most disabled people do receive their care unpaid from family members and friends, primarily women. However, greater geographic dispersion of families, smaller family sizes, and the large percentage of women who work outside the home are straining the capacity of this care source. Large numbers of potential caregivers in the baby boom generation may ease this strain in the near future. However, as members of this generation become disabled themselves and need assistance, they may have fewer family members available to care for them. Fewer informal caregivers, even with no increase in disability prevalence, could increase demand on public programs. In addition, some people may be able to purchase the assistance they need with private funds. Some people, even with very severe disabilities, do not want assistance from others.

Finally, an individual's environment can also play a role in the need for government assistance. Community resources, such as public transportation, and accommodation in public places, such as workplaces and housing, can make it easier to function with a disability without the assistance of another person.

Conclusions

The current long-term care population's size and diversity have implications for how public and private programs are designed and administered. Because most people needing long-term care live in their own communities—not nursing homes or institutions—services available in the home and community are increasingly important. The long-term care needs of the large number of disabled working-age adults and children are often different from those of the disabled elderly. Furthermore, not everyone with a disability needs long-term care to function independently. Within the long-term care population severity of need varies, with some people needing only occasional aid and a much smaller number requiring substantial assistance. Need for publicly subsidized services is often a function of several factors in addition to

disability, including individual financial resources, availability of family and other unpaid caregivers, and community resources. Finally, there is uncertainty about the extent of growth in future need and demand for long-term care.

We discussed a draft of this report with officials from the Department of Health and Human Services, and they generally agreed with our findings. As agreed with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from the date of this letter. At that time, we will send copies to the Secretary of Health and Human Services and other interested parties and make copies available to others upon request.

Please call me on (202) 512-7215 if you or your staff have any questions concerning this report. Other contacts for this report are listed in appendix III.

Jane L. Ross
Director, Income Security Issues

Contents

Abbreviations

ADL	activity of daily living
AIDS	acquired immunodeficiency syndrome
ASPE	Office of the Assistant Secretary for Planning and Evaluation
IADL	instrumental activity of daily living
SIPP	Survey of Income and Program Participation

Methodology

To address our objectives for this report, we interviewed researchers, practitioners, and long-term care consumers, and held panel discussions with experts in the long-term care field. We visited several state and local programs providing long-term care services for the elderly and nonelderly to identify disability groups currently receiving long-term care services, to examine the prevalence of their needs, and to learn about the diversity of long-term care needs within and among disability groups. These included programs in Massachusetts, Michigan, Minnesota, Oregon, Pennsylvania, Texas, and Vermont.

In addition, we synthesized key literature in the area of long-term care. Finally, we used information from a forum we held in July 1993 on long-term care reform issues that brought together federal and state program officials, representatives of different disability groups, academic experts, and congressional staff to discuss service delivery, program accountability, and cost control issues.

We conducted our review between January and September 1994 in accordance with generally accepted government auditing standards.

Source of Population Estimates

The population estimates presented in this report were based on data from several sources. This appendix discusses these sources by subpopulation.

Institutional Residents, All Ages

The number of people in institutions, by age, was calculated by Michele Adler of the Office of Disability and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services. These estimates include people with long-term care needs in nursing homes, homes for the physically handicapped, intermediate care and other facilities for those with mental retardation, facilities for people with mental illness, child welfare/foster care for children with mental retardation, and correctional facilities, as well as residents of shelters or other facilities for the homeless. Not all of these facilities are large; some may only have a few beds. The data sources for these estimates were the 1990 Decennial Census; the Center for Mental Health Services, Substance Abuse and Mental Health Administration; and Charlie Lakin of the Center on Residential Services and Community Living at the University of Minnesota. These data will be published in an upcoming ASPE Research Note, "Population Estimates of Disability and Long-Term Care."

Adults With ADL and IADL Limitations

Researchers at ASPE used data from the Survey of Income and Program Participation (SIPP), conducted by the Bureau of the Census, to estimate that 4,380 working-age (aged 18 to 64) and 5,690 elderly adults need assistance with one or more activities of daily living (ADL) or instrumental activities of daily living (IADL). These estimates are drawn from the third wave of the 1990 SIPP panel and represent the noninstitutionalized adult population of the United States. IADLs, which are household and social tasks, assessed in SIPP include going outside the home, for example to shop or visit a doctor's office; keeping track of money and bills; preparing meals; doing light housework, such as washing dishes or sweeping a floor; and using the telephone. ADLs, which are basic self-care tasks, include getting in or out of a bed or a chair; taking a bath or shower; dressing; eating; or using the toilet, including getting to the toilet.

Using the same SIPP data provided by ASPE, we estimated that 3.8 million people aged 18 and older need assistance with 1 or more ADL and 1.3 million need assistance with 3 or more.

Children With Disabilities Living at Home

Researchers from the Institute for Health Policy Studies at the University of California, San Francisco used data from the 1991 Health Interview Survey to estimate that approximately 330,000 children under age 18 were unable to perform a major activity typical for their age group as a result of their disabilities. The Health Interview Survey, which is conducted annually by the National Center for Health Statistics, measures limitations in ordinary play for children under 5 years of age and limitations in school attendance for children aged 5 to 17. This estimate was originally published in a paper for the Child Health Consortium, "Meeting Children's Long-Term Care Needs Under the Health Security Act's Home and Community-Based Services Program," in January 1994.

ASPE researchers estimated in August 1994 that 170,000 children under age 18 were severely disabled and needed long-term care. Severe disability was defined as limitations in at least one ADL for children aged 6 and older and a comparable level of impairment for children under this age. This estimate was based on the 1989 National Health Interview Survey and the 1987 National Medical Expenditure Survey, and will also be published in the forthcoming "Population Estimates of Disability and Long-Term Care."

People With Severe Mental Disabilities

ASPE researcher John Drabek estimated that approximately 1.4 million people have a level of cognitive impairment similar in severity to needing assistance with three or more ADLs. This population includes 140,000 people of all ages with severe or profound mental retardation or another developmental disability, 150,000 people aged 18 to 64 with severe mental illness, and 1,100,000 elderly people with Alzheimer's disease or other mental illness. Severe cognitive impairment among the elderly was defined as (1) missing four or more questions on the Short, Portable, Mini-Mental Status Questionnaire; and (2) one of the following: needing assistance with medication management, money management, or telephoning; evidence of a behavior problem; or needing assistance with one or more ADLs. These data were drawn from the 1989 National Long-Term Care Survey. Data on nonelderly adults with mental illness were derived from SIPP, the 1989 Health Interview Survey, and the East Baltimore Mental Health Survey of the National Institute of Mental Health's Epidemiological Catchment Area program. Data on mental retardation and developmental disabilities were supplied by Charlie Lakin.

Nonelderly People With Mental Retardation or Developmental Disabilities

Using data from wave 3 of the 1990 SIPP provided by ASPE researchers, we estimated that approximately 670,000 people aged 18 to 64 need assistance with at least one ADL or IADL because of mental retardation or a developmental disability. The ADLs and IADLs assessed were the same as those discussed previously.

Using data compiled by the Center on Residential Services and Community Living at the University of Minnesota and provided by Charlie Lakin, we estimated that 140,000 people with mental retardation or a related condition live in institutions and an additional 180,000 live in small community residential settings. These data encompass all persons under age 65, including children. Institutions are defined as facilities with 16 or more beds that were designed specifically for the care of people with mental retardation or developmental disabilities, as well as other psychiatric facilities and nonspecialized nursing homes. Small community residential settings are facilities with 1 to 15 beds. These data, which are for 1993, were adjusted to represent residents under age 65 only, based on the percentages of elderly residents in these facilities found in the 1987 National Medical Expenditure Survey. Not every state provided data for all years or all institution types; some states provided data from earlier years.

Nonelderly Adults With Mental Illness

The 750,000 nonelderly adults who need long-term care as a result of mental illness include 140,000 adults in institutions and 610,000 living in the community. We used data, provided by ASPE researchers, from wave 3 of the 1990 SIPP to estimate that 610,000 people aged 18 to 64 need assistance with at least one ADL or IADL because of a mental or emotional condition. The activities assessed were the same as for the population with mental retardation. We derived the estimate of institutionalized adults with mental illness by using unpublished data from the 1990 Inventory of Mental Health Organizations. These data were supplied by the federal Center for Mental Health Services and include adults aged 18 to 64 who have severe mental illness. The institutions inventoried include state and county mental hospitals, private psychiatric hospitals, Department of Veterans Affairs psychiatric organizations, residential treatment centers, multiservice mental health organizations, and general hospital psychiatric units.

Adults With Alzheimer's Disease or Other Dementia

We also used the data from wave 3 of the 1990 SIPP provided by ASPE to estimate that approximately 550,000 people aged 65 and older report needing assistance with ADLs or IADLs as a result of Alzheimer's disease or

another dementia. The same activities were measured for this population as for the populations with mental illness and mental retardation.

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Related GAO Products

Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly (GAO/HEHS-94-227, Sept. 6, 1994).

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

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

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).

Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform (GAO/T-HEHS-94-140, Apr. 12, 1994).

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

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Long-Term Care Insurance: Actions Needed to Reduce Risks to Consumers (GAO/T-HRD-92-44, June 23, 1992). Reports on same topic: GAO/HRD-92-66, Mar. 27, 1992, and GAO/HRD-92-14, Dec. 26, 1991. Testimonies on same topic: GAO/T-HRD-92-31, May 20, 1992, and GAO/T-HRD-91-14, Apr. 11, 1991.

Long-Term Care: Projected Needs of the Aging Baby Boom Generation (GAO/HRD-91-86, June 14, 1991).

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