

# Midlife and Older Americans with Disabilities: Who Gets Help?

A Chartbook

Public Policy Institute

by Enid Kassner and Robert W. Bectel



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The Public Policy Institute, formed in 1985, is part of the Research Group in the AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of interest to older Americans. This publication represents part of that effort. Any views expressed in this publication are for information, debate, and discussion, and do not necessarily represent formal policies of the Association.

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## Foreword

The challenges and opportunities presented by an aging society are nowhere more dramatic than in the area of long-term care. As unprecedented numbers of Americans live to advanced ages, policymakers need to know whether greater longevity will be accompanied by improvements in health status, a growing demand for health and long-term care services, or both. While Americans generally welcome the thought of a longer life span, they also are concerned about their future health and whether they will have adequate incomes in retirement. Because our nation still has no universally available program that provides long-term care to people with disabilities, questions about the affordability of long-term care are paramount in the minds of many mid-life and older Americans.

Yet despite these challenges, there is great potential for the future. There is growing evidence that disability rates are declining. Whether this trend will be sustained remains to be seen, but, if it is, a greater number of healthy years could provide new opportunities for older Americans. Moreover, our nation's long-term care system is changing, albeit slowly, responding to consumers' strong preference for receiving care in their own homes and, in some cases, allowing consumers to take greater charge of managing the services they receive.

The purpose of this chartbook is to present easy-to-understand data on the characteristics of mid-life and older Americans with disabilities who receive long-term care help. This publication is part of AARP's ongoing mission to ensure that mid-life and older Americans have adequate access to health and long-term care services. In addition to describing the population age 50 and older that receives long-term care, we present data on the characteristics of long-term care providers, the financing of long-term care, and public attitudes about various types of service providers. We also make projections of the number of older people who will receive long-term care in the future. By presenting these charts and accompanying text, we hope to provide a greater understanding of the need for long-term care in the United States, both now and in the future.

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## Introduction

The phrase “long-term care” encompasses a broad range of personal, social, and medical supports and services. People who need long-term care generally have lost, or never acquired, the ability to perform basic life functions or activities expected for their age. The types of conditions that may create a need for long-term care include mental retardation, chronic illness, cognitive or mental impairments, and physical frailty or disability. In order for a condition to be considered *long-term*, it usually must be expected to last for an extended period of time. Some researchers and policymakers consider a need for services that is expected to last three months or longer to constitute an indicator of the need for long-term care.

Many long-term care services are not paid for by our nation’s health care system, the primary function of which is to prevent and cure illness and treat life-threatening diseases and events. Over the past two decades, however, there has been a growing recognition of the need to develop and improve the long-term care system in the United States (U.S.). State and federal programs that serve people with long-term care needs have grown. Policymakers have worked to devise effective and affordable long-term care programs. Advocates have lobbied for the development of programs that rely less on institutional forms of care than on home- and community-based long-term care services.

In order to develop and implement effective long-term care public policies and programs, it is important to document the number and characteristics of people in the U.S. who receive long-term care, the types of services they receive, how they pay for these services, and what the demand for services is likely to be in the future. Because a growing number of individuals will have firsthand experience with the need for long-term care, either for themselves or for a member of their immediate family, our nation must be able to plan for its future long-term care needs.

This chartbook presents the most recently available data on the characteristics of people age 50 and older who receive long-term care. Unless otherwise noted, these data describe people who live in the community, and do not include people with disabilities who live in institutions. Because the need for long-term care tends to increase with age, some long-term care data were available only for the population age 65 and older. As a result, in some sections of the chartbook, our focus is more narrow.

There are numerous ways to characterize or define the need for long-term care. Some researchers use a very broad definition of disability, including all individuals who have physical, cognitive, or mental impairments, or who have difficulty performing a wide range of daily activities. While there is no single correct way to define either disability or the need for long-term care, the breadth of available data required the authors to narrow the scope of the data included in this publication. In this chartbook, the primary focus is on persons with moderate to severe levels of disability because such individuals are at greatest risk of needing long-term care services. The needs and characteristics of people with lower levels of disability are not generally addressed here.

For example, some people have *difficulty* performing certain activities, such as bathing, but they do not rely on others for assistance. Instead, they may bathe less frequently or in a more limited fashion. Other people may have physical *impairments*, such as a missing limb, but these impairments may not result in any activity limitation. For example, a person with a missing leg may walk independently with the aid of a prosthesis, or a person with a missing arm may have learned to perform many functions single-handedly. There is a complex interplay of impairments, limitations, and disabilities that may result in the need for long-term care services.

The focus of this chartbook is on individuals who *receive help* with basic life activities – often called Activities of Daily Living (ADLs). There is some variation in what activities researchers include as ADLs. In the primary database used for this chartbook, ADLs include:

- eating;
- bathing;
- dressing;
- toileting; and
- getting in or out of a bed or chair (transferring).

In general, “receiving help” is defined in this chartbook to include not just actual hands-on assistance, but supervision or cueing, as well. This distinction is especially important for people with cognitive impairments who may be physically able to perform certain activities, but only do so if they are “cued” or reminded about how and when to perform those activities.

People who receive help with two or more ADLs often are considered to be severely disabled. For example, recent federal legislation established standards that long-term care expenses and insurance policies must meet to qualify for favorable tax treatment. This legislation uses disability in two ADLs as one of its primary eligibility criteria. Wherever possible, this chartbook includes data on people age 50 and older who receive help with two or more of the five ADLs listed above. However, in some cases we also include data on people with more moderate disabilities – that is, people who receive help with any ADL or with Instrumental Activities of Daily Living (IADLs). IADLs are more complex life activities that also are used to measure disability. In the primary database used in this chartbook, IADLs include:

- meal preparation;
- shopping;
- managing money;
- using the telephone;
- doing heavy work around the house; and
- doing light work around the house.

Such data can provide a broader view of disability in the U.S. More detailed descriptions of the major sources of data used, the definition of terms, and the methods used to generate data are contained in the Technical Appendix.

Our overall goal is to present an accurate and realistic picture of the population that receives help with long-term care in the U.S. Because there is considerable unmet need for long-term care services in the U.S., this chartbook does not fully describe the characteristics of all who may *need* help, but fail to receive it. Although a description of the *need* for long-term care would present a more complete picture, data are more readily available for people who actually *receive* help with their long-term care needs. While the intent of this chartbook is to shed new light on the characteristics of mid-life and older Americans with disabilities who receive help, we have attempted to round out our description of the long-term care landscape by including data on the characteristics of long-term care providers, the methods of financing long-term care, and public preferences for various long-term care options.

## Part I

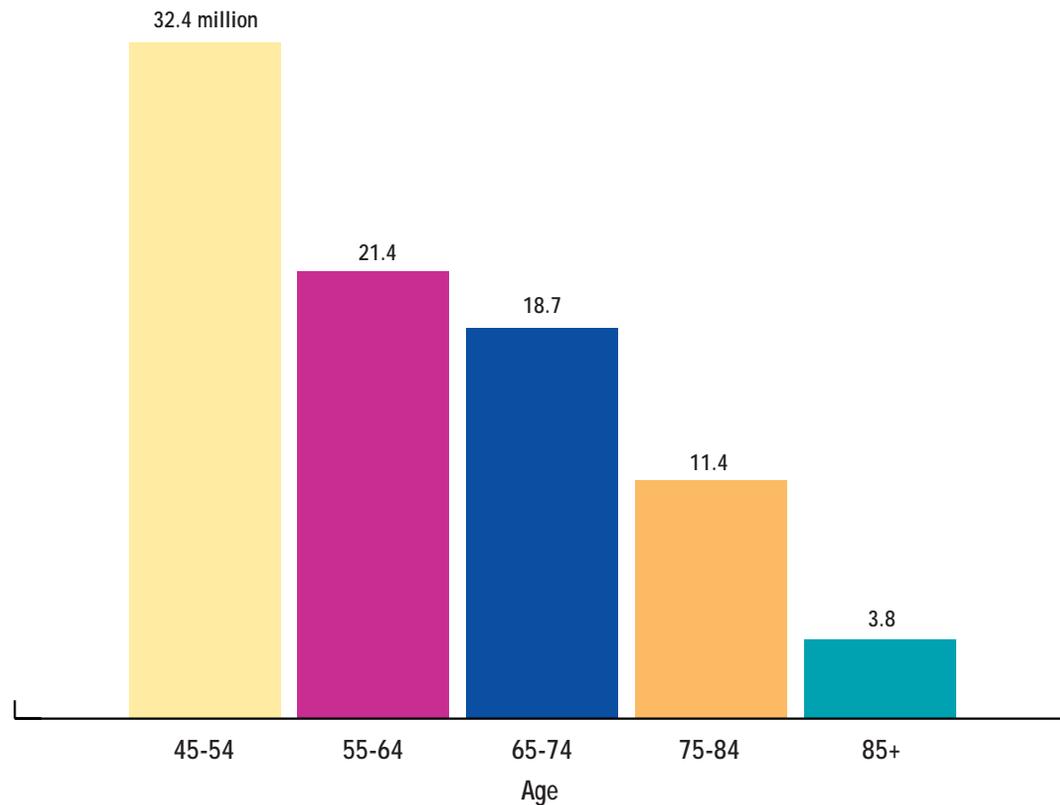
### General Profile

#### Introduction

We live in an aging society. With the maturing of the baby boom generation, the ranks of mid-life and older Americans will grow to all-time highs. This trend, accompanied by advances in medical technology and improved health status, is expected to result in unprecedented numbers of people who live to advanced age. We can gain a better understanding of how these trends will affect the need for long-term care in the U.S. by examining the context in which they are taking place. Consider the following facts:

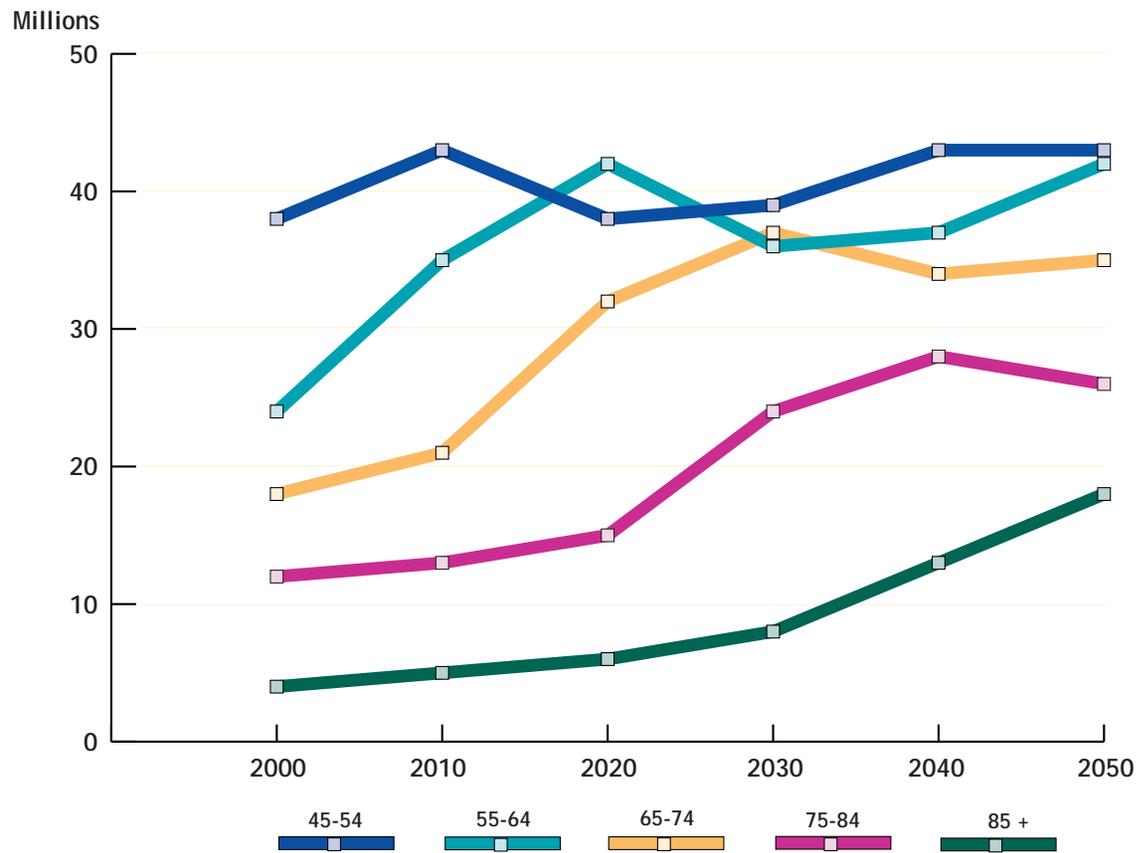
- Women currently outlive men, a trend that is expected to continue. Yet, despite their greater longevity, women are more likely, at every age, to have a disability.
- People with disabilities are much more likely to have low incomes than the general population.
- Minority populations are expected to grow rapidly over the next half century. This trend will affect the demand for long-term care because the prevalence of disability among African-Americans and people of Hispanic origin is higher than among whites.
- People with disabilities are less likely to live with a spouse but more likely to live with others than the general population age 50 and older.
- People age 85 and older have the highest rates of disability. The proportion of the population age 85 and older is expected to grow from 1.6 percent in the year 2000 to 2.1 percent in the year 2025 – a 31 percent increase.

**Figure I-1**  
Population Age 45+, by Age, 1996



There are 87.7 million people age 45 and older in the U.S. (including people living in institutions). Of these, some 33.9 million are age 65 and older, and nearly 3.8 million are age 85 and older.

**Figure I-2**  
 Projected Population Age 45+, by Age: 2000-2050



The aging of the baby boom generation, combined with improvements in health and increased longevity are expected to fuel a major expansion of the mid-life and older population over the next half century. The population age 45 to 54 is expected to remain relatively stable, increasing from 37 million in 2000 to 43 million in 2050. The population age 55 to 64 is projected to grow more substantially – from 24 million in 2000 to 42 million in 2050. Growth in the older populations is expected to be even more dramatic: the population age 65 to 74 will nearly double – from 18 million in 2000 to 35 million in 2050; the population age 75 to 84 will more than double – from 12 million in 2000 to 26 million in 2050. By far, the most dramatic rate of growth is projected for the population age 85 and older. It is estimated to more than quadruple, from 4 million in 2000 to 18 million in 2050. Because the prevalence of disability increases with age, these population trends have important implications for our nation’s future long-term care needs. These projections include the institutionalized population.

Source: U.S. Bureau of the Census, *Current Population Reports*, P25-1130 (Middle Series of Projections).

**Table I-1**

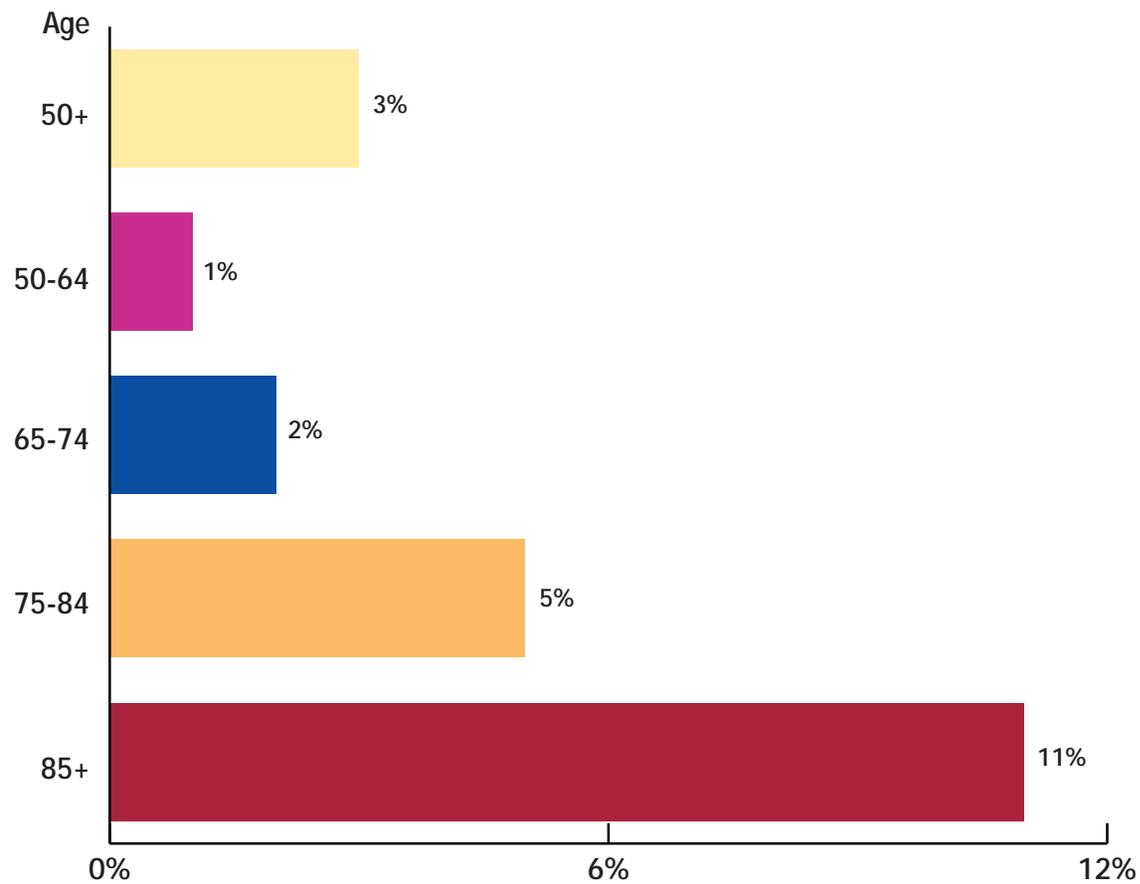
Number of People Receiving Help with ADLs and IADLs, by Degree of Disability, 1994

Age	1+ ADLs	2+ ADLs	3+ ADLs	Any ADL or IADL
50-64	615,000	394,000	231,000	2,879,000
65-74	572,000	366,000	241,000	2,529,000
75-85	832,000	538,000	339,000	2,704,000
85+	513,000	297,000	204,000	1,347,000
<b>Total</b>	<b>2,532,000</b>	<b>1,595,000</b>	<b>1,015,000</b>	<b>9,459,000</b>

In a broad view of disability, close to 9.5 million people age 50 and older receive help with any ADL or IADL. However, just under 1.6 million people age 50 and older receive help with two or more (out of five) ADLs. Because there are fewer people at the oldest ages, the number of people with disabilities tends to decline somewhat with age.

### Figure I-3

Percent of Population Age 50+ Receiving Help with 2+ ADLs, by Age, 1994

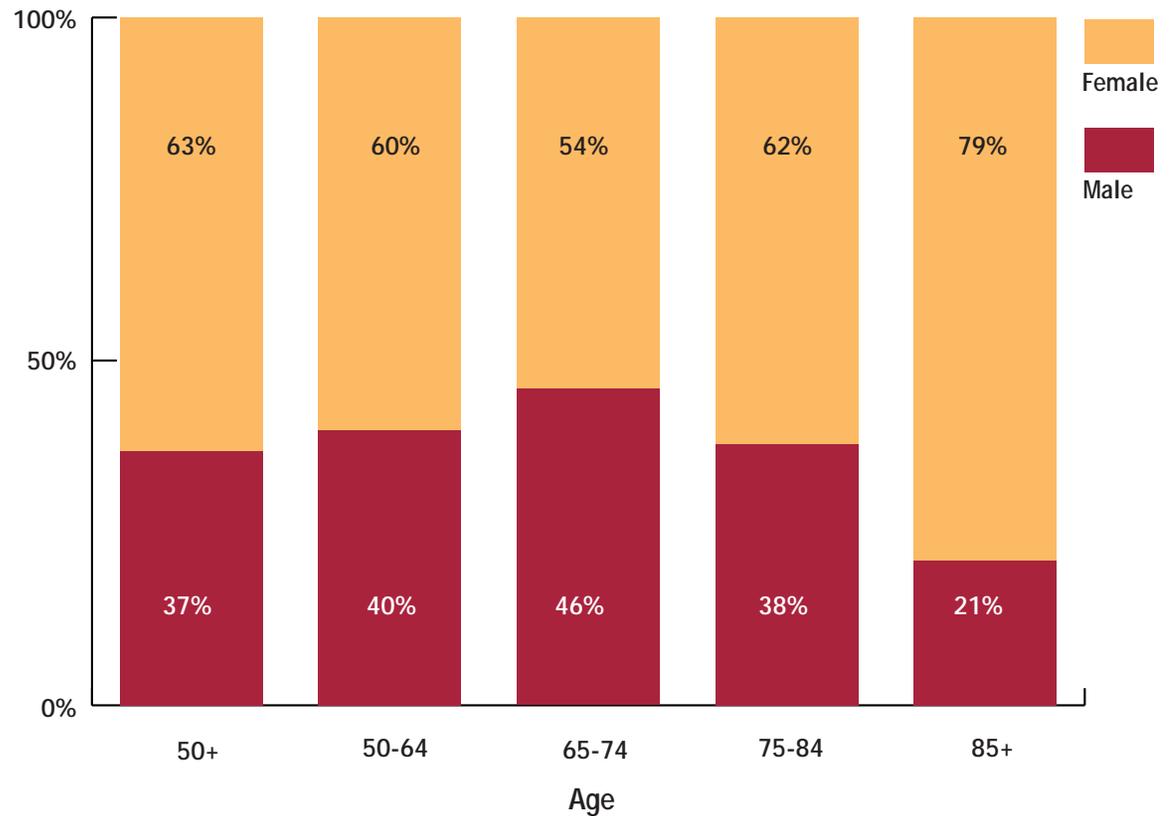


The prevalence of disability increases sharply with advancing age. Of the nearly 65 million people age 50 and older, close to 1.6 million receive help with two or more ADLs. This means that only 3 percent of the total population age 50 and older receive help with two or more ADLs. However, among those age 85 and older, 11 percent receive help with two or more ADLs.

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.

**Figure I-4**

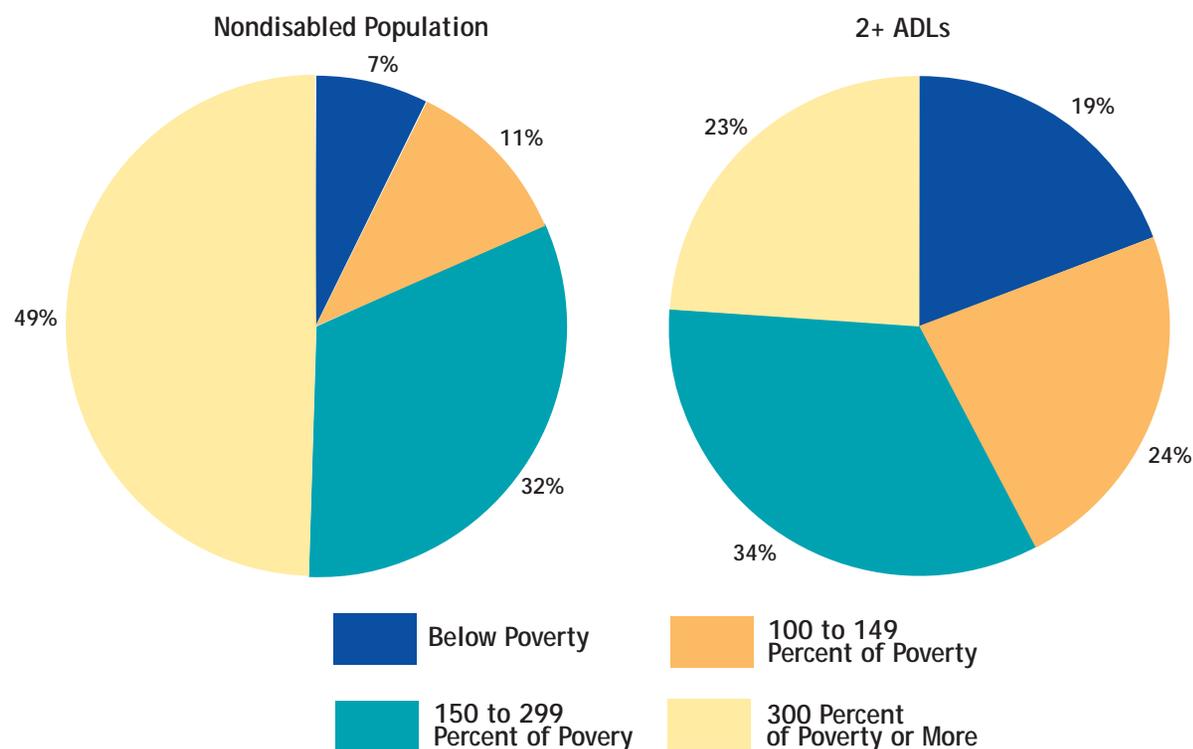
Gender Distribution of People Age 50+ Receiving Help with 2+ ADLs, by Age, 1994



Women constitute about 55 percent of the population age 50 and older. Because women as a group live longer than men, 72 percent of the population age 85 and older is female. Despite women's greater longevity, they are more likely than men to have disabilities. Although with increasing age, both men and women are more likely to need help with ADLs, women are more likely than men to need help at every age.

## Figure I-5

### Income Distribution Among the Population Age 50+, by Disability Status, 1994

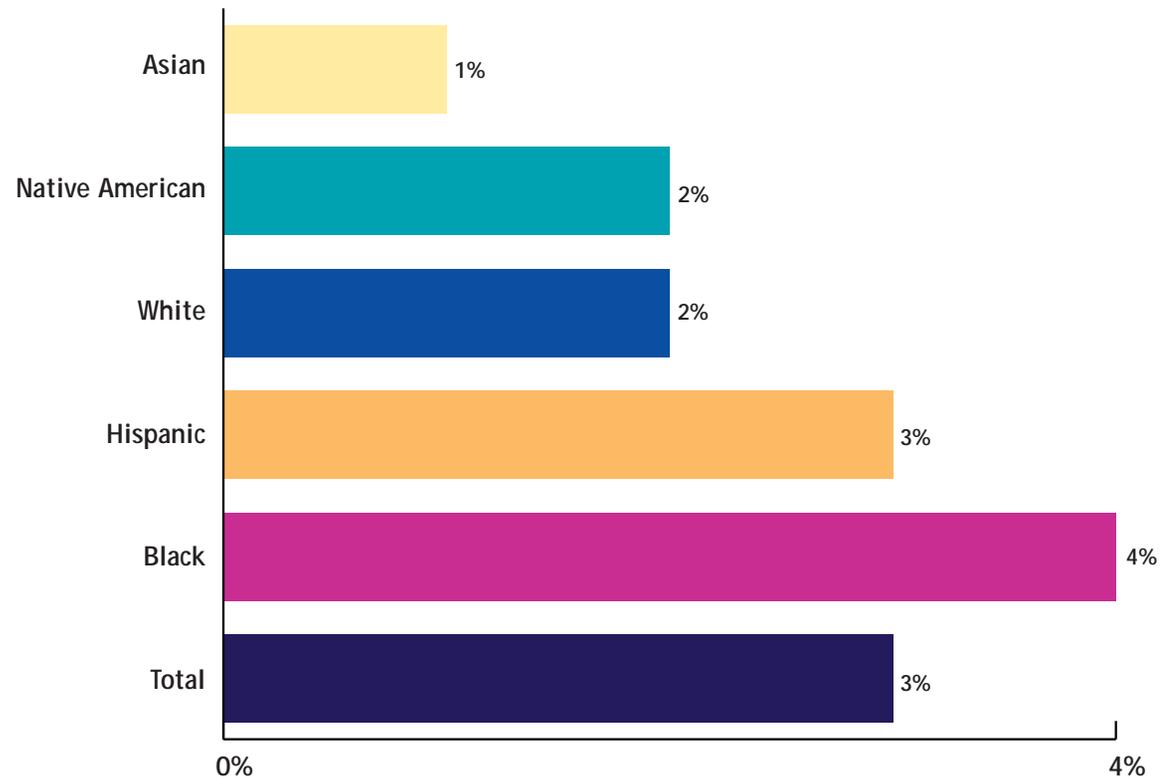


This figure illustrates the dramatic difference in income distribution between people age 50 and older with disabilities and those without disabilities. While 7 percent of the nondisabled population age 50 and older has an income below the poverty level, 19 percent of people who receive help with two or more ADLs have below-poverty incomes. Conversely, 49 percent of the nondisabled population age 50 and older has income at or above 300 percent of poverty, whereas only 23 percent of the population receiving help with two or more ADLs has income at this level. In 1998, the federal poverty level for a single individual is \$8,050 per year in the continental U.S.

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.  
Note: Numbers do not add to 100% due to rounding.

**Figure I-6**

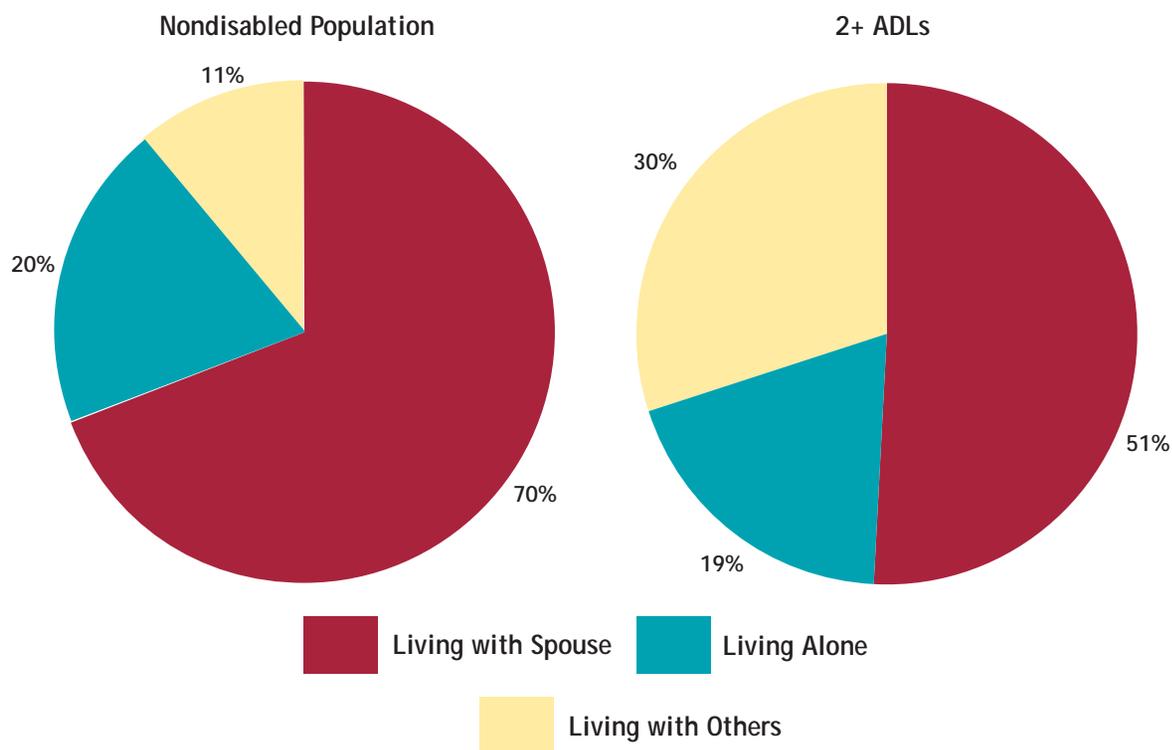
Percent of People Age 50+ Receiving Help with 2+ ADLs, by Race/Ethnicity, 1994



For the age 50 and older population, receiving help with two or more ADLs is more prevalent among African Americans and persons of Hispanic origin than among the white population. Receiving help with two or more ADLs is least prevalent among Asian Americans.

## Figure I-7

Distribution of the Population Age 50+, by Living Arrangement and Disability Status, 1994



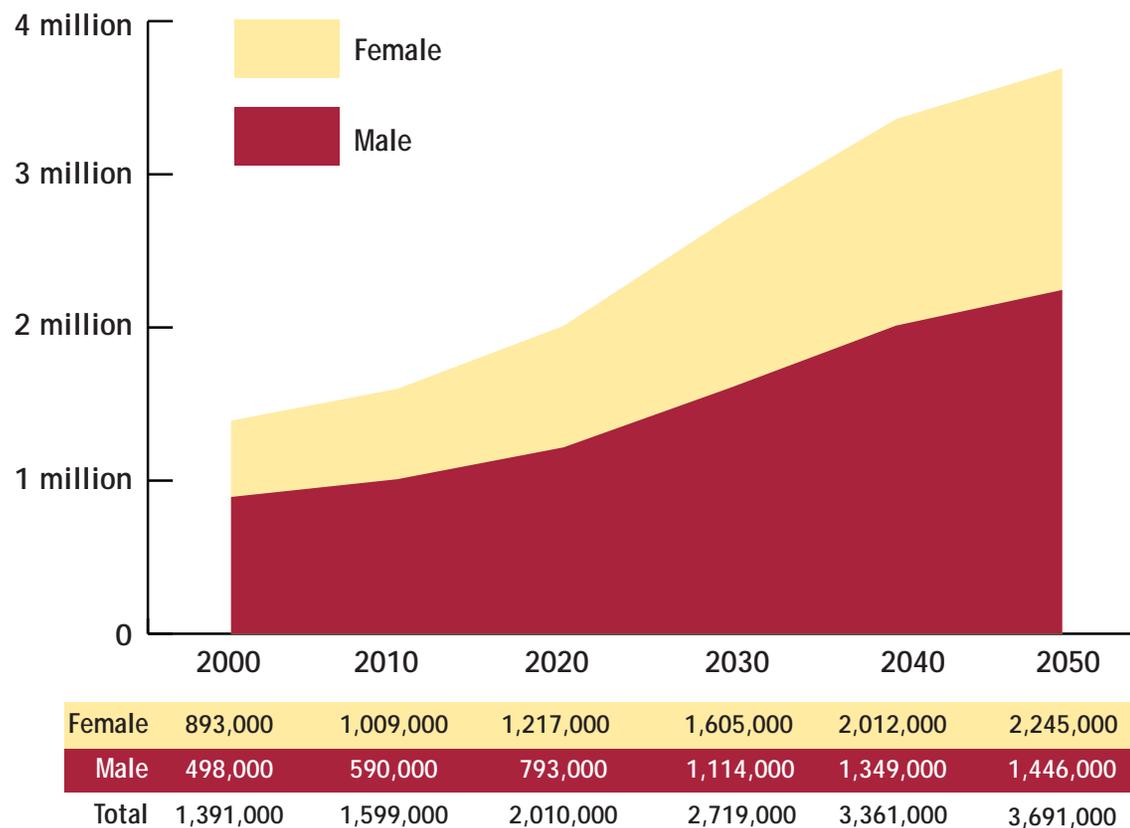
This figure compares the living arrangements of people age 50 and older who receive help with two or more ADLs to those of the nondisabled population. People with disabilities are less likely than the population age 50 and older without disabilities to live with a spouse and are nearly three times as likely to live with others. These trends may result from people becoming disabled after outliving their spouses, and ultimately being unable to manage on their own.

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.  
Note: Numbers do not add to 100% due to rounding.

In order to plan for the future needs of an aging society, it is important to estimate the number of people who are likely to receive help with ADLs in the future. In this way, policymakers and program planners can take steps to improve programs and sources of payment for long-term care services. The total number of people who receive help with 2 or more ADLs is expected to nearly double, from 1.4 million in 2000 to 2.7 million in 2030, and growing to 3.7 million by 2050.

**Figure I-8**

Projected Population Age 65+ Receiving Help with 2+ ADLs, 2000-2050



## **Introduction**

In this section, disability is measured by reporting the number of people who receive help, or need supervision or cueing to perform basic life activities. The term “receives help” is used to include supervision or cueing, as well as hands-on help. For example, some people with cognitive impairments need supervision to prevent them from starting a fire or wandering off. Some people with physical limitations need to have someone nearby to prevent falls or other injuries. The need for cueing often is a factor for people who have cognitive or mental impairments. Such individuals may need prompts or reminders to complete activities on their own. For example, a man with Alzheimer’s disease may be physically capable of dressing, but need continual reminders to put his arm through the sleeve, put the button through the buttonhole, and so on.

## **Part II**

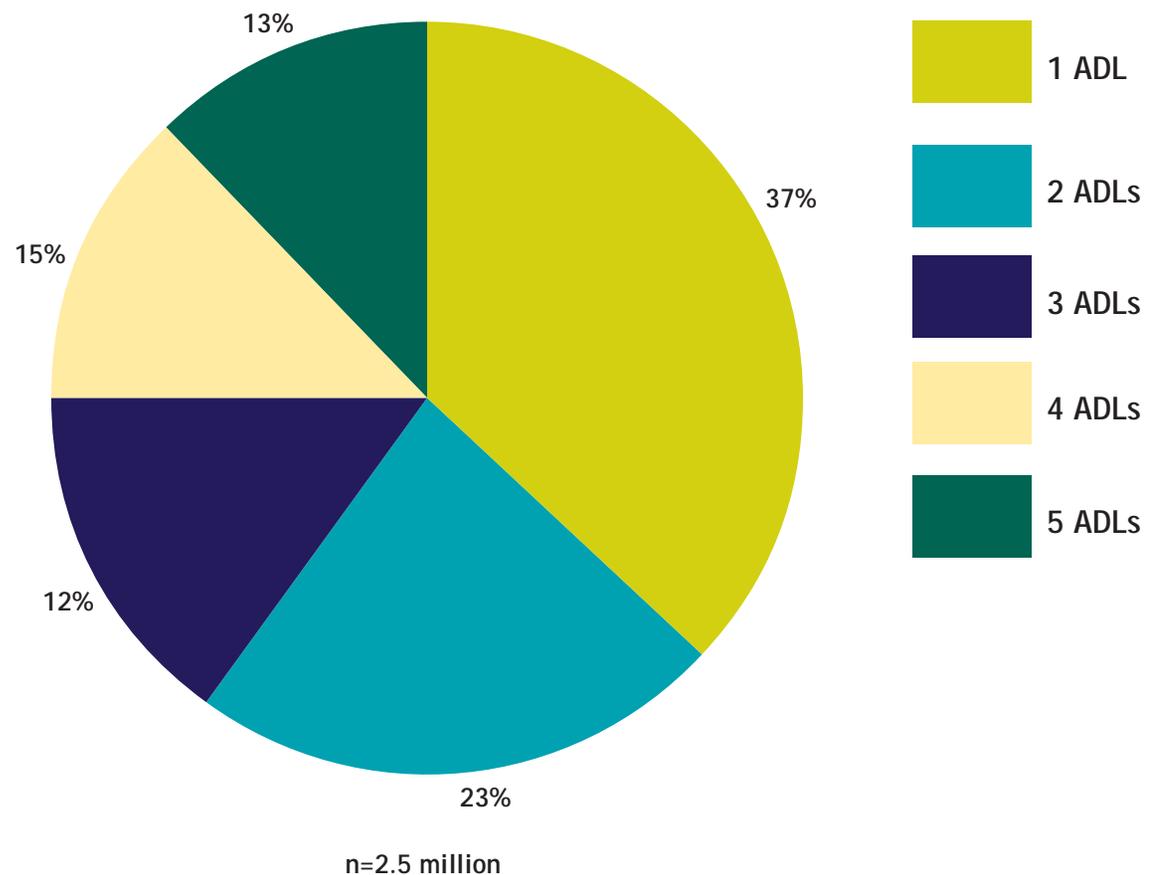
### **Disability Among People Age 50+**

**Figure II-1**

Distribution of People Age 50+ Receiving Help with ADLs, by Degree of Disability, 1994

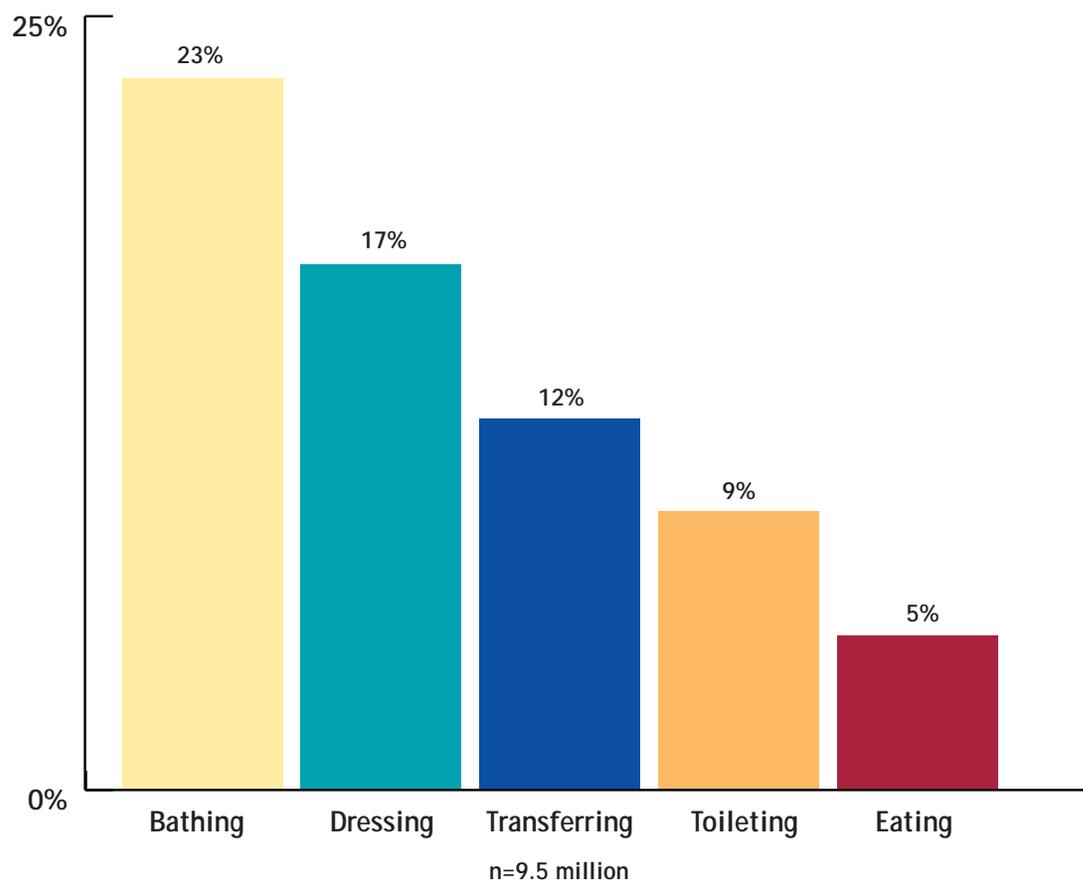
Of the nearly 9.5 million people age 50 and older who receive help with ADLs or IADLs, nearly three-fourths (6.9 million) are disabled in IADLs only. Of the 2.5 million people age 50 and older who are disabled in ADLs, this figure illustrates their distribution by the number of ADLs with which they receive help:

- 936,000 (37 percent) receive help with 1 ADL;
- 580,000 (23 percent) receive help with 2 ADLs;
- 315,000 (12 percent) receive help with 3 ADLs;
- 369,000 (15 percent) receive help with 4 ADLs;
- 332,000 (13 percent) receive help with 5 ADLs.



## Figure II-2

Percent of People Age 50+ Receiving Help with Any ADL or IADL, by Specific ADL, 1994



Among people who have disabilities, there are some ADLs with which help is received more frequently than others. Looking at the 9.5 million people age 50 and older who receive help with at least one ADL or IADL, this figure illustrates the percent who receive help with each of the five ADLs. To facilitate comparisons between the prevalence of receiving help with ADLs and IADLs, figures II-2 and II-3 use a common population base – that is, the number of people who need help with any ADL or IADL.

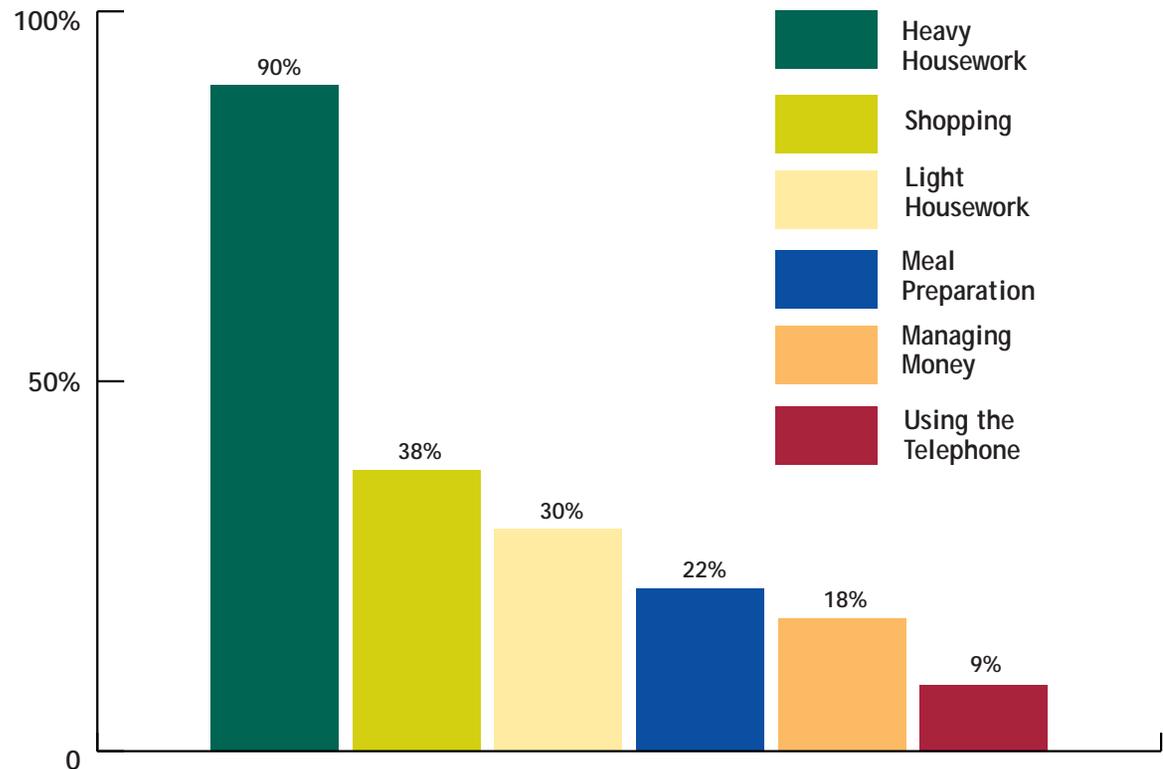
The ADL limitation with which help is most frequently received is bathing (23 percent). This is followed by receiving help with dressing (17 percent), transferring (12 percent) and toileting (9 percent). Receiving help with eating is least frequently reported (5 percent). (Some individuals receive help with more than one ADL and may be “double counted” on this chart.)

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.

**Figure II-3**

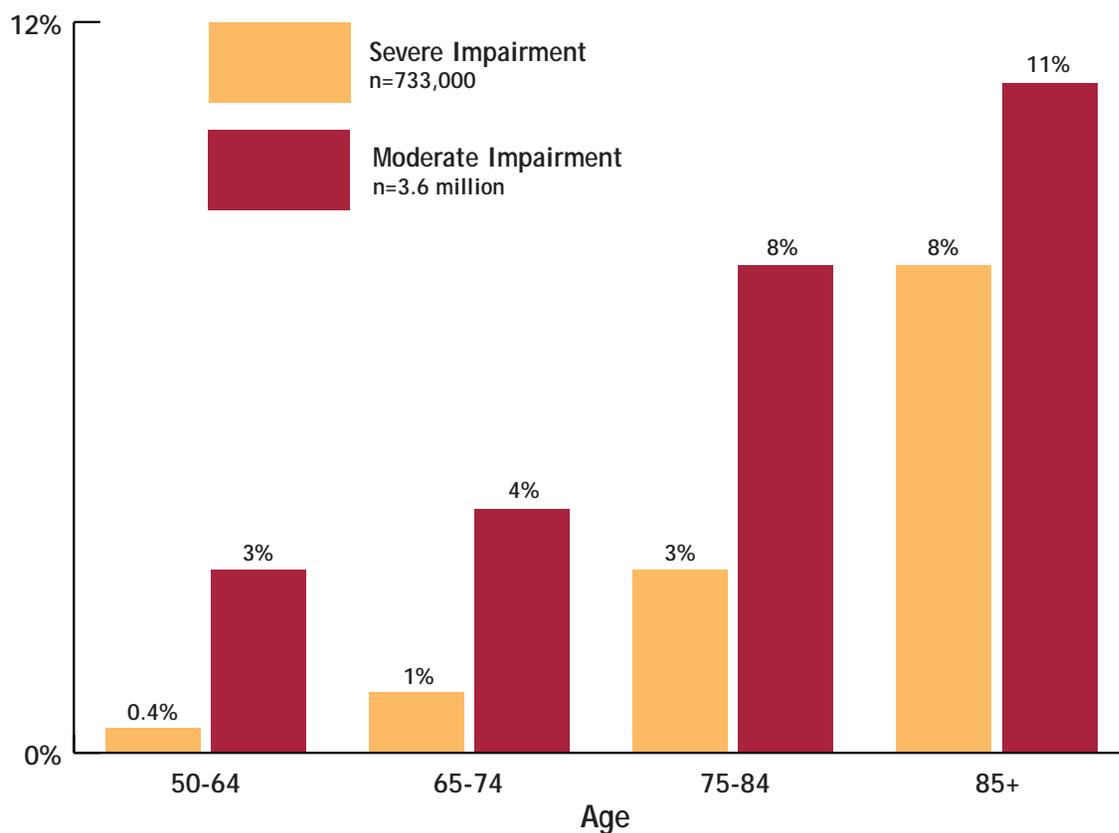
Percent of People Age 50+ Receiving Help with Any ADL or IADL, by Specific IADL, 1994

In general, among people who have functional limitations, it is more common to receive help with IADLs than with ADLs. There are 9.5 million people age 50 and older who receive help with at least one ADL or IADL. The percent of these individuals receiving help with each of the six IADLs is shown in this figure. Receiving help with heavy housework (90 percent), shopping (38 percent), and light housework (30 percent) are most common. Help is received less frequently with meal preparation (22 percent), managing money (18 percent), and using the telephone (9 percent). (Some individuals receive help with more than one IADL and may be “double counted” on this chart.)



## Figure II-4

Percent of People Age 50+ with Cognitive Impairment, by Severity of Impairment and Age, 1994

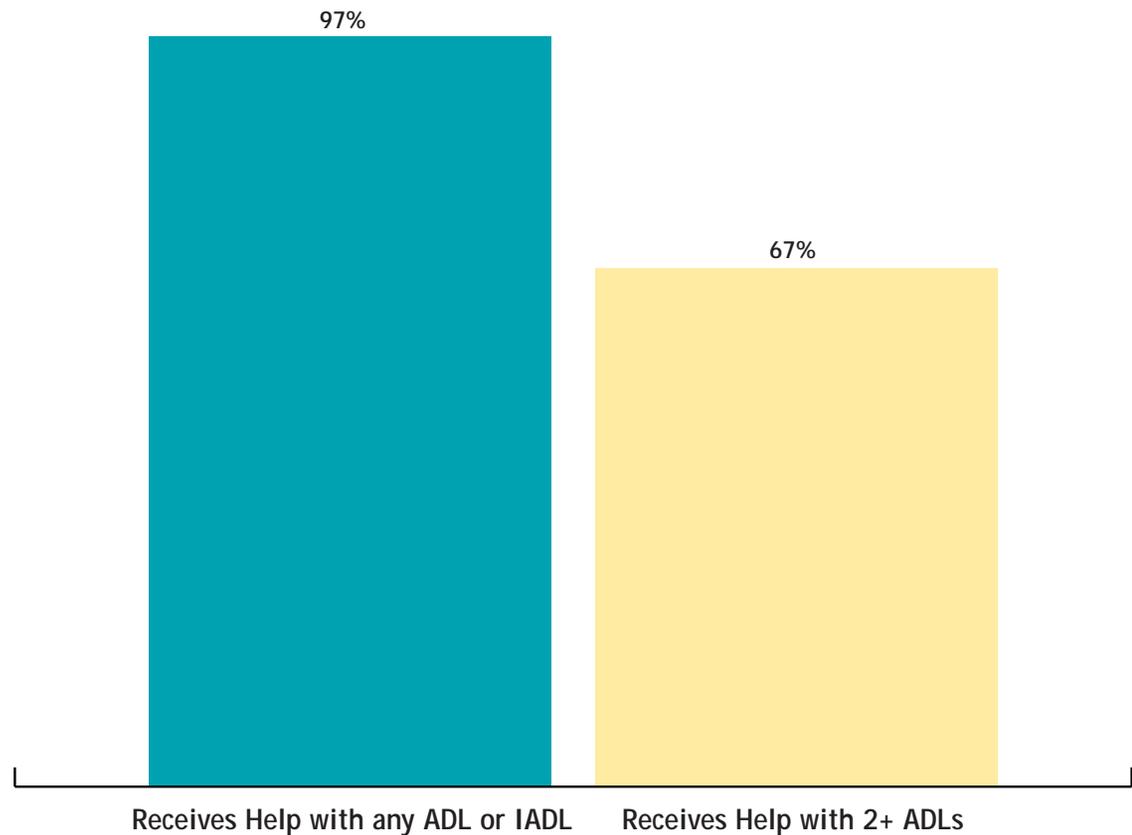


One of the major reasons that people need long-term care services is because they are cognitively impaired. Cognitive impairment can result from conditions such as Alzheimer's disease, brain injury, or mental retardation. People who have difficulty remembering things, processing information, and reasoning can need supervision, cueing, or reminding to perform basic life activities. The measurement of cognitive impairment is a highly complex process. The measures used greatly affect estimates of the size and characteristics of the population with cognitive impairments. Under one method of estimation prepared for AARP by The Lewin Group, some 3.6 million people age 50 and older have cognitive impairments; however, only 733,000 of these individuals are classified as having "severe" cognitive impairments. This figure shows that the prevalence of cognitive impairment rises dramatically with increasing age.

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.

## Figure II-5

Percent of People Age 50+ with Severe Cognitive Impairments Receiving Help with ADLs/IADLs, 1994



Cognitive impairments can affect an individual's ability to perform ADLs and IADLs. The percent of persons age 50 and older with severe cognitive impairments who receive help with any ADL or IADL, and the percent who receive help with two or more ADLs are shown in this figure.

## **Introduction**

There is an overwhelming preference among people with disabilities and their families to remain in their own homes for as long as possible. The majority of people with disabilities do not live in institutions and are able to remain in their homes and communities. Most community-based long-term care is provided by family members and friends. This kind of informal (unpaid) caregiving includes help provided to people who have physical, cognitive, or mental disabilities.

People with disabilities may not live with their caregivers, but they often have children or friends who live nearby and help with activities like shopping, meal preparation, bill paying, and home maintenance. Most informal caregivers are women, either adult daughters or wives. Caregiving activities can place physical, emotional, and financial burdens on informal caregivers.

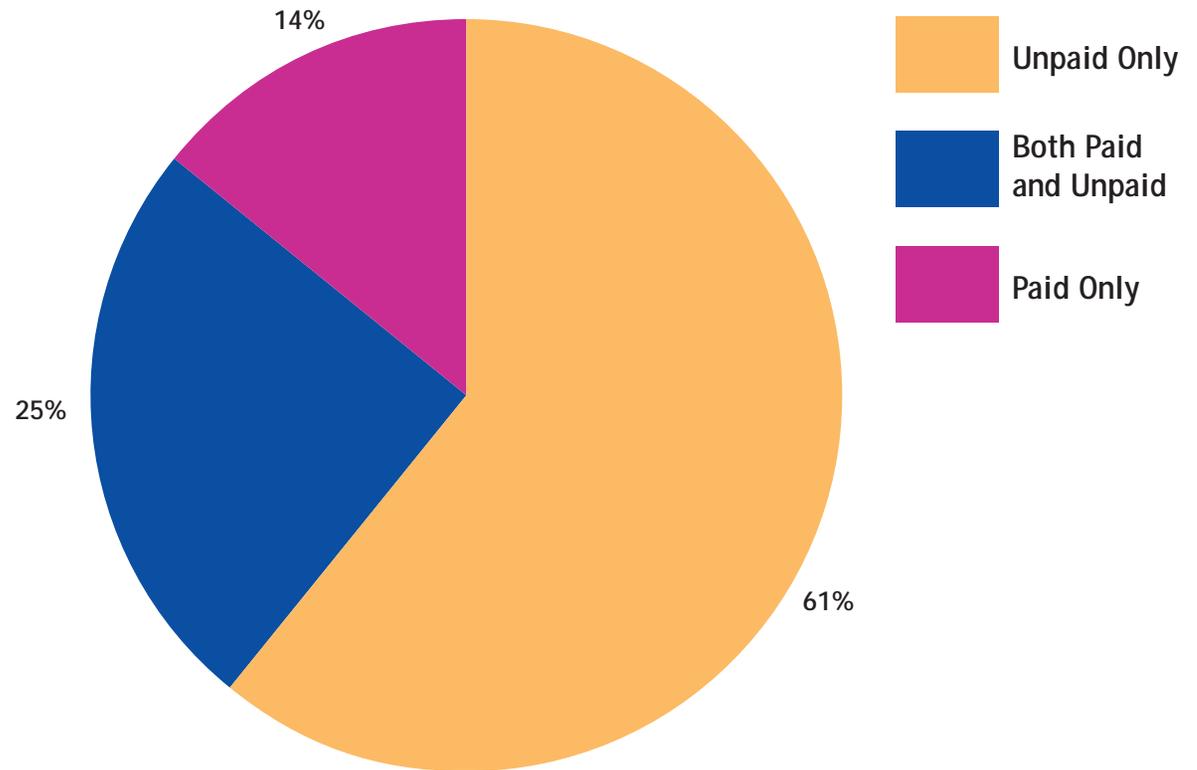
Some people with disabilities use paid caregivers either to supplement informal caregiving or as an alternative to relying on family members or friends. Also called “formal” caregivers, these paid caregivers may be hired independently or through home care agencies. Some home care services are provided by public programs, such as Medicare, Medicaid, or the Older Americans Act. Paid caregivers often provide personal care (such as help with bathing and dressing) and more skilled care, such as nursing services. Some people with disabilities also use paid caregivers to help with tasks like housekeeping.

## **Part III**

### **Availability of Help in the Community**

**Figure III-1**

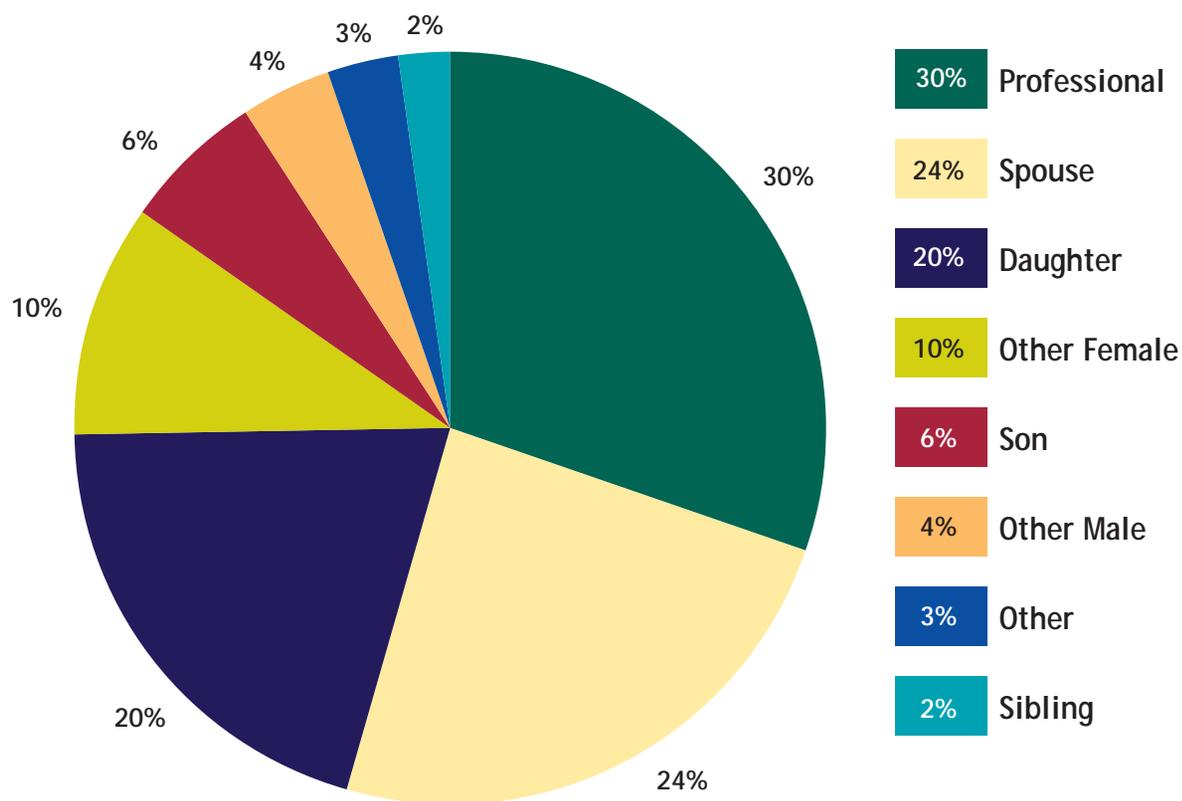
Distribution of People Age 50+ Receiving Help with 2+ ADLs, by Type of Assistance Received, 1994



Among people age 50 and older who live in the community and receive help with two or more ADLs, the majority (61 percent) receive help only from unpaid caregivers. These family members and friends shoulder the main responsibility for caregiving, even among people with severe disabilities. Twenty-five percent of people age 50 and older who get help with two or more ADLs receive both formal (paid) and informal help, and 14 percent receive formal help only.

**Figure III-2**

Distribution of Caregivers Who Help People Age 65+ with ADLs, by Relationship of Caregiver to Recipient, 1994



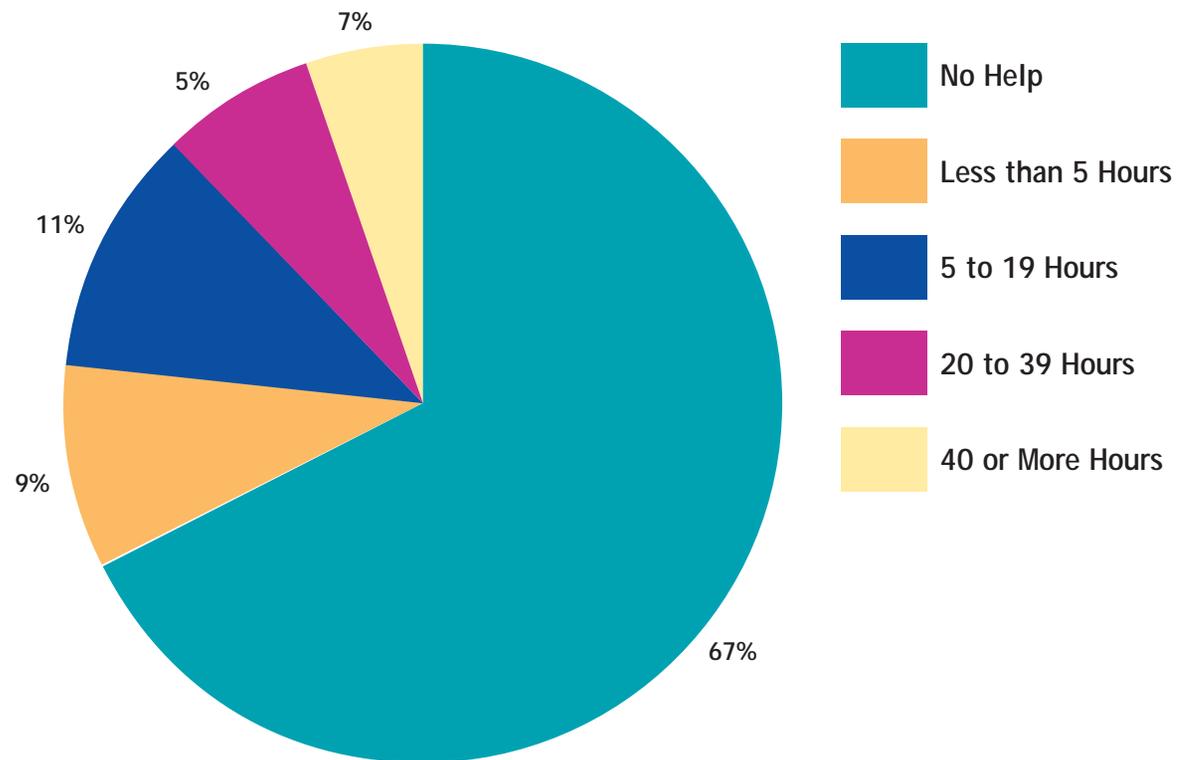
Many types of caregivers help people age 65 and over with at least one ADL. While professional caregivers constitute the largest single category of caregivers (30 percent), spouses (24 percent) and daughters (20 percent) are the two largest categories of informal caregivers.

Source: The Lewin Group Analysis of the 1994 National Long-Term Care Survey.  
Note: All caregivers are included, not just primary caregivers. Numbers do not add to 100% due to rounding.

### Figure III-3

Distribution of People Age 65+ Receiving Help with 2+ ADLs, by Number of Hours per Week of Formal (Paid) Help with ADLs, 1994

Even people who receive help with two or more ADLs generally receive relatively few hours per week of formal (paid) care. More than two-thirds (67 percent) receive no paid help with ADLs. There are several reasons that people with long-term care needs tend to rely on informal sources of care. Some people simply prefer to receive help from family members or friends. For others, the cost of purchasing formal home care can be prohibitive. The demand for public programs that provide home care services often exceeds the supply. Moreover, public programs generally have specific eligibility criteria – functional, financial, or both. These criteria may be difficult to meet for some people who need services.



## Part IV

### Characteristics of Home Health Recipients

#### Introduction

People who receive formal home health services represent a subset of all people with long-term care needs. Although the majority of people with disabilities who live in the community depends entirely on informal sources of help, a growing number of people are receiving help from paid caregivers. While some people with disabilities pay caregivers whom they locate and hire on their own, most formal care is provided through home care agencies. The most readily available source of data on formal home care services comes from home health agencies. These agencies can provide a combination of skilled nursing services, personal care (such as help with bathing and dressing), housekeeping, and chore services.

People who receive services from a home health agency may be more disabled, have a greater need for skilled medical services, or have less access to informal caregivers than people who receive informal services only. Since 1990, there has been a rapid growth in the use of the Medicare home health benefit, which currently pays for close to half of all home health care in the U.S. The use of home healthcare has increased for a number of reasons, including: an effort to control health care costs by decreasing the length of hospital stays; decreased use of nursing homes; growth in the older population; and a preference for receiving care at home. According to Haupt's 1998 analysis of the 1996 National Home and Hospice Care Survey (NHHCS):

- the number of home health and hospice care agencies in the U.S. increased from 8,000 in 1992 to 13,500 in 1996;
- ninety-eight percent of the people served were receiving home health care (and two percent were receiving hospice care); and
- the number of people served on a given day by these agencies grew from 1.3 million in 1992 to 2.5 million in 1996.

Of the people receiving home health services in 1996:

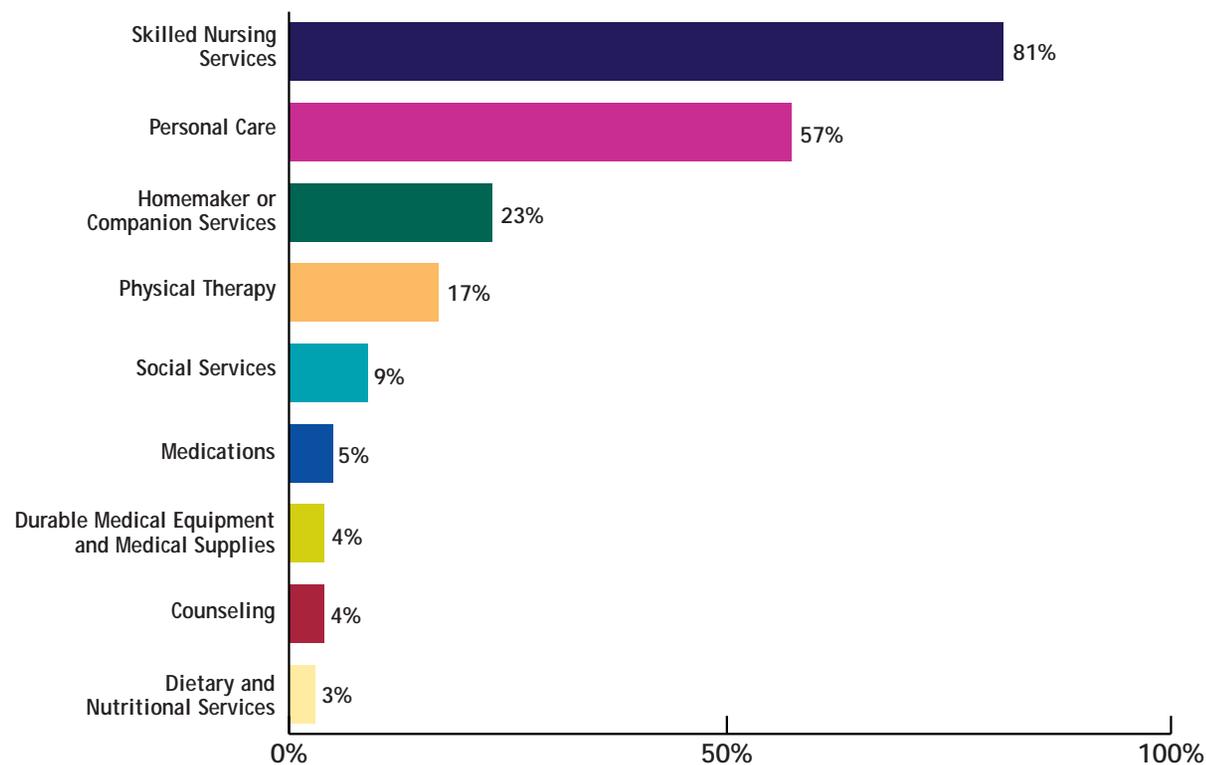
- two-thirds were female;
- seventy-two percent were age 65 and older and 14 percent were under 45 years of age;
- sixty-five percent were white;
- twenty-nine percent were married; and
- thirty-five percent were widowed.

- Thirty-one percent of home health recipients in 1996 had a surgical or diagnostic procedure related to their admission.
- Three-fourths of home health care recipients had two or more diagnoses when they were admitted to the agency.

The detailed data that follow were derived from the 1996 NHHCS, the most recently published, comprehensive data on the characteristics of home health care users age 65 and older. Detailed data are not available on the under-65 population. It should be noted that these data focus on help provided by *home health agencies* in relation to ADLs and IADLs and do not include help provided by other sources (Dey, 1996). While the five ADLs included in this survey (eating, bathing, dressing, transferring, and toileting) match those included in the National Health Interview Survey (NHIS) that are reported in other sections of this chartbook, there is a slight difference in the IADLs used. The NHHCS did *not* include doing heavy housework as an IADL but did include taking medications, which was not included as an IADL in the NHIS.

## Figure IV-1

### Percent of Home Health Recipients Age 65+ Receiving Specific Services, 1994

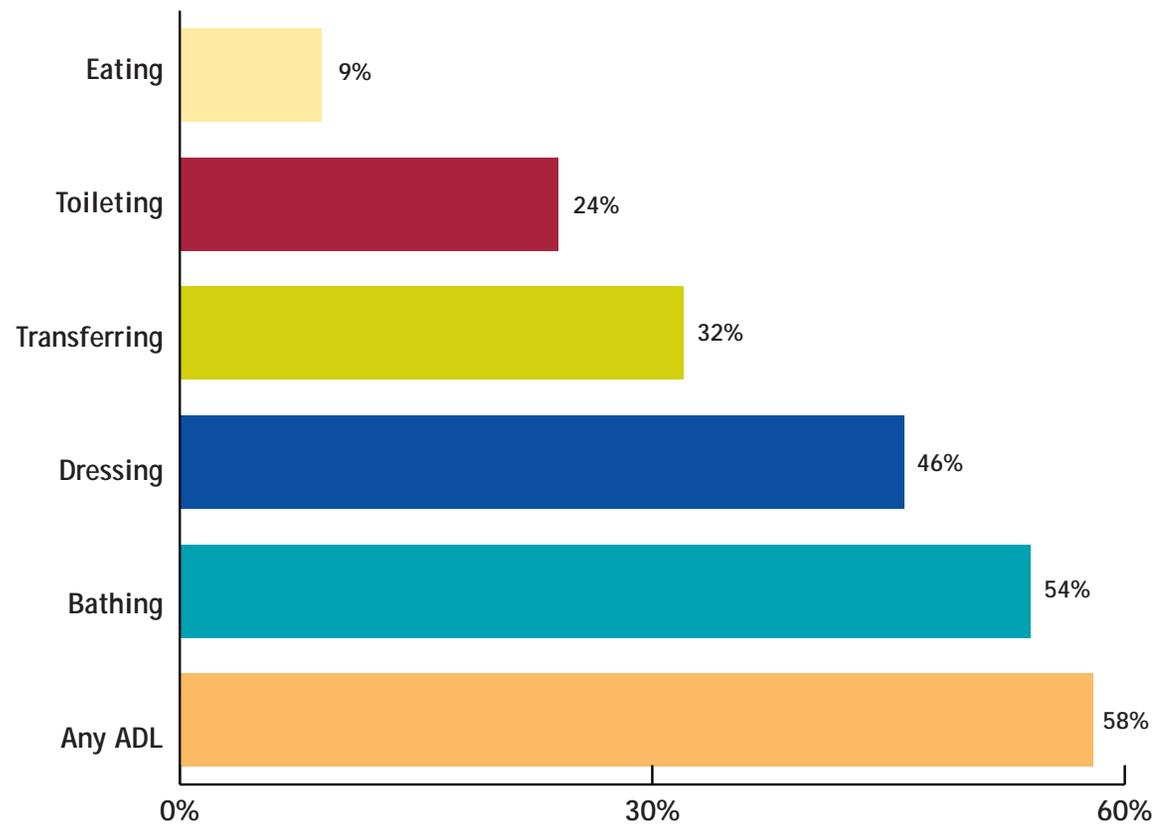


The service used most frequently by home health recipients age 65 and older is skilled nursing, used by 81 percent of recipients. Personal care services are the next most frequently used (57 percent of recipients). Other common services include homemaker/companion services and physical therapy. Less frequently used services include social services, administering medications, medical equipment and supplies, counseling, and dietary/nutritional services. The least frequently provided services (received by less than 3 percent of home health recipients) include transportation, meals on wheels, occupational, vocational, or speech therapy, physician care, or high-tech care such as intravenous therapy.

Source: Dey Achintya N. "Characteristics of Elderly Home Health Care Users: Data from the 1994 National Home and Hospice Care Survey," Advance Data Number 279, National Center for Health Statistics, September 26, 1996.

**Figure IV-2:**

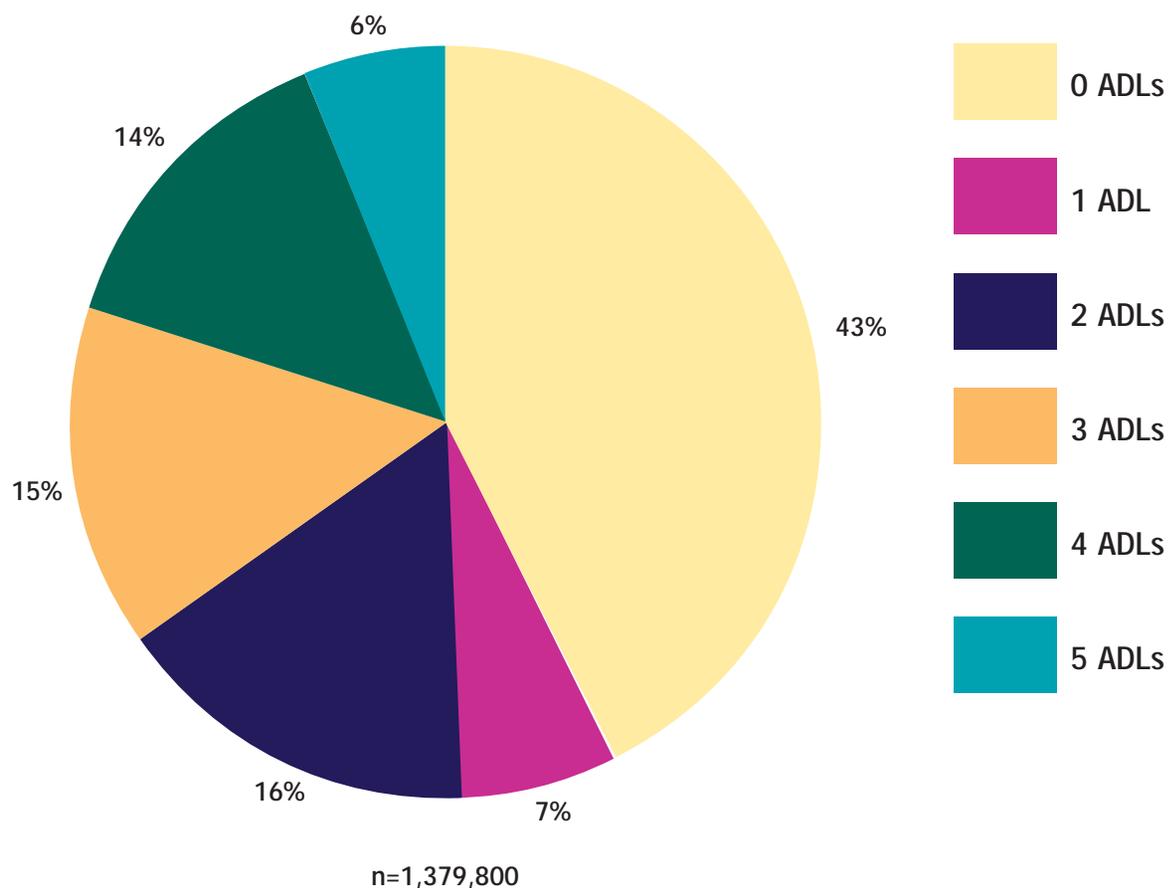
Percent of Home Health Recipients Age 65+ Receiving Help with Specific ADLs, 1994



Most home health recipients age 65 and older receive help with ADLs. Bathing is the ADL with which recipients receive help most frequently (54 percent); help with eating is received by only 9 percent of recipients.

### Figure IV-3

Distribution of Home Health Recipients Age 65+, by Number of ADLs for Which Help Is Received, 1994



While many home health recipients age 65 and older receive help with ADLs, about two-fifths (43 percent) do not receive help with any ADLs. It is likely that these individuals receive more medically oriented services such as skilled nursing or physical therapy.

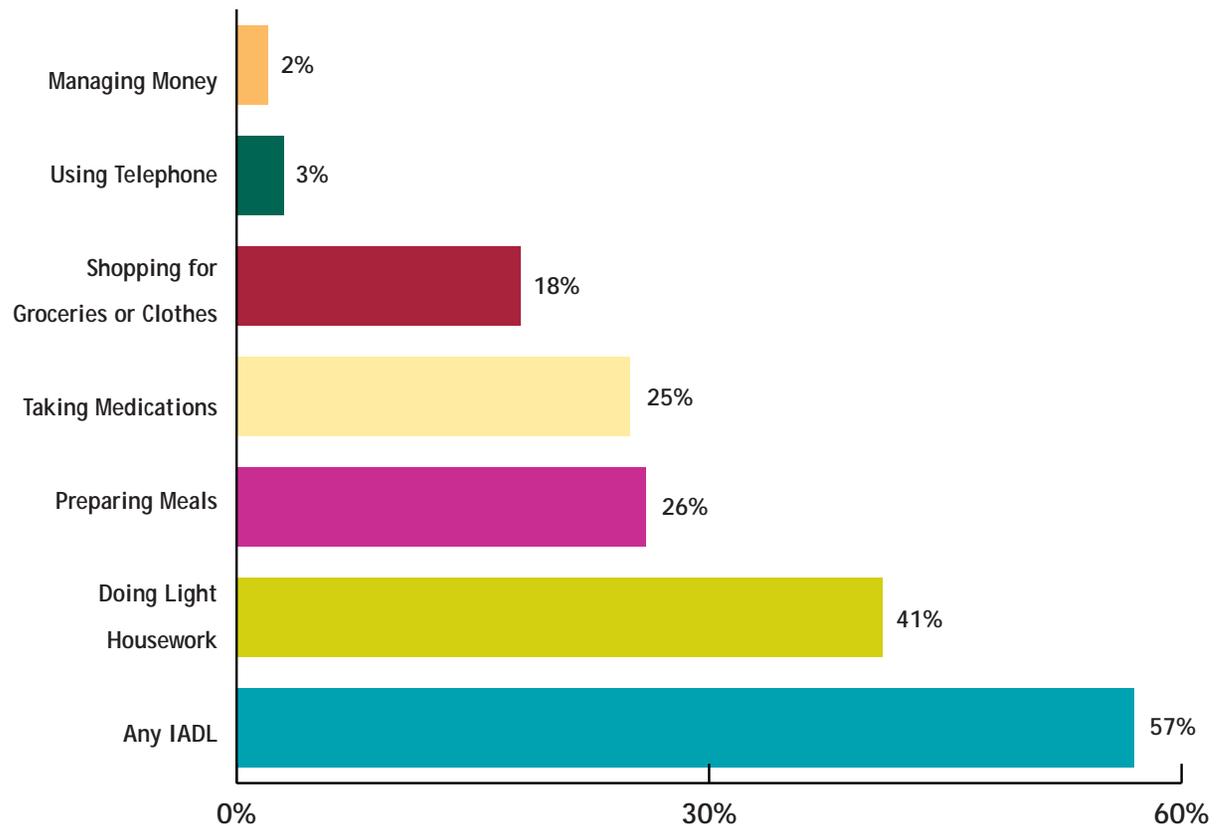
Source: Dey Achintya N. "Characteristics of Elderly Home Health Care Users: Data from the 1994 National Home and Hospice Care Survey," Advance Data Number 279, National Center for Health Statistics, September 26, 1996.

Note: Numbers do not add to 100% due to rounding.

Many home health recipients age 65 and older also receive help with IADLs: 57 percent receive help with at least one IADL. Help with light housework is the IADL with which recipients receive help most frequently (41 percent). Managing money is the IADL with which recipients receive help least frequently from a home health agency (2 percent). It is possible that money management is provided more frequently by family members or other types of social service agencies, rather than home health agencies.

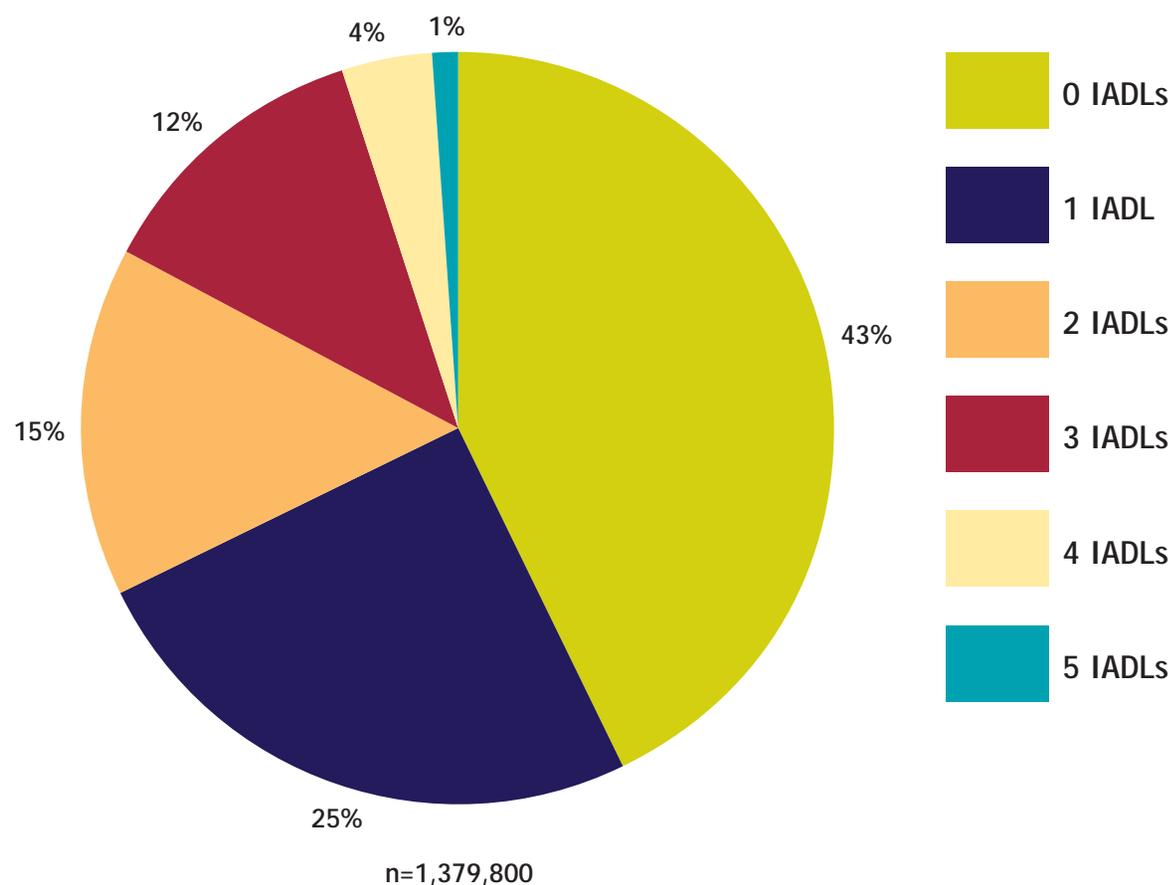
### Figure IV-4

Percent of Home Health Recipients Age 65+ Receiving Help with Specific IADLs, 1994



**Figure IV-5**

Distribution of Home Health Recipients Age 65+, by Number of IADLs for Which Help Is Received, 1994



As with ADLs, a significant proportion of older home health recipients (43 percent) do not receive any IADL help. However, it must be remembered that many people rely on home health agencies to provide skilled medical care; they may receive *unskilled care*, such as help with IADLs, from family members or friends.

Source: Dey Achintya N. "Characteristics of Elderly Home Health Care Users: Data from the 1994 National Home and Hospice Care Survey," Advance Data Number 279, National Center for Health Statistics, September 26, 1996.

## Part V Characteristics of Nursing Home Residents

### Introduction

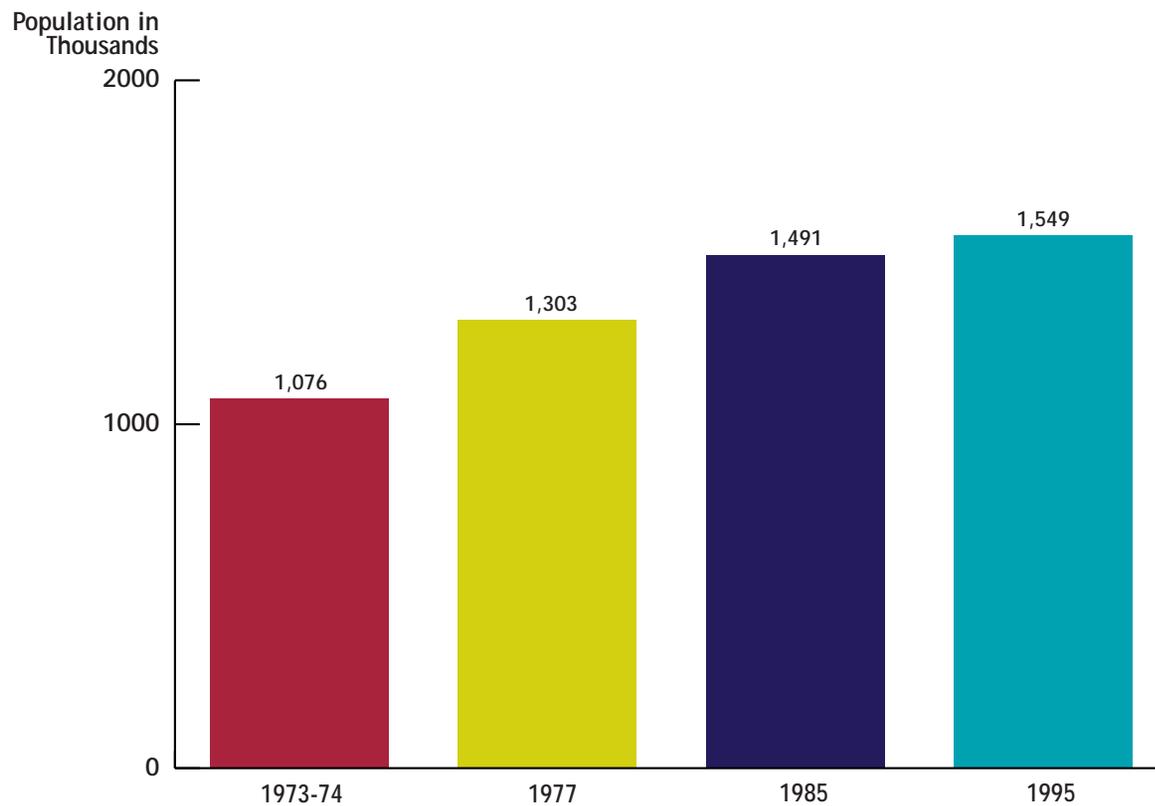
Many people automatically think of nursing homes when they hear the term “long-term care.” However, most people prefer to remain in their own homes for as long as possible, and the desire to avoid nursing homes drives much of the public concern about long-term care. Because the likelihood of needing nursing home care increases dramatically with age, the data in this section concentrate on the population age 65 and older. Little detailed information is available about the characteristics of nursing home residents under age 65.

In 1995, about 1.3 percent of people age 65 to 74 lived in nursing homes, compared to 5.2 percent of people age 75 to 84, and 15.2 percent of people age 85 and older.\* Although only about 4 percent of the population age 65 and older reside in a nursing home at any point in time, the lifetime risk of needing nursing home care is considerably higher. While estimates vary, one source places the *lifetime* risk of institutionalization for those reaching age 65 in 1990 at 43 percent – 52 percent for women and 33 percent for men (Kemper and Murtaugh, 1991). However, research has shown that most nursing home admissions are of relatively short duration – three of four are for less than one year (Liu et al., 1991).

In addition to being very old (typically age 75 and older), nursing home residents are predominantly female (72 percent) and white (88 percent). Cognitive impairments are widespread among nursing home residents. According to data from the 1996 Medical Expenditure Panel Survey (MEPS), nearly half (48 percent) of nursing home residents have some form of dementia (Krauss, et al., 1997).

The charts that follow provide detailed data on the characteristics of nursing home residents. All data in this section are derived from Dey’s and Strahan’s 1997 analyses of the 1995 National Nursing Home Survey (NNHS).

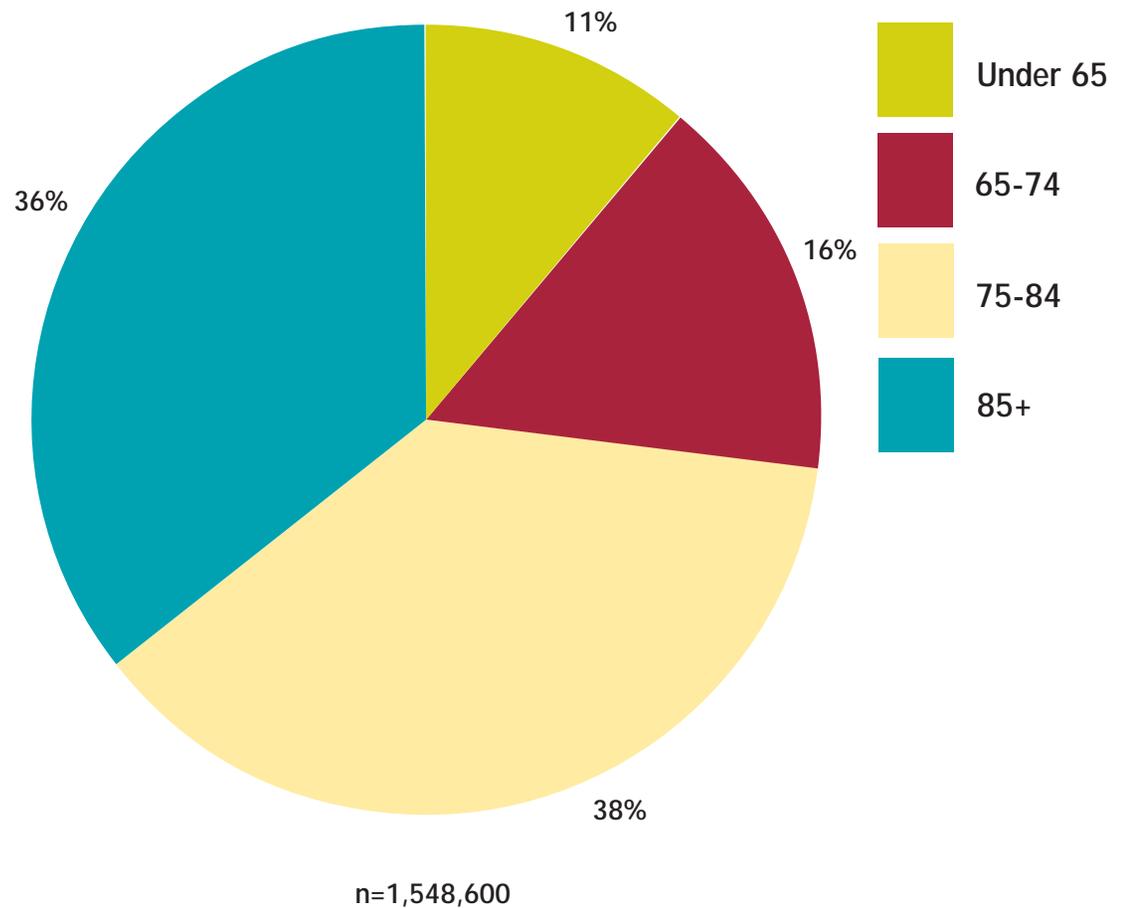
**Figure V-1**  
Nursing Home Residents, 1973-1995



More than 1.5 million people (of all ages) live in nursing homes on a given day in the U.S. Fueled by rapid growth of the population age 65 and older, especially those age 85 and older, and a lack of home and community-based alternatives, the number of people in nursing homes increased by nearly 50 percent between 1973 and 1985. However, between 1985 and 1995, the increase in the number of nursing home residents was slight, despite growth in the population age 85 and older. Declining use of nursing homes has been attributed to the expansion of home and community-based alternatives, which began in the 1980s, and improved health and functional status of the aging population.

Source: Strahan, Genevieve W. "An Overview of Nursing Homes and Their Current Residents, Data from the 1995 National Nursing Home Survey," Advance Data Number 280, National Center for Health Statistics, January 23, 1997.

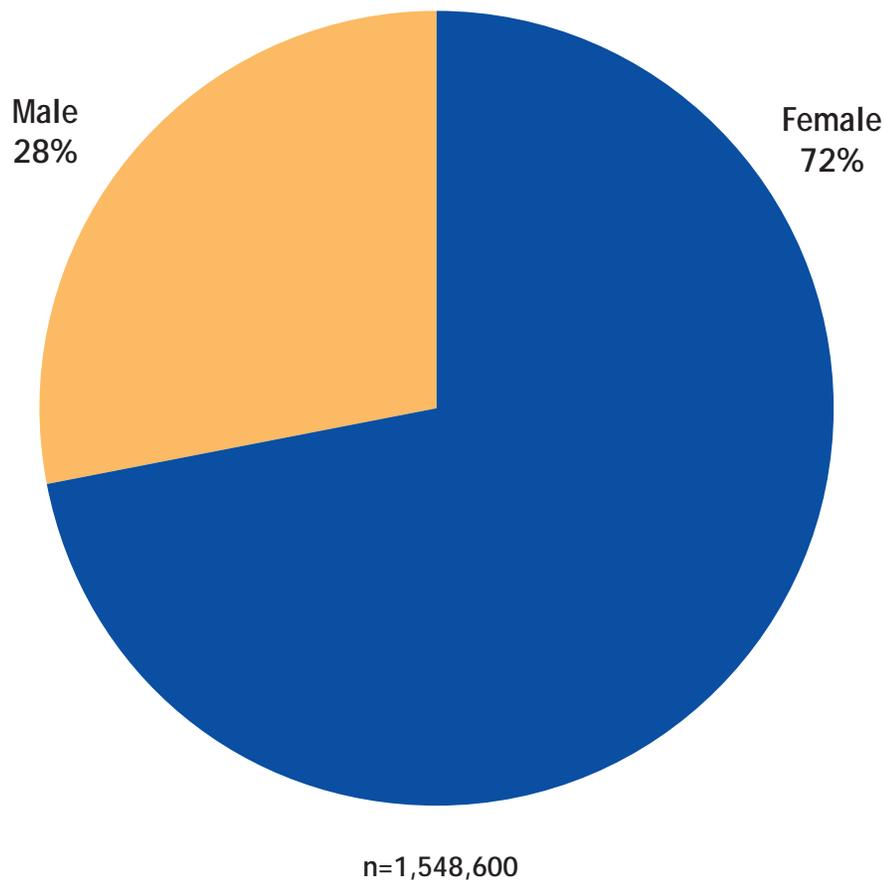
**Figure V-2**  
Distribution of Nursing Home Residents by Age, 1995



Most nursing home residents are age 75 or older. Because the prevalence of disability increases with age, it is not surprising that 38 percent of nursing home residents are age 75 to 84 and 36 percent are age 85 and older. Only 11 percent of nursing home residents are younger than 65.

**Figure V-3**

Distribution of Nursing Home Residents by Gender, 1995

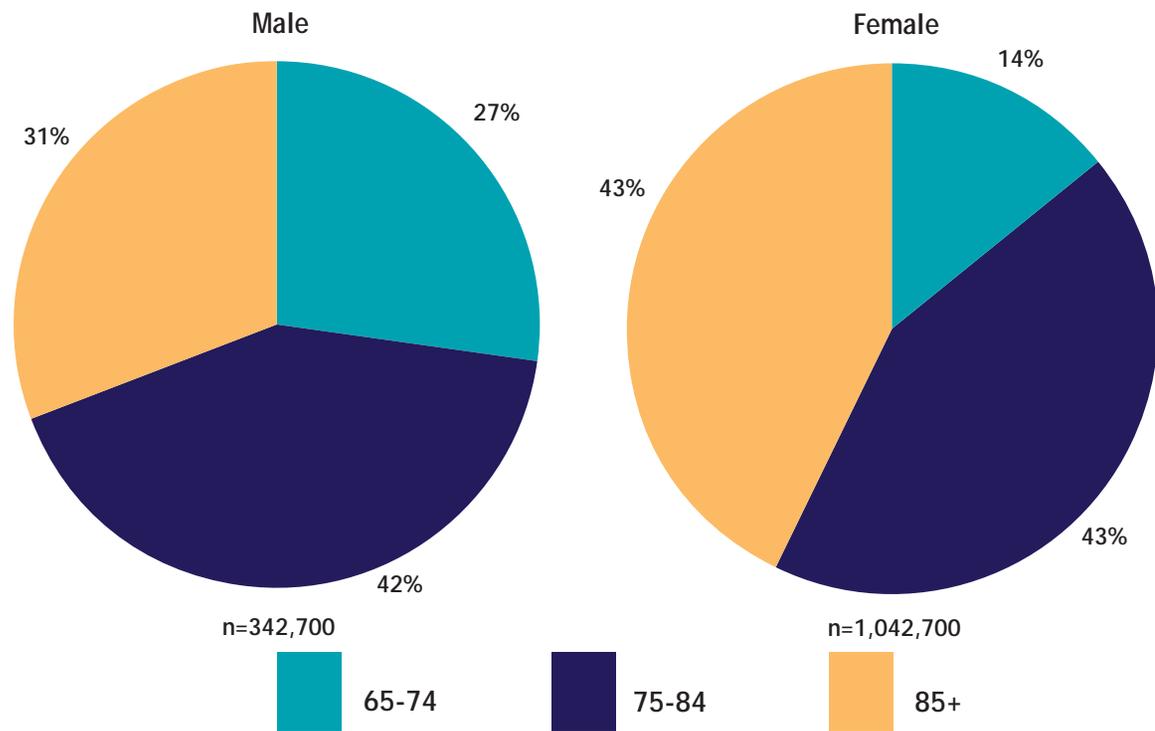


Nearly three-fourths of nursing home residents of all ages (72 percent) are female. Because women tend to outlive their spouses, they are less likely to have a caregiver available in the home should they become disabled. Lack of an informal caregiver increases the likelihood of needing nursing home care. Men with disabilities are often able to delay or avoid institutionalization if their spouse provides care at home. While women tend to live longer than men, they also are more likely to have disabilities. This factor also contributes to the high proportion of nursing home residents who are female.

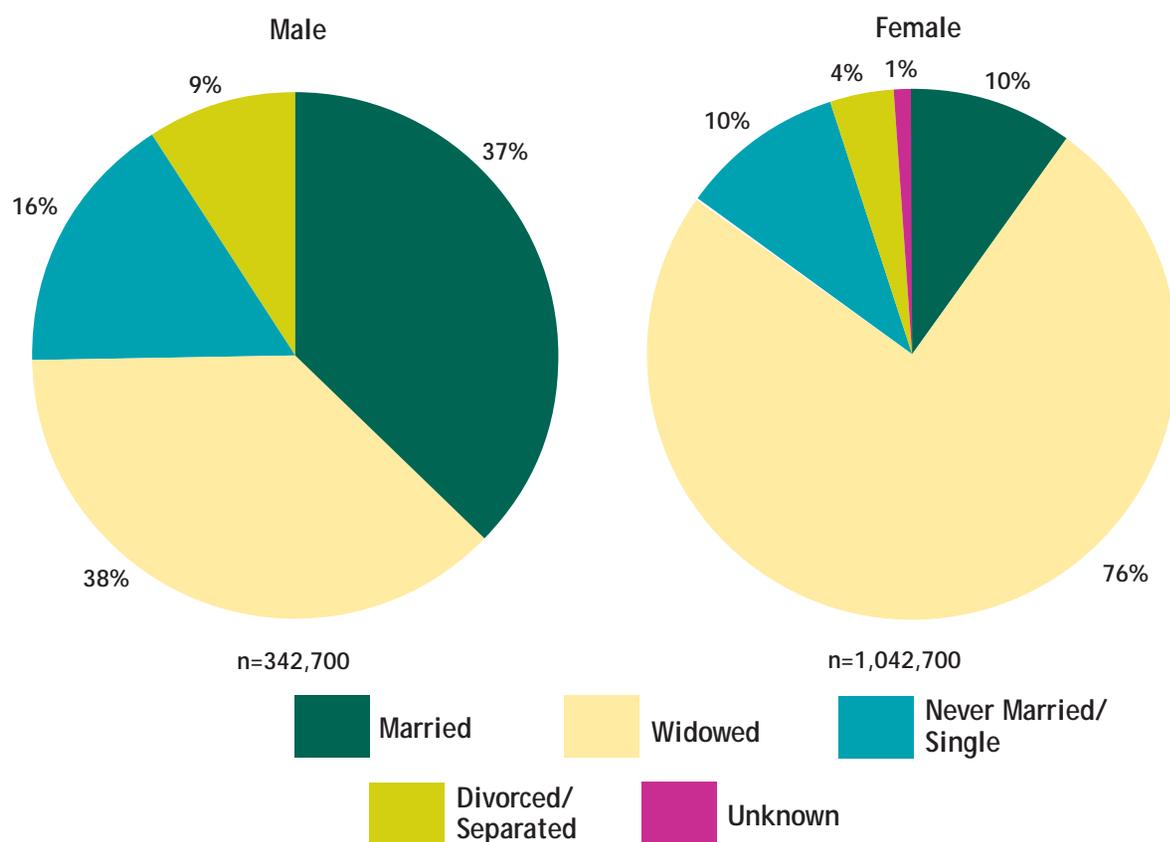
Source: Strahan, Genevieve W. "An Overview of Nursing Homes and Their Current Residents, Data from the 1995 National Nursing Home Survey," Advance Data Number 280, National Center for Health Statistics, January 23, 1997.

Most older nursing home residents are at least 75 years old at the time they are admitted to a nursing home. Among nursing home residents who are age 65 and older at the time of admission, 42 percent are admitted between the ages of 75 and 84 and 40 percent are admitted at age 85 or older. However, men tend to be admitted to nursing homes at younger ages than are women. For example, while 14 percent of women are admitted to nursing homes between the ages of 65 and 74, this proportion increases to 27 percent for men. Alternatively, while only 31 percent of men are age 85 and older when they are admitted to a nursing home, 43 percent of women are admitted at age 85 and older. This finding indicates that men tend to become disabled at younger ages than women and are more likely to use nursing home services at younger ages, despite the greater availability of informal caregivers.

**Figure V-4**  
Age at Nursing Home Admission, by Gender, 1995\*



**Figure V-5**  
**Marital Status of Nursing Home Residents Age 65+ at Admission, by Gender, 1995**



Only 17 percent of nursing home residents who are age 65 and older at admission are married. This finding illustrates the important role that spouses often play as informal caregivers who are able to help their partners delay or avoid the need for nursing home care. Nearly two-thirds of older nursing home residents (65 percent) are widowed. However, there are dramatic differences in the marital status of nursing home residents by gender.

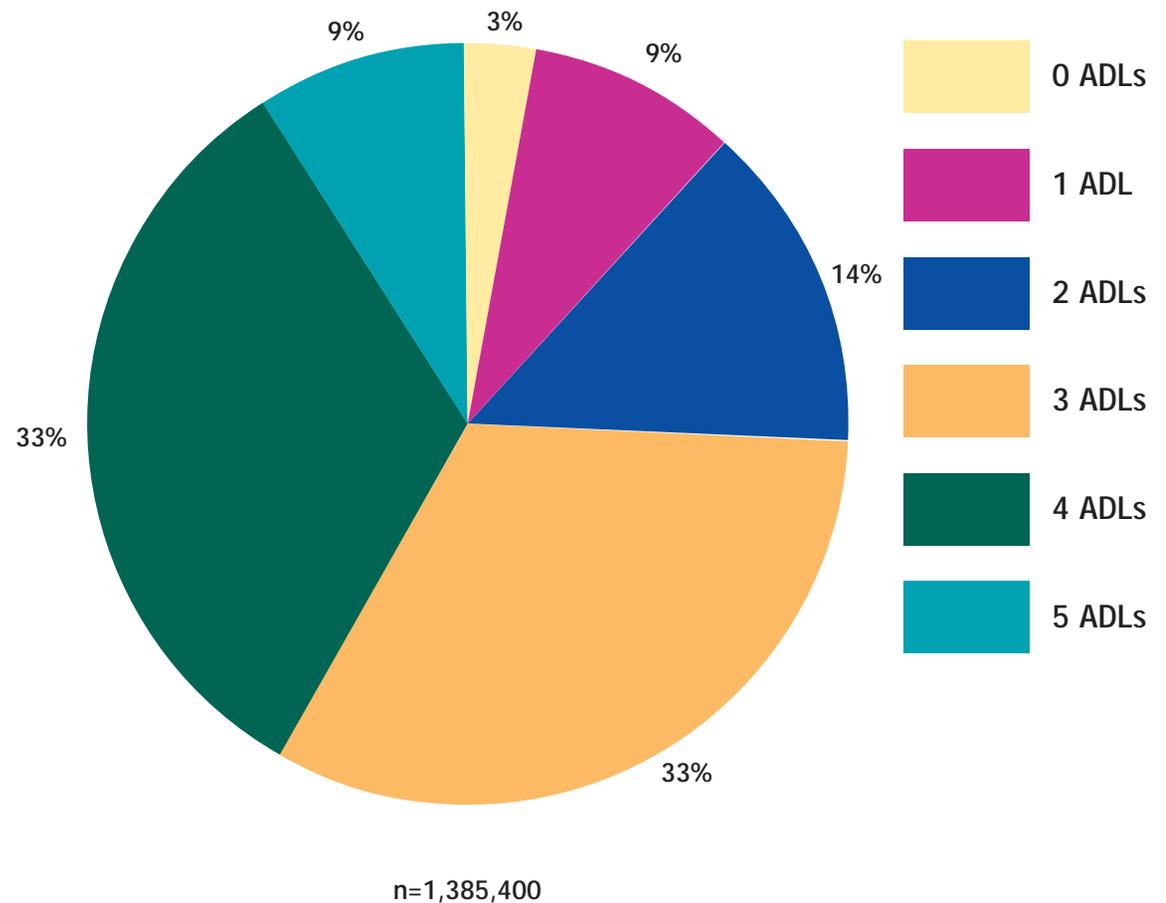
While male nursing home residents are almost equally likely to be married (37 percent) or widowed (38 percent), female nursing home residents are overwhelmingly widowed.

Three-fourths (76 percent) of female nursing home residents are widowed and only 10 percent are married. These findings reinforce the fact that women are more likely to outlive their spouses. They also show, however, that the availability of a spouse by no means guarantees the avoidance of institutionalization. Once a person's disabilities become severe, even the availability of a spouse or other caregiver may be inadequate to prevent the need for nursing home care.

Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey," Advance Data Number 289, National Center for Health Statistics, July 2, 1997.  
 Note: Numbers do not add to 100% due to rounding.

**Figure V-6**

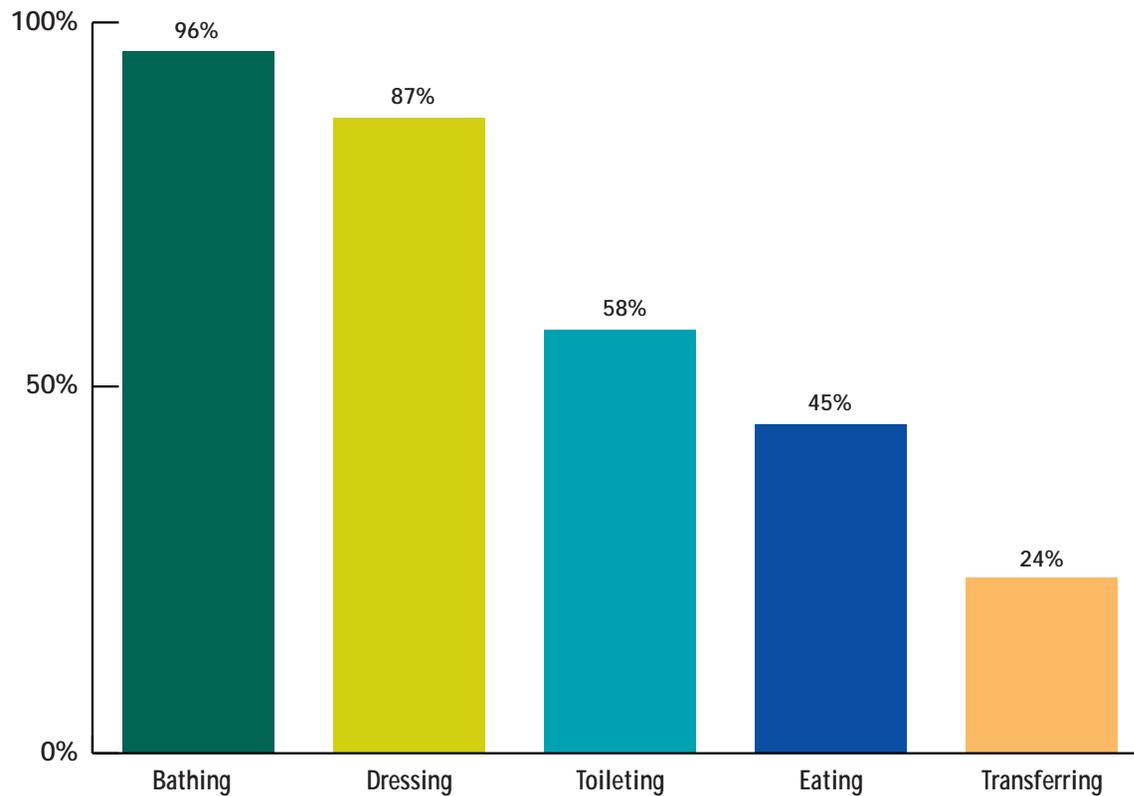
Distribution of Nursing Home Residents Age 65+ at Admission, by Number of ADLs for Which Help Is Received, 1995



Residents of nursing homes tend to have more severe disabilities than people with disabilities who live in the community. Three-fourths (75 percent) of nursing home residents who are age 65 and older at admission receive help with three or more ADLs. Only 3 percent of older nursing home residents do not receive any help with ADLs.

## Figure V-7

Percent of Nursing Home Residents Age 65+ at Admission, Receiving Help with Specific ADLs, 1995



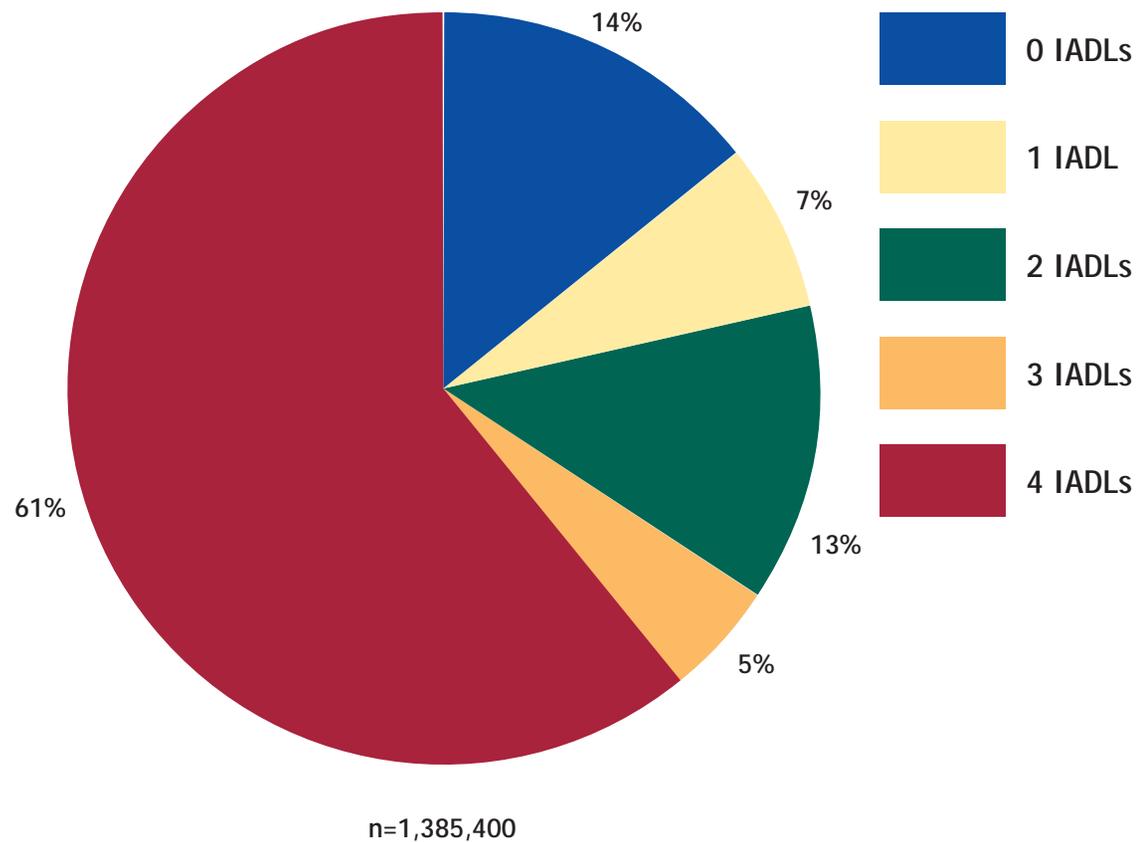
Nearly all older nursing home residents receive help with bathing (96 percent) and dressing (87 percent). Some 58 percent receive help with toileting. This figure illustrates the percentage of nursing home residents who are age 65 and older at admission who receive help with specific ADLs. The five ADLs are defined here as:

- bathing or showering;
- dressing;
- eating;
- transferring in or out of beds or chair; and
- using toilet room.

Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey." Advance Data Number 289, National Center for Health Statistics, July 2, 1997.

**Figure V-8**

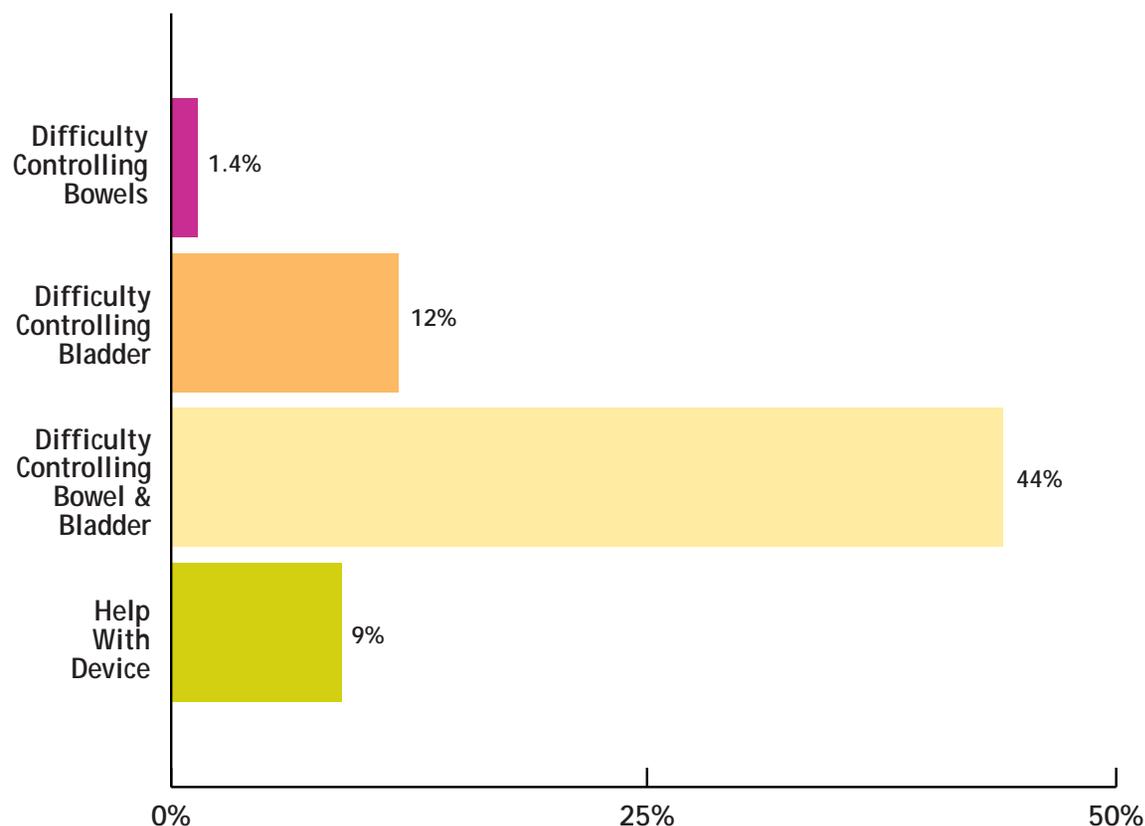
Distribution of Nursing Home Residents Age 65+ at Admission, by Number of IADLs for Which Help Is Received, 1995



Nursing home residents also tend to receive help with IADLs. Close to two-thirds of residents who are age 65 and older at admission (61 percent) receive help with all four of the IADLs measured by the NNHS. The IADLs measured in this survey are: needing help using the telephone (69 percent); securing personal items (77 percent); caring for personal possessions (78 percent); and managing money (89 percent). It should be noted that these IADLs differ from those generally used to measure disability for people who live in the community. Because nursing home residents are not expected to shop, prepare meals, or do housework, such measures are not used to assess the disability of nursing home residents.

## Figure V-9

Percent of Nursing Home Residents Age 65+ at Admission, by Continence Difficulty, 1995

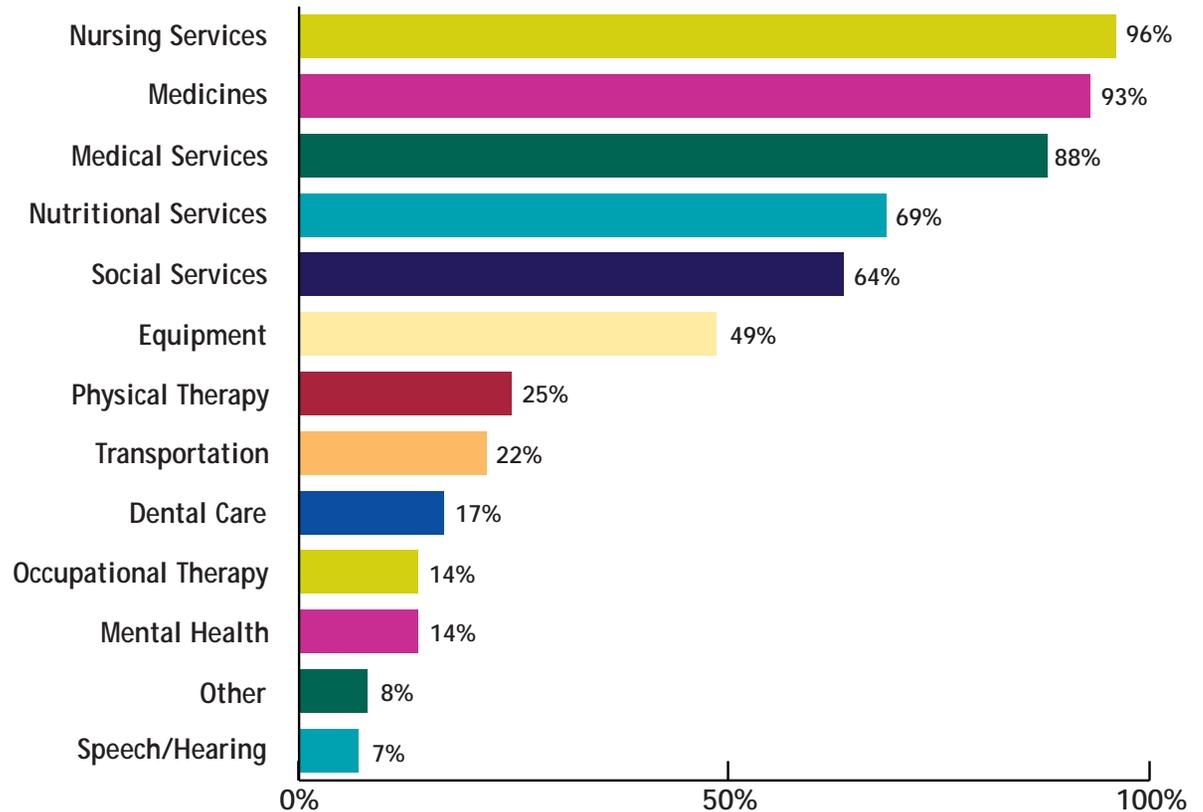


Serious continence difficulties may also result in a greater need for nursing home care and are found among a substantial proportion of older nursing home residents. Some 57 percent of nursing home residents who are age 65 and older at admission have difficulty controlling either bowel or bladder functions. Nine percent of residents have a device, such as an ostomy or an indwelling catheter, with which they receive help.

Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey." Advance Data Number 289, National Center for Health Statistics, July 2, 1997.

**Figure V-10**

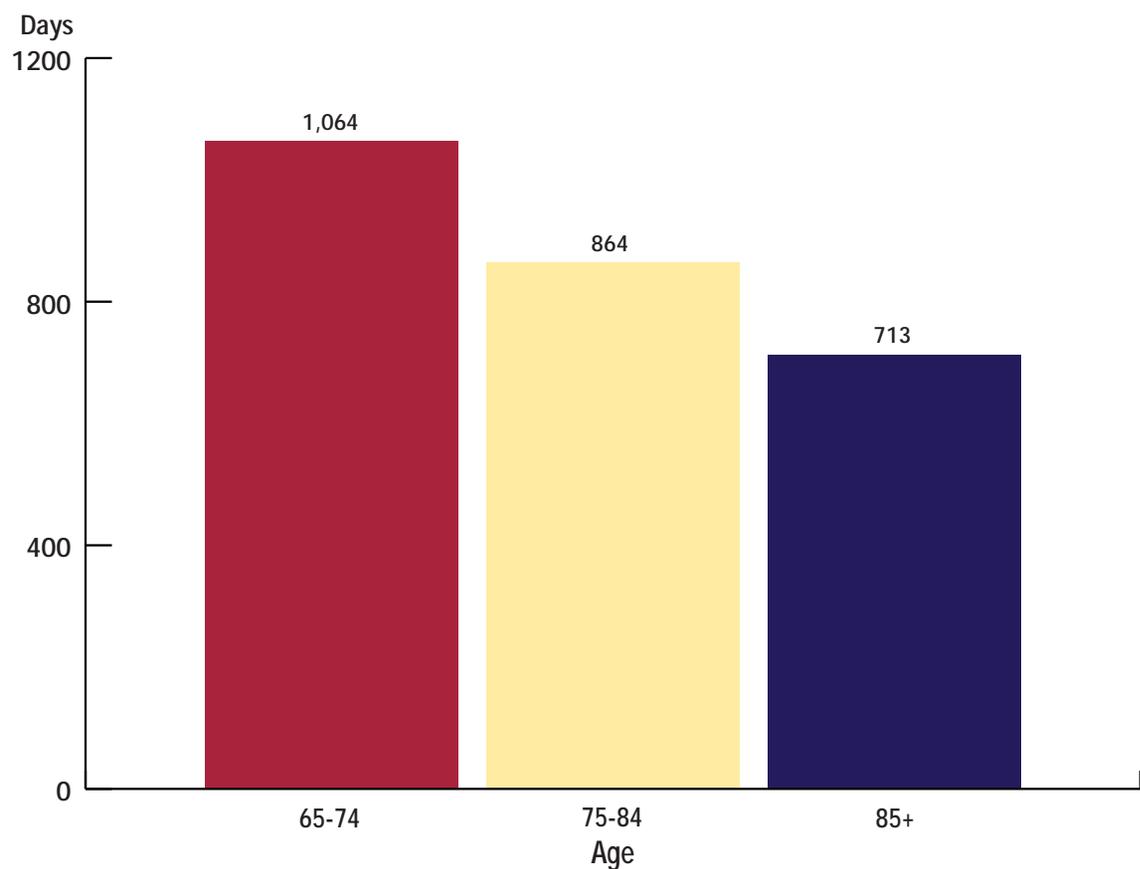
Percent of Nursing Home Residents Age 65+ at Admission Receiving Selected Services, 1995



Nursing home residents generally have medical needs, in addition to disabilities that result from physical limitations or cognitive impairments. Nearly all residents who are age 65 and older at admission receive nursing services (96 percent), medicines (93 percent), and medical services (88 percent). Social and nutritional services also are received by substantial proportions of nursing home residents.

## Figure V-11

Average Length of Stay (in Days) for Nursing Home Residents, by Age, 1995\*



The average length of stay for nursing home residents who are age 65 and older at admission is 838 days (about 28 months). Length of stay is measured from time of nursing home admission to the date of the survey interview and does not reflect how long the completed length of stay will be. Female residents tend to have somewhat longer stays than do males (on average, close to seven months longer). Length of stay decreases with age: the oldest residents (those age 85 and older) stay, on average, two years, while residents age 65 to 74 have stays that average nearly three years. This finding likely reflects the greater mortality of the oldest nursing home residents.

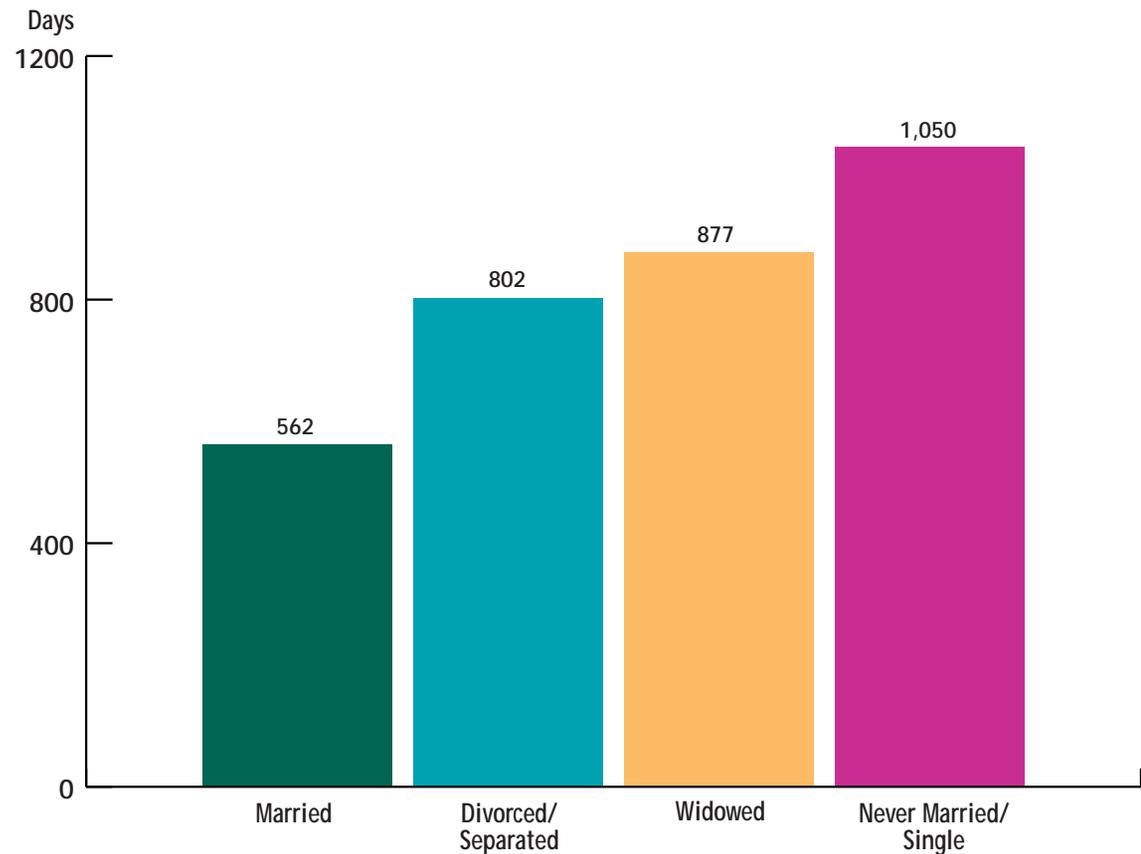
Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey," Advance Data Number 289, National Center for Health Statistics, July 2, 1997.

Note: Length of stay is measured from time of nursing home admission to the date of the survey interview. It indicates how long current residents have been in the nursing home, not how long the completed length of stay will be.

\*Residents Age 65+ at Admission.

**Figure V-12**

Average Length of Stay (in Days) for Nursing Home Residents, by Marital Status, 1995\*



Nursing home residents who have never been married have average stays that are nearly twice as long as those of married residents. The average stay for married residents is less than two years (562 days), illustrating the role that spousal caregivers may play in delaying or shortening the need for nursing home care. Residents who have always been single have average stays that are nearly three years long (1,050 days). Such individuals are less likely to have either life partners or children to serve as informal caregivers.

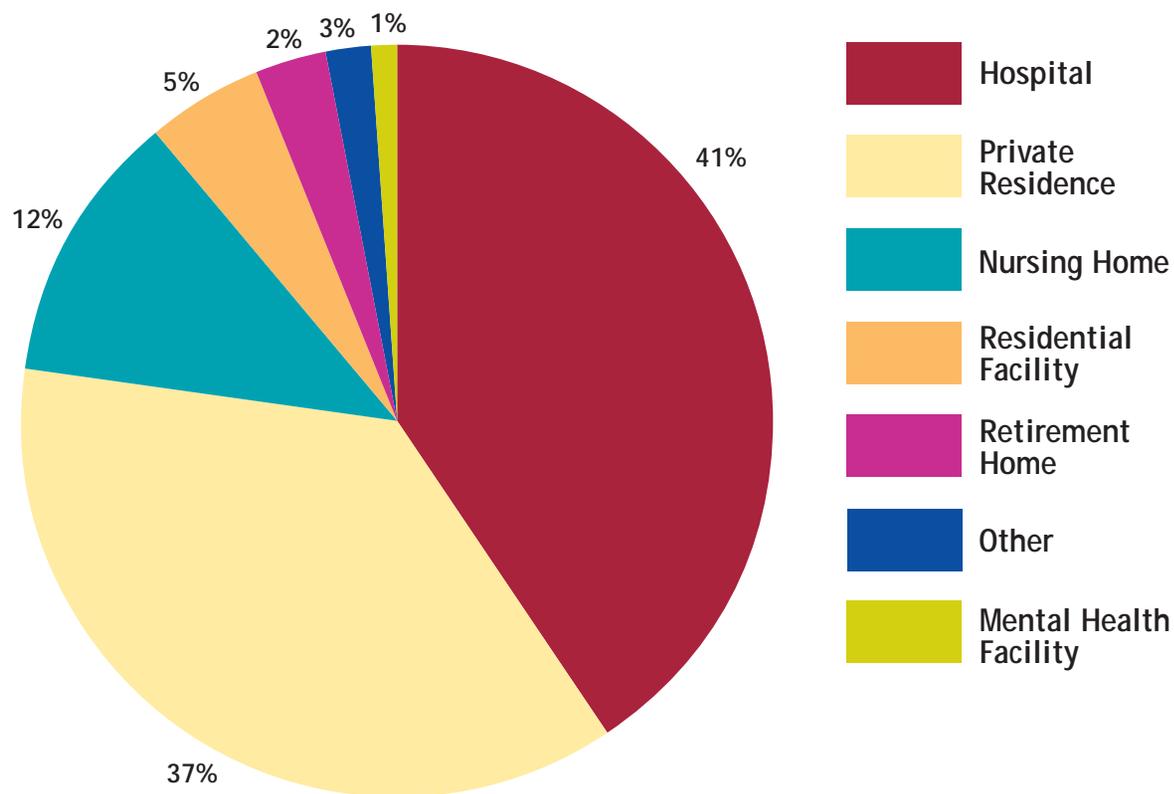
Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey." Advance Data Number 289, National Center for Health Statistics, July 2, 1997.

Note: Length of stay is measured from time of nursing home admission to the date of the survey interview. It indicates how long current residents have been in the nursing home, not how long the completed length of stay will be.

\*Residents Age 65+ at Admission.

## Figure V-13

Distribution of Nursing Home Residents Age 65+ at Admission, by Prior Living Quarters, 1995



Because most nursing home residents have chronic conditions and medical problems, many enter a nursing home directly from a hospital. More than half of nursing home residents who are age 65 and older at admission enter from a hospital (41 percent) or another nursing home (12 percent). Yet more than one-third of admissions (37 percent) are from a private residence.

Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey," Advance Data Number 289, National Center for Health Statistics, July 2, 1997.  
Note: Numbers do not add to 100% due to rounding.

## Part VI

# Characteristics of Long-Term Care Providers

### Introduction

In 1995 there were 1.8 million nursing home beds in 16,700 nursing homes across the U.S. More than 1.5 million individuals resided in nursing homes on a given day in 1995, resulting in an 87 percent occupancy rate (Strahan, 1997).

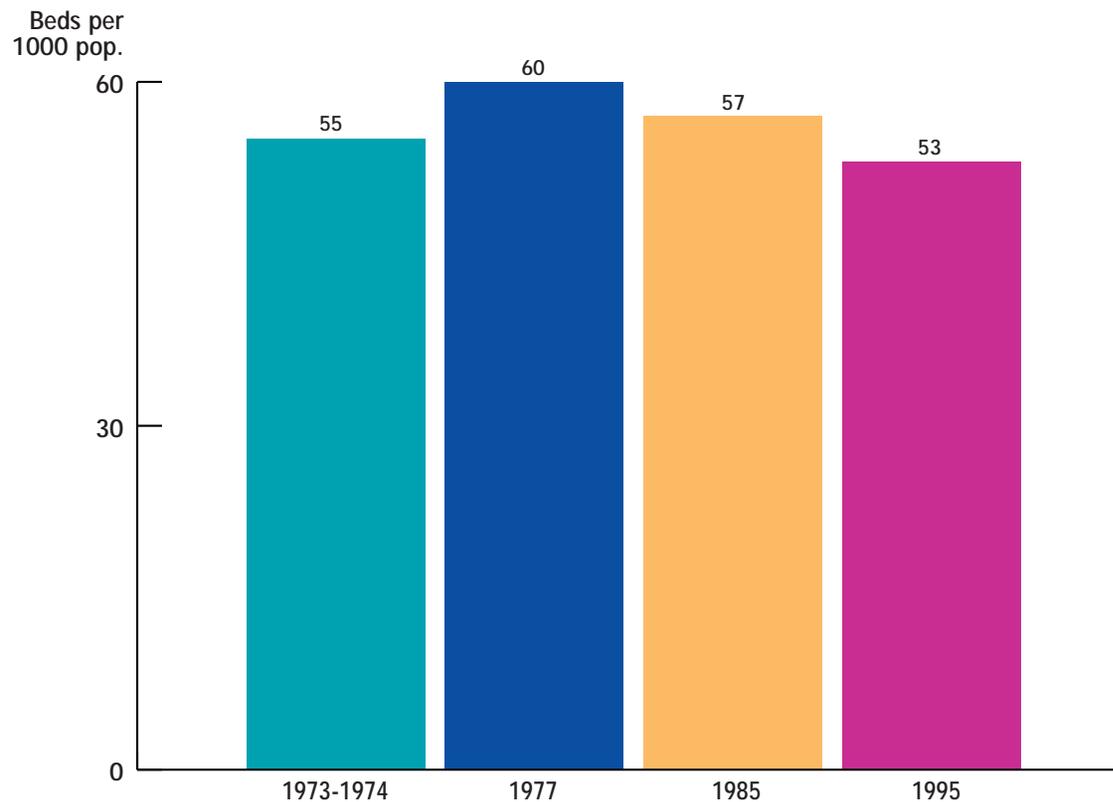
In 1996 there were 13,500 home health and hospice care agencies in the U.S. Close to 2.5 million persons were served by these agencies on a given day in 1996, 98 percent of whom were served by home health agencies (Haupt, 1998).

There is no good estimate of the number of people who reside in assisted living facilities in the U.S. Based on data collected by the U.S. Department of Health and Human Services and industry projections, the National Center for Assisted Living (1997) estimated that 25,000 assisted living facilities served 800,000 residents in 1997.

The nursing home data in this section are derived from Strahan's 1997 analysis of the 1995 National Nursing Home Survey (NNHS). The home health care agency data are derived from Haupt's 1998 analysis of the 1996 National Home and Hospice Care Survey (NHHCS).

## Figure VI-1

### Nursing Home Beds per 1,000 Population Age 65+, 1973-1995

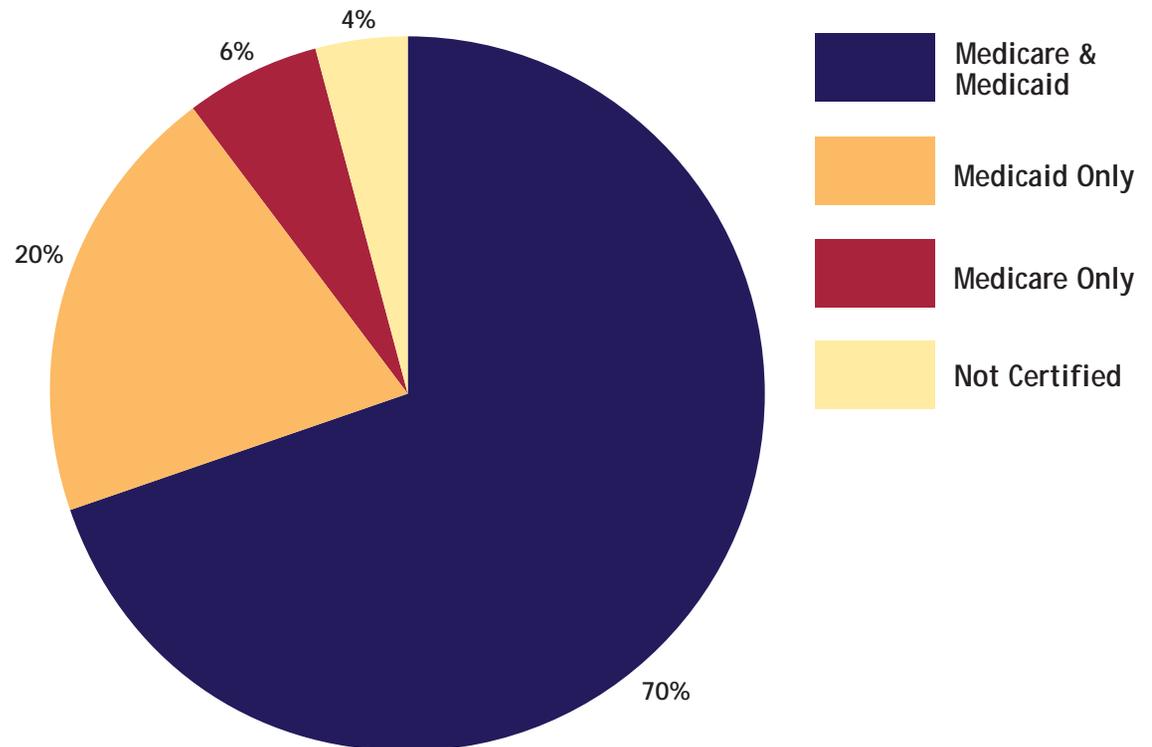


The number of nursing home beds per 1,000 persons age 65 and older has begun to decline over the past two decades, despite rapid growth in the older population. As the popularity and availability of home and community-based alternatives to nursing homes has increased, the demand for nursing home care has slowed. In addition, the high cost of nursing home care, much of which is paid for by the federal-state Medicaid program, has motivated states to limit nursing home construction. This figure shows the trends in the number of nursing home beds per 1,000 population age 65 and older.

Source: Strahan, Genevieve W. "An Overview of Nursing Homes and Their Current Residents, Data from the 1995 National Nursing Home Survey," Advance Data Number 280, National Center for Health Statistics, January 23, 1997.

**Figure VI-2**

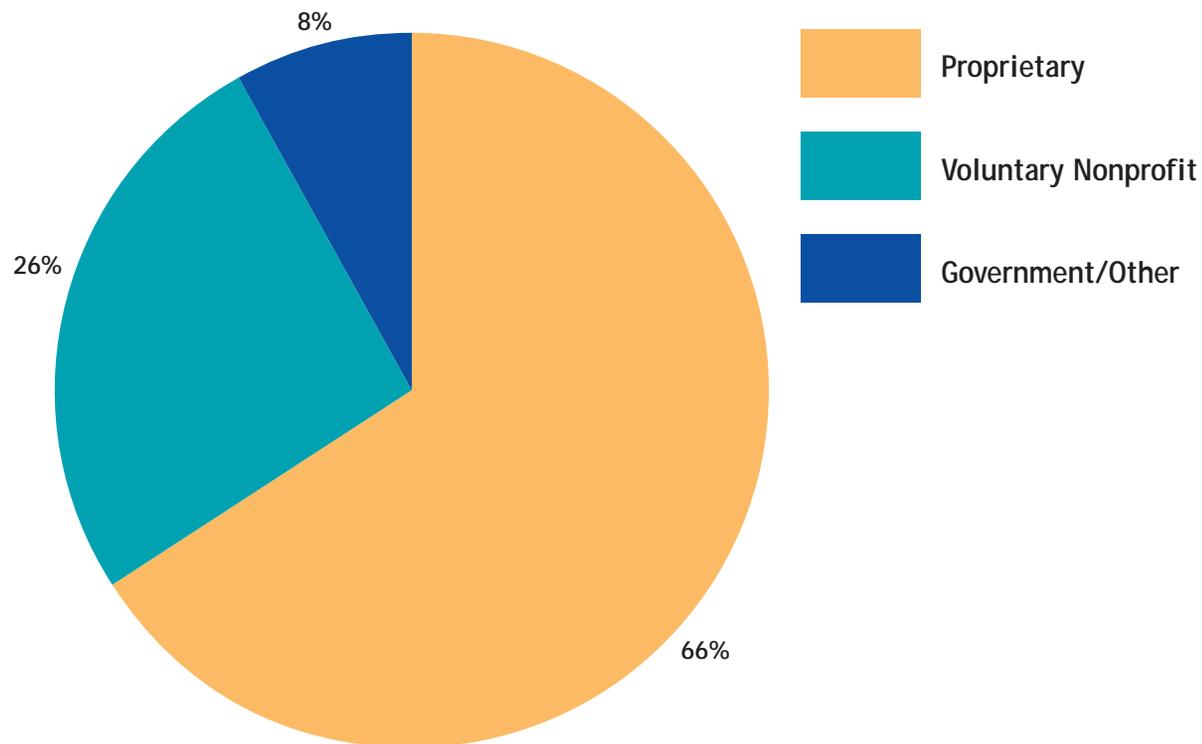
Distribution of Nursing Homes by Certification Status, 1995



Nearly all nursing homes (90 percent) are certified by Medicaid, and most (70 percent) are certified by both Medicare and Medicaid. Because the average cost of a nursing home was more than \$47,000 a year in 1996, most residents must rely, at least in part, on public sources of funding for their care. As a result, few nursing homes can survive financially if they are certified by neither Medicare nor Medicaid. Only 4 percent of nursing homes are not certified.

**Figure VI-3**

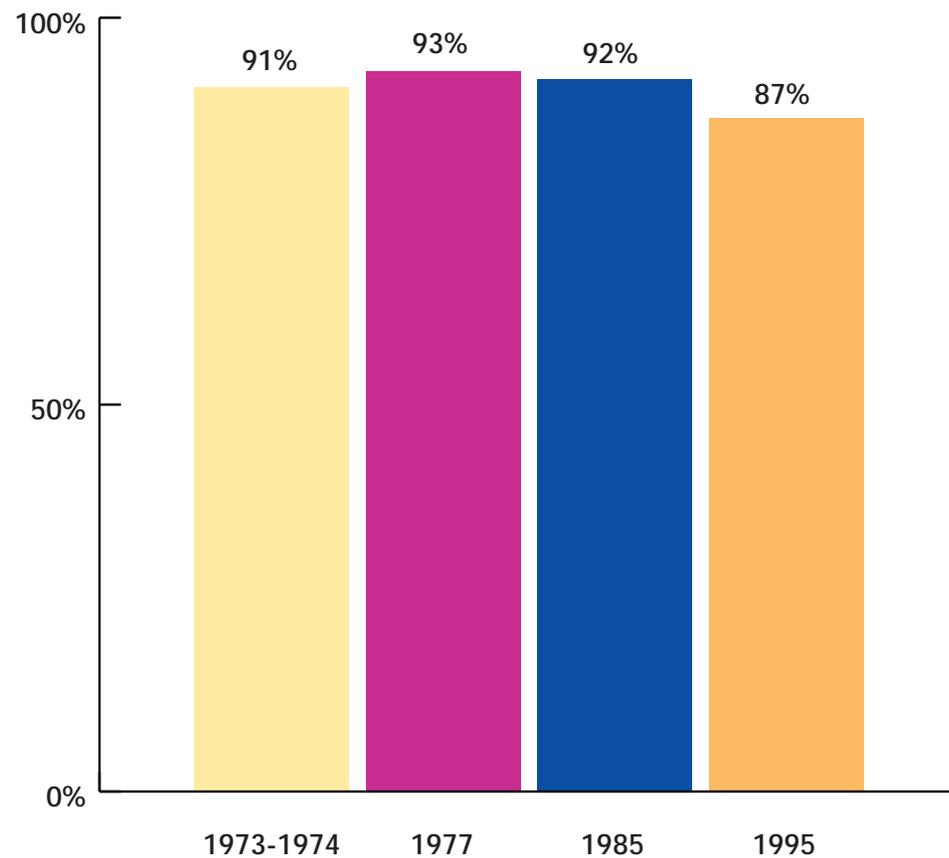
Distribution of Nursing Homes by Ownership Status, 1995



The majority (66 percent) of nursing homes in the U.S. are owned by for-profit companies. Only 26 percent are operated by voluntary, non-profit entities. The remainder are primarily government-owned facilities, operating under auspices of agencies such as the Veterans Administration.

Source: Strahan, Genevieve W. "An Overview of Nursing Homes and Their Current Residents, Data from the 1995 National Nursing Home Survey," Advance Data Number 280, National Center for Health Statistics, January 23, 1997.

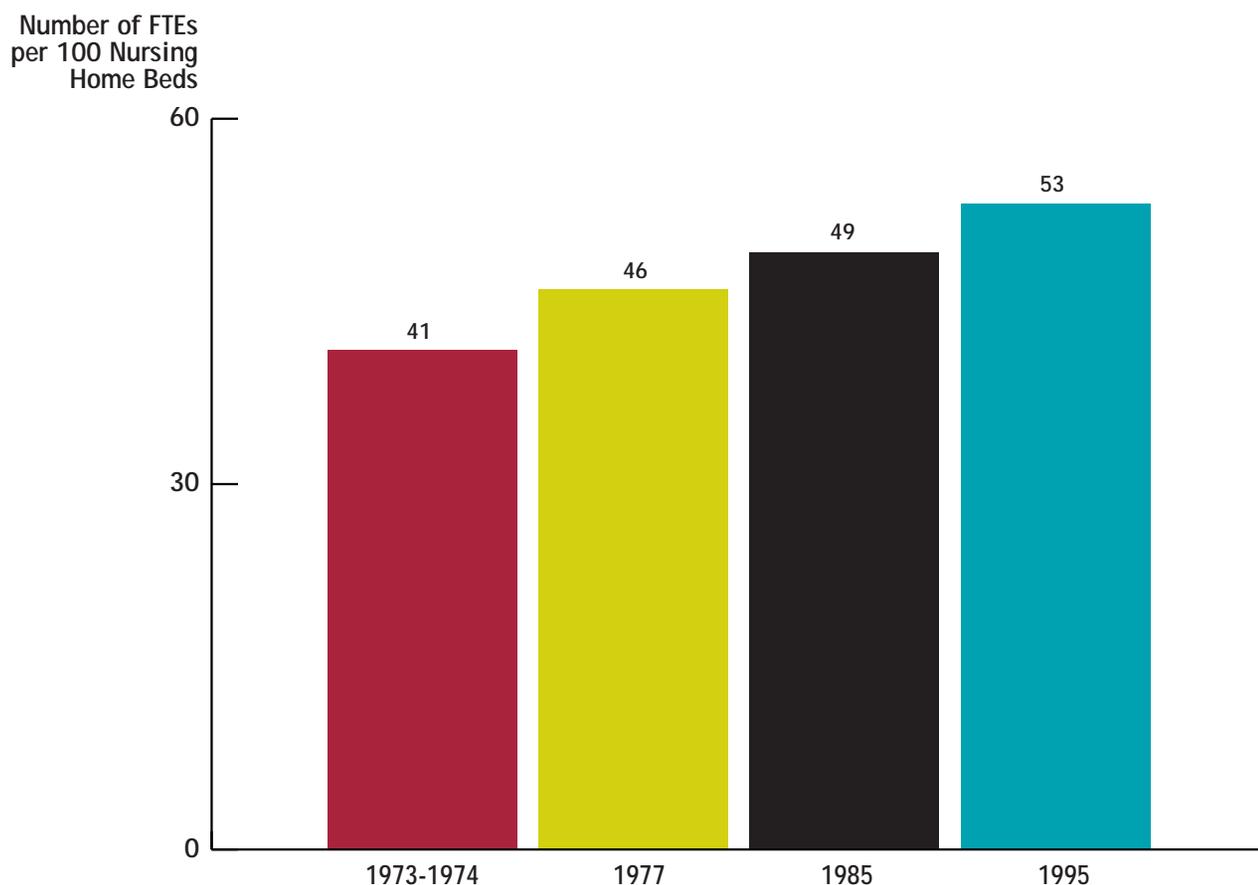
**Figure VI-4**  
Nursing Home Occupancy Rates, 1973-1995



Nursing home occupancy rates have declined slightly over the past two decades from a high of 93 percent in 1977 to 87 percent in 1995. As alternatives to nursing homes have flourished, the demand for nursing home care has begun to decline. Some nursing homes are beginning to convert a portion of their beds to assisted living facilities, which provide lower levels of care, or to post-acute facilities, which provide highly skilled care and command higher reimbursement rates.

## Figure VI-5

Number of Full-Time Equivalent Staff per 100 Nursing Home Beds, 1973-1995\*

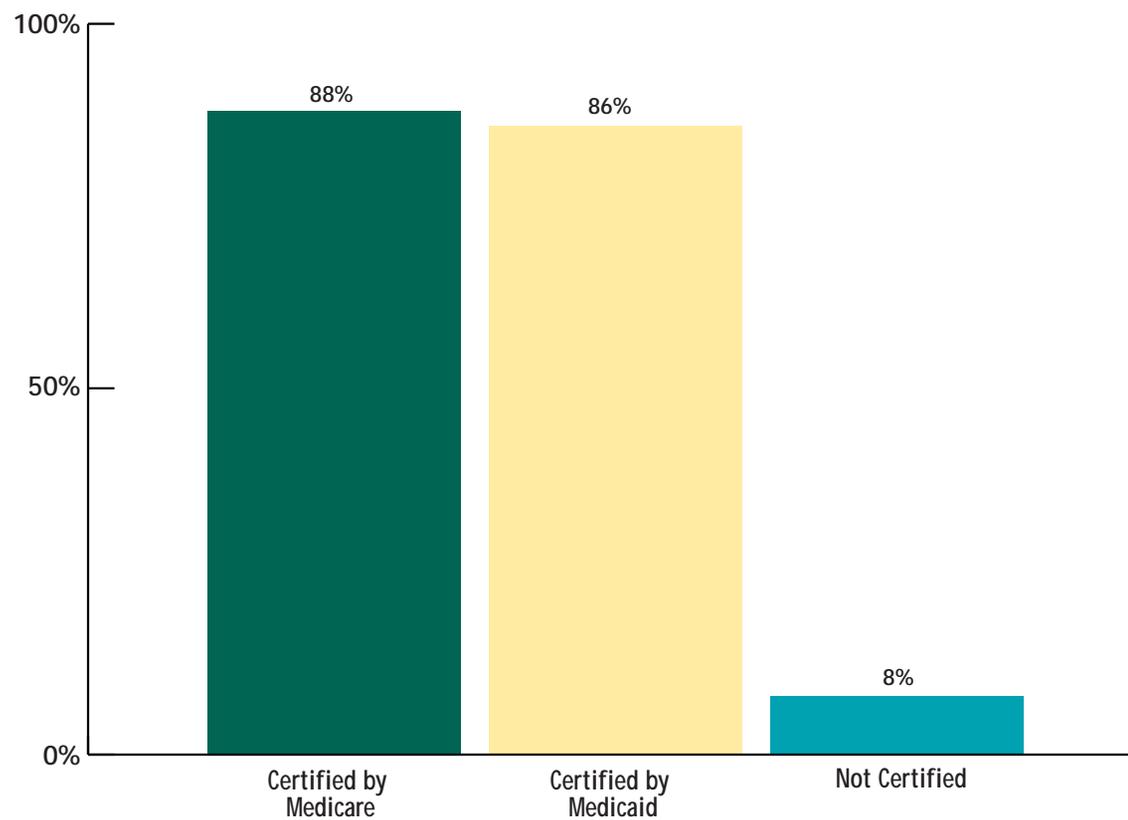


There have been substantial changes in the number of full-time equivalent staff (FTEs) per 100 nursing home beds over the past two decades. The number of FTEs per 100 beds that *provide direct patient care* increased from 41 in 1973 to 53 in 1995, a growth of more than 25 percent. This change in 1987 is attributable, in large part, to the enactment of federal nursing home quality regulations, which contained certain staffing requirements. Higher nurse staffing ratios have been shown to improve quality of care for residents. Despite this improvement in nursing home staffing ratios, it should be noted that few of these nursing staff are registered nurses. For example, of the 53 FTEs providing direct patient care per 100 nursing home beds, 52 are nursing staff. But of these 52, 34 are nurse's aides and orderlies, 11 are licensed practical nurses, and 7 are registered nurses (Strahan, 1997).

Source: Strahan, Genevieve W. "An Overview of Nursing Homes and Their Current Residents, Data from the 1995 National Nursing Home Survey," Advance Data Number 280, National Center for Health Statistics, January 23, 1997.

\*Includes only those providing direct patient care: administrative, medical and therapeutic staff; registered nurses; licensed practical nurses; nurses' aides and orderlies.

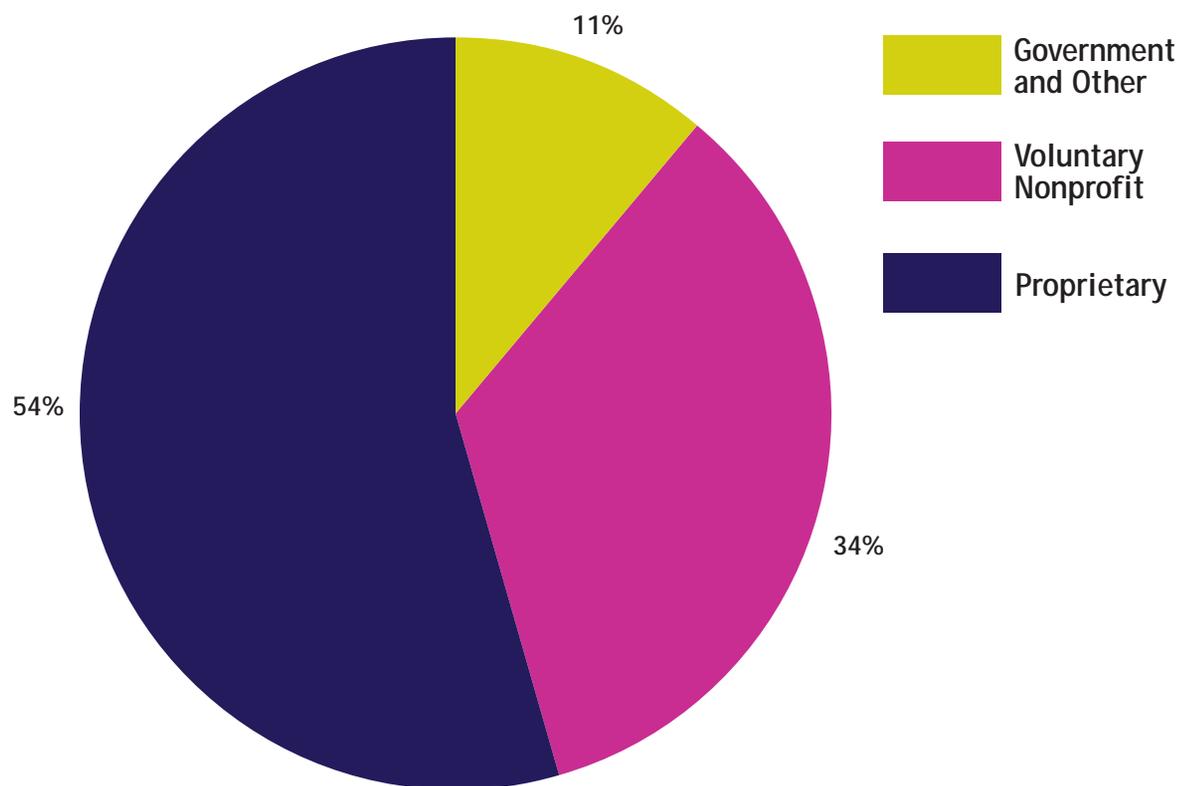
**Figure VI-6**  
Certification Status of Home Health and Hospice Care Agencies, 1996



Most home care agencies are certified by Medicare and Medicaid. Eighty-eight percent of agencies providing home health or hospice care are Medicare-certified and 86 percent are Medicaid-certified. Only 8 percent are not certified.

## Figure VI-7

Distribution of Home Health and Hospice Care Agencies, by Ownership Status, 1996



Home health and hospice care agencies are more likely to be operated by voluntary nonprofit entities than are nursing homes. However, a majority of home care agencies (54 percent) are owned by for-profit companies and 34 percent are operated by voluntary nonprofit entities.

Source: Haupt, Barbara J. "An Overview of Home Health and Hospice Care Patients: 1996 National Home and Hospice Care Survey" Advance Data Number 297, National Center for Health Statistics, April 16, 1998.  
Note: Numbers do not add to 100% due to rounding.

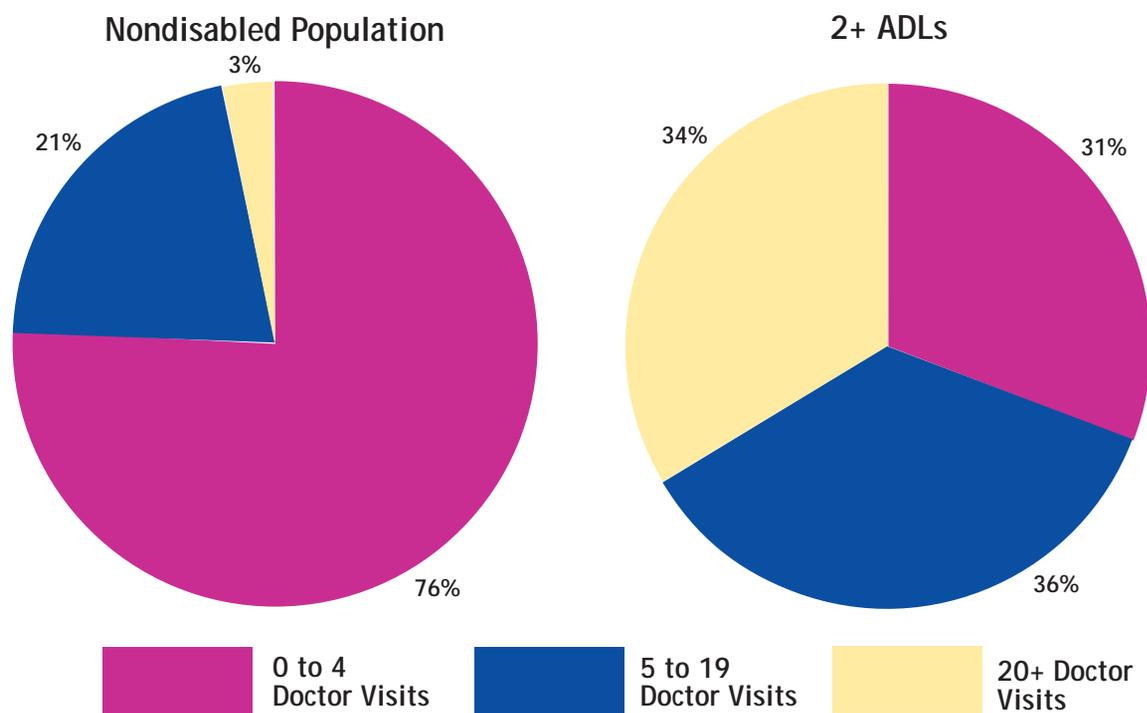
## Part VII **Introduction**

### Use of Acute Care Services

People who need long-term care services often have multiple chronic health conditions. Impairments in vision and hearing; and chronic medical conditions such as arthritis, hypertension, heart conditions, osteoporosis, and diabetes can result in a need for long-term care and acute care services. The following charts illustrate the use of acute care services (doctor and hospital visits) by community-dwelling individuals age 50 and older.

## Figure VII-1

Distribution of People Age 50+, by Annual Number of Doctor Visits and Disability Status, 1994



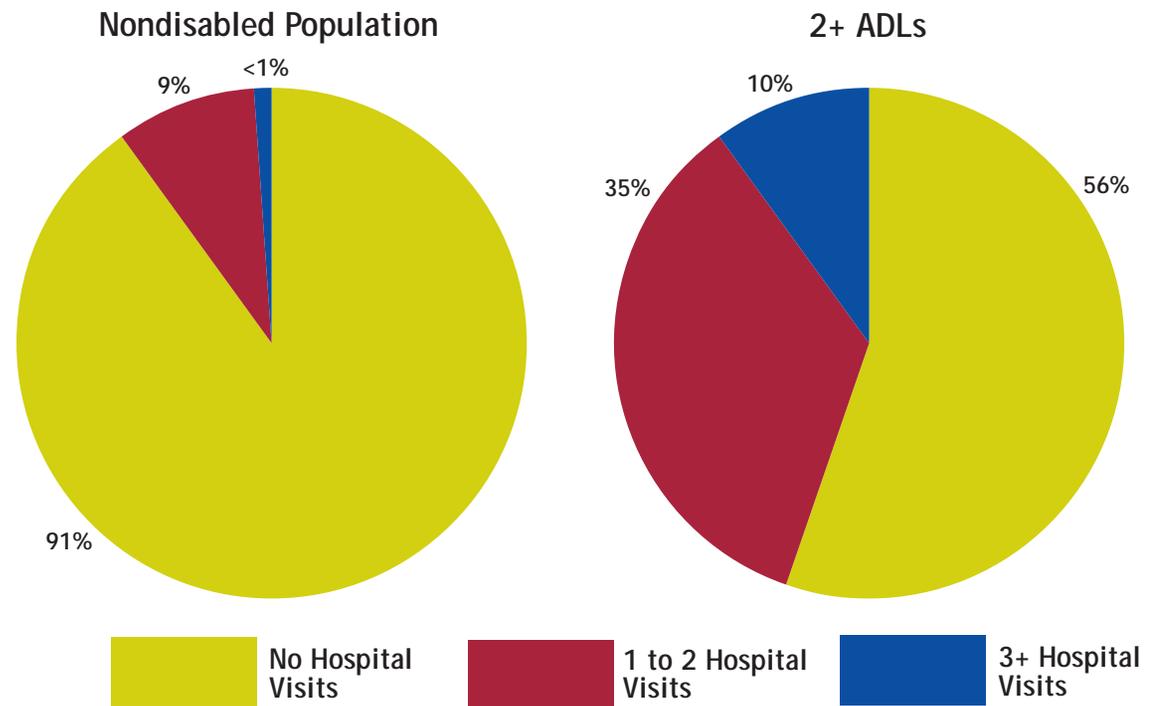
While many people who receive help with two or more ADLs have relatively few doctor visits per year, one-third (34 percent) have 20 or more doctor visits annually. This distribution is dramatically different from the distribution among the nondisabled population. Among the population age 50 and older without disabilities, 76 percent have four or fewer doctor visits per year, and only 3 percent have 20 or more doctor visits annually. This figure illustrates the distribution of the population age 50 and older by their annual number of doctor visits and disability status.

Source: The Lewin Group Analysis of the 1994 National Health Interview Survey of Disability, Phase I, 1994.  
Note: Numbers do not add to 100% due to rounding.

## Figure VII-2

Distribution of People Age 50+, by Annual Number of Hospital Visits and Disability Status, 1994

While more than half of those who receive help with two or more ADLs (56 percent) have no hospital visits in a year, a small proportion (10 percent) have three or more annual hospital visits. As with the number of doctor visits, the population age 50 and older without disabilities has dramatically lower use of hospitals. Some 91 percent of the population age 50 and older who receive no help with ADLs or IADLs have no hospital visits in a year and less than 1 percent have three or more hospital visits.



## Introduction

Long-term care is expensive. Most Americans have little or no protection from the high cost of long-term care services. The federal Medicare program covers only limited long-term care services – short stays in skilled nursing facilities following a hospitalization, and a home health benefit with many restrictions on eligibility and duration of services. The federal-state Medicaid program is the primary source of public payment for long-term care services, but eligibility is based on very strict income and asset rules. The Medicaid program also has an institutional bias. In 1997, Medicaid spent \$56.1 billion on long-term care. Of this amount, \$32.5 billion paid for nursing home services and \$10 billion paid for intermediate care facilities for the mentally retarded (Burwell, 1998). Three-quarters of Medicaid long-term care expenditures paid for care in institutional settings in 1997, although the proportion of funds devoted to home and community-based care has grown substantially over the past decade.

Out-of-pocket payments for long-term care services create serious economic hardship for many families. Consider these facts:

- The average cost of a nursing home was estimated to be more than \$47,000 a year in 1996.
- The average cost of a home care visit was estimated to be \$77 in 1997.

Average home care costs vary by the type of visit. For example, an average visit by a nurse was estimated to cost \$98 in 1997, while the average visit by a home care aide was estimated to cost \$54 (NAHC, 1997). An individual who needs frequent care could easily find these costs prohibitive. Few individuals have private long-term care insurance policies that can help them pay for services, either in their homes or in nursing homes. Many people who need long-term care and can no longer rely on informal help deplete their life savings and ultimately turn to Medicaid for help.

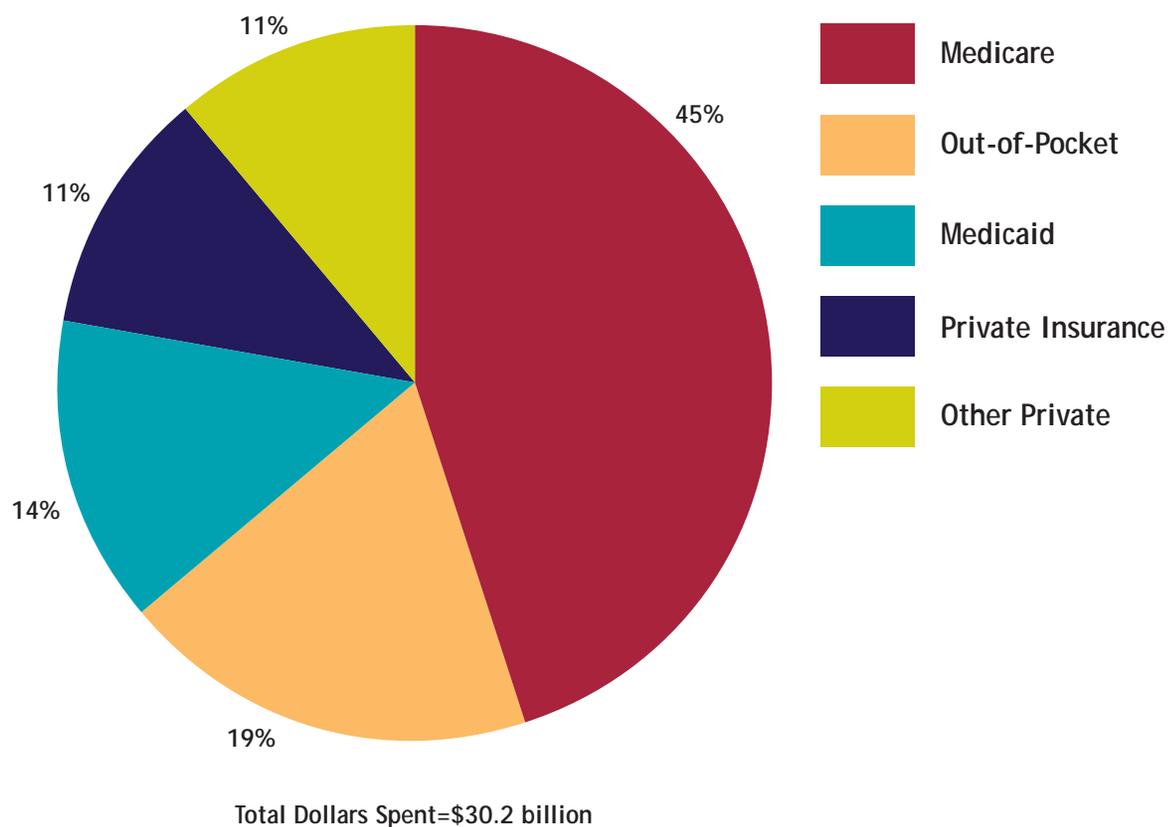
The high cost of long-term care, combined with our nation's reliance on Medicaid as the primary source of long-term care financing, has led to a quest for alternative ways to pay for services. Chief among these alternatives has been the emergence of private long-term care insurance. Long-term care insurance may be attractive to people who do not believe they have adequate resources to pay for long-term care, but want to preserve the savings they do have for future needs or for their heirs.

Although private insurance currently pays for less than 7 percent of long-term care services (Levit, et al., 1997), there has been substantial growth in the sale of policies in recent years. Between 1987 and December 1996, close to 5 million long-term care insurance policies were sold in the U.S. The annual rate of growth in the sale of long-term care insurance policies during this period averaged 22 percent. In 1996, more than 600,000 policies were sold. Although many companies sell private long-term care insurance, some 80 percent of all individual and group policies were sold by just 12 companies in 1996 (Coronel, 1998).

While average premiums for private long-term care insurance policies decreased by 5 percent in 1996, their high cost is still a factor that discourages or prevents many individuals from purchasing these policies. Factors that affect the cost of a policy include the age at time of purchase, the amount of coverage purchased, the duration of coverage, and whether the benefits include inflation protection or a “nonforfeiture” benefit. A nonforfeiture benefit provides a partial long-term care benefit to people who stop paying their premiums. According to Coronel (1998), the average annual premium for a private long-term care insurance policy ranged from \$364 for a 50-year-old purchaser of a base plan, to \$7,440 for a 79-year-old purchaser of a policy that included a nonforfeiture benefit and lifetime 5 percent compounded inflation protection. These premium estimates were for a policy offering \$100 per day for nursing home care, \$50 per day for home care, and providing four years of coverage with a 20-day waiting period, based on data from the leading sellers in 1996.

**Figure VIII-1**

Distribution of Sources of Payment for Home Health Care, 1996\*



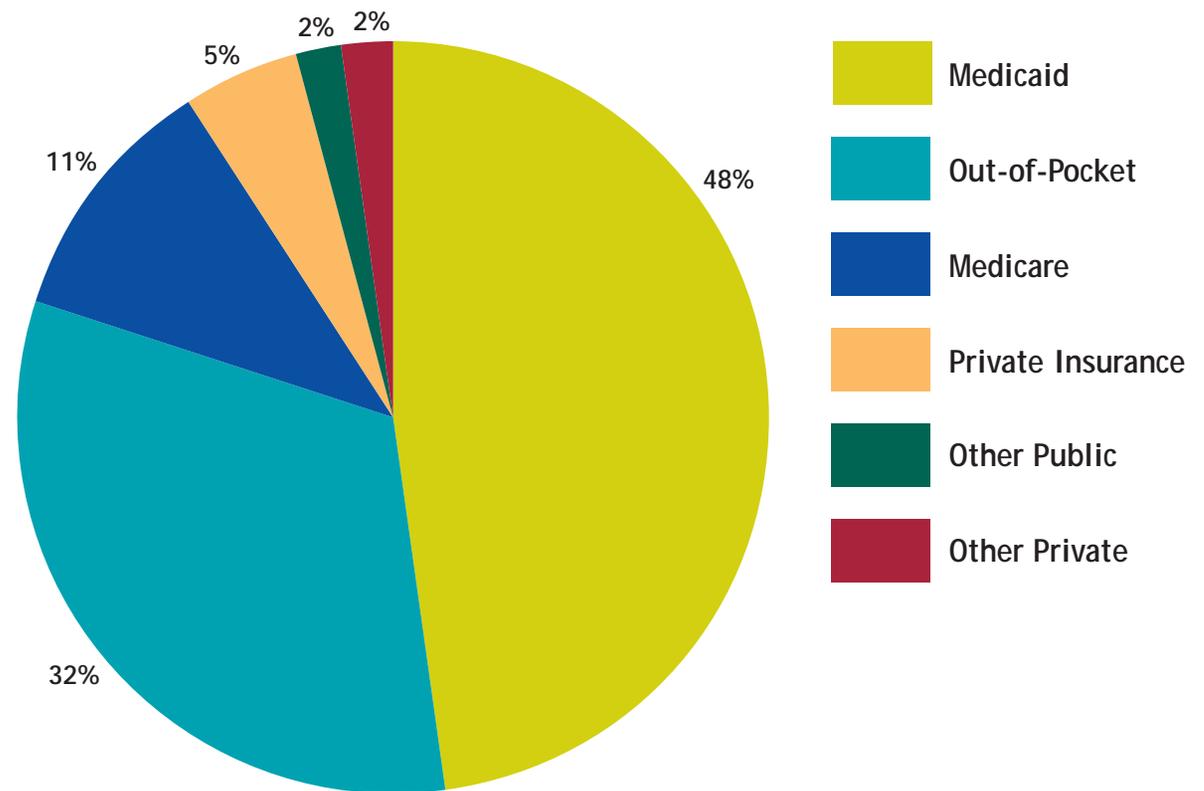
The Medicare home health benefit has grown rapidly in recent years. Despite its limitations on services provided, it has surpassed Medicaid as a source of financing for home care. Because nearly all persons age 65 and older participate in Medicare, they have comparatively easy access to its home health benefits. On the other hand, Medicaid offers only limited home and community-based long-term care services, and individuals must have few resources to receive benefits. For example, most state Medicaid programs allow people to have no more than \$2,000 in financial assets (excluding the value of one's home and certain other assets). This figure illustrates the sources of payment for home health care provided by free-standing home care agencies for persons of all ages. Total spending on home health care amounted to \$30.2 billion in 1996 from free-standing home care agencies. An additional \$7.8 billion was spent on home health care services provided by hospital-based agencies, but the sources of payment for hospital-based agency services were not available.

Source: Levit, Katherine R., Helen C. Lazenby, et al. "National Health Expenditures, 1996," *Health Care Financing Review*, Fall 1997, Volume 19, Number 1: 161-200.

\*Includes only home care provided by free-standing home care agencies.

**Figure VIII-2**

Distribution of Sources of Payment for Nursing Home Care, 1996\*

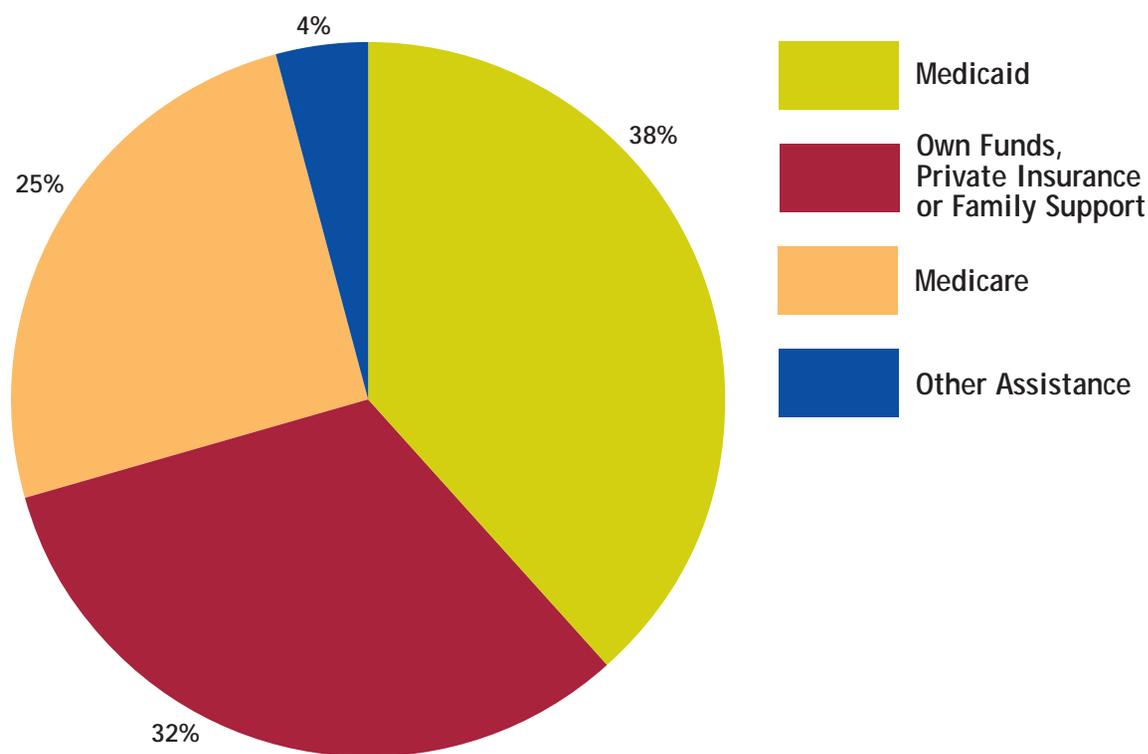


Total Dollars Spent=\$78.5 billion

Medicaid is the primary source of payment for nursing home care in the U.S. Out-of-pocket spending is the next largest source of nursing home care financing. Public and private spending on nursing home care provided in free-standing facilities to persons of all ages totaled \$78.5 billion in 1996. The sources of payment for these services are illustrated in this figure. An additional \$9.0 billion was spent on nursing home services provided in hospital-based facilities, but sources of payment for these services were not available.

**Figure VIII-3**

Distribution of Nursing Home Residents Age 65+ at Admission, by Primary Source of Payment at Admission, 1995

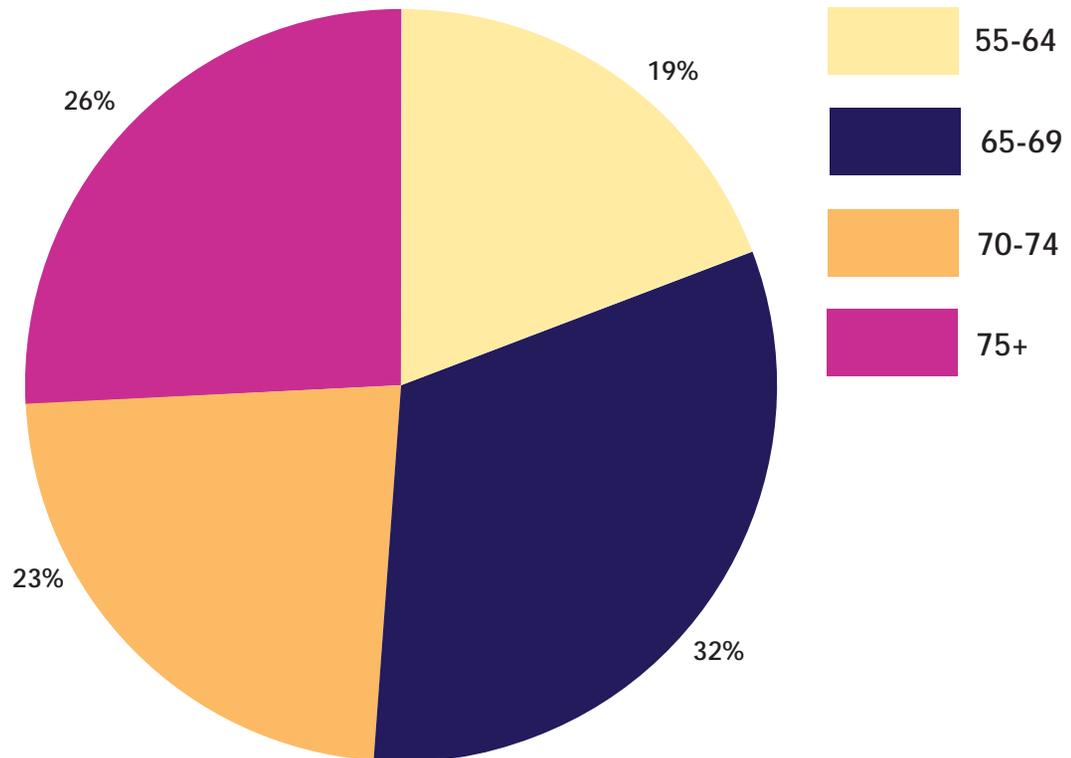


The primary source of payment for older nursing home residents at the time of admission most often is Medicaid (38 percent). One-fourth of residents (25 percent) rely on Medicare at admission. Most of the remaining residents (32 percent) use their own funds, private insurance, or family help to pay for their care at the time of admission.

The distribution of payment source at admission is different from patterns seen on a given day in nursing homes. Medicare only covers the first 100 days of care offered in a *skilled* nursing facility, and offers meaningful coverage for only the first 20 days. (Beyond 20 days, residents must pay a very high coinsurance – \$95.50 per day in 1998.) So while Medicare coverage at *admission* is significant, its overall role in funding nursing home care is considerably smaller. Conversely, the role of Medicaid in funding nursing home care increases, as individuals who are able to pay for their own care at the time of admission ultimately deplete their resources and come to rely, at least in part, on Medicaid.

Source: Dey Achintya N. "Characteristics of Elderly Nursing Home Residents: Data from the 1995 National Nursing Home Survey," Advance Data Number 289, National Center for Health Statistics, July 2, 1997.  
Note: Numbers do not add to 100% due to rounding.

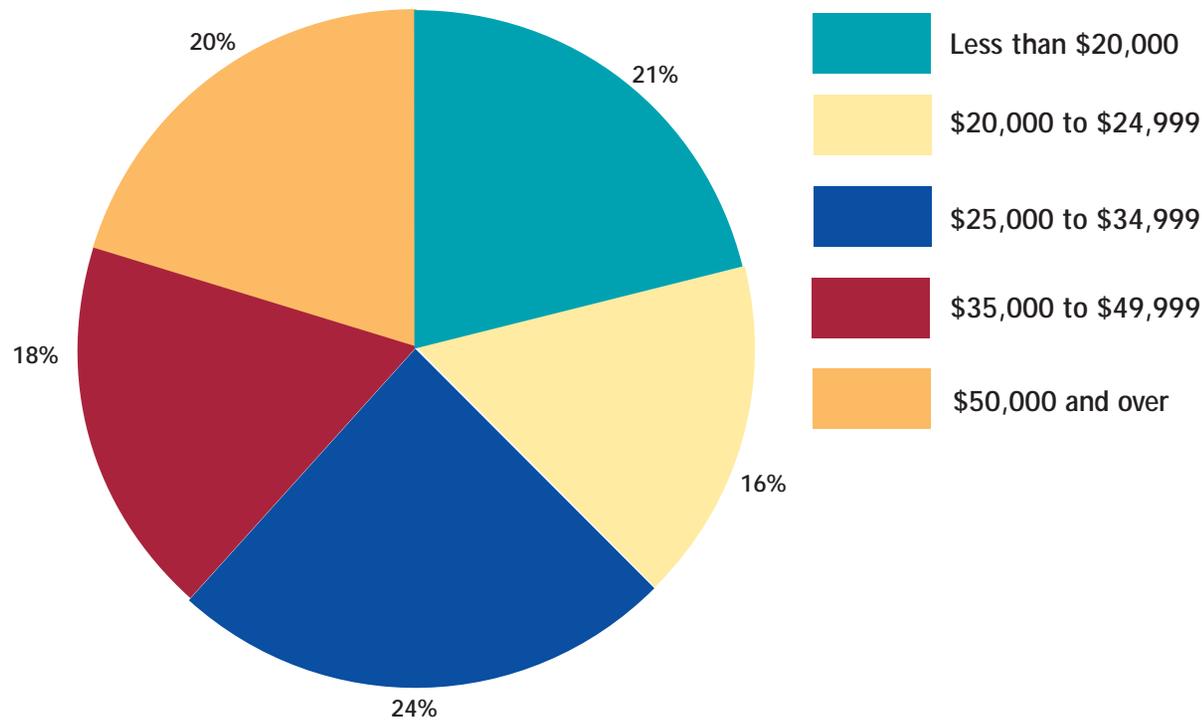
**Figure VIII-4**  
Distribution of LTC Insurance Purchasers, by Age, 1994\*



The average age at which individuals purchase long-term care insurance policies is 69. This figure illustrates the distribution of long-term care insurance purchasers by age at time of purchase. Although the cost of long-term care insurance is considerably lower when purchased at younger ages, most individuals do not begin to be concerned about their future need for long-term care until they are older.

**Figure VIII-5**

Distribution of LTC Insurance Purchasers, by Income, 1994\*

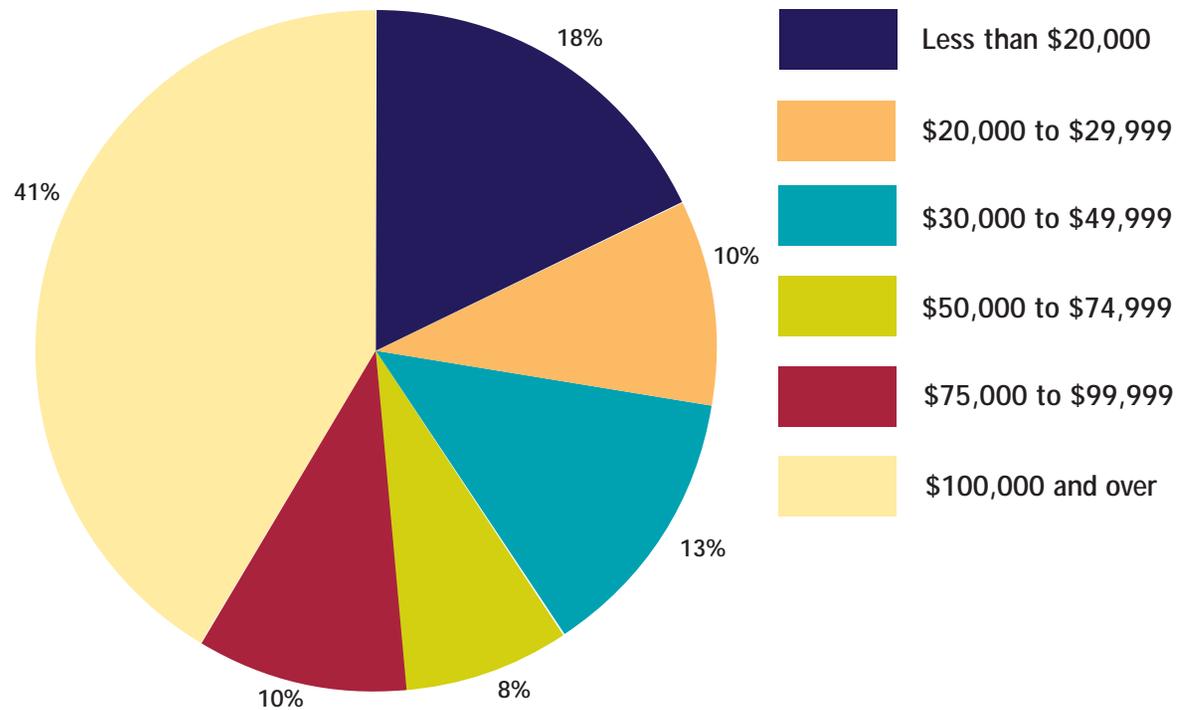


People with very low incomes are more likely to be eligible for Medicaid coverage of their long-term care expenses. However, because Medicaid has very restrictive asset rules, some individuals with relatively low incomes have too many assets to qualify for Medicaid. Rather than deplete their assets and then turn to Medicaid, some individuals choose to purchase long-term care insurance. This figure illustrates the distribution of long-term care insurance purchasers, by income.

Source: LifePlans Inc., "Who Buys Long-Term Care Insurance? 1994-1995 Profiles and Innovation in a Dynamic Market," Health Insurance Association of America, 1995.  
Note: Numbers do not add to 100% due to rounding.  
\*Based on a survey of 2,601 purchasers.

**Figure VIII-6**

Distribution of LTC Insurance Purchasers, by Total Liquid Assets, 1994\*



Long-term care insurance is most attractive to people who have substantial assets. A plurality of purchasers (41 percent) have \$100,000 or more in assets. Yet a notable percentage of purchasers have relatively low liquid assets; 18 percent have less than \$20,000.

## **Introduction**

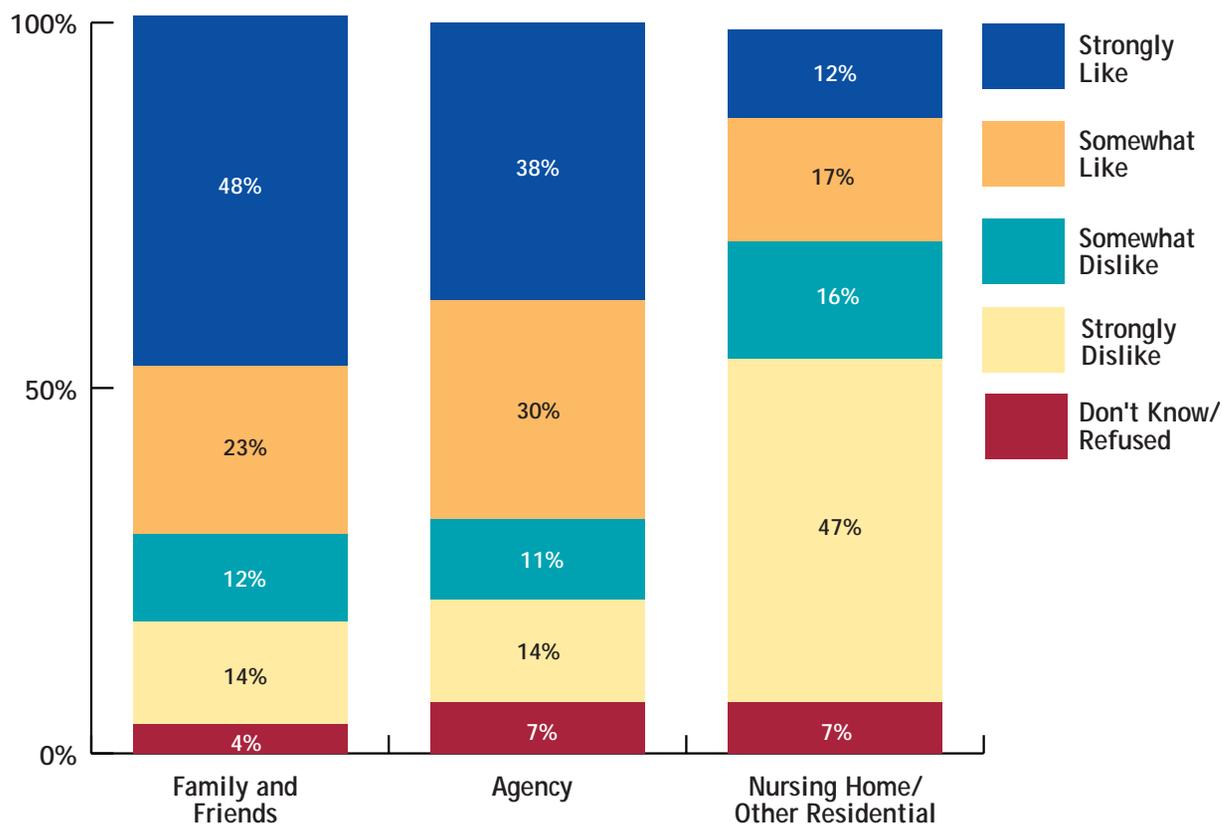
Despite the overwhelming preference of Americans to receive long-term care services in their own homes for as long as possible, the majority of public spending for long-term care remains devoted to institutional forms of care. This disparity between public preferences and public policy highlights the continuing need for reform of long-term care systems at the federal and state levels. Until public spending on long-term care allows more people with disabilities to receive services in their homes, without the threat of impoverishment, families will continue to incur the physical, emotional, and financial hardships associated with caregiving as they attempt to keep their loved ones out of institutions. This section presents the results of a 1997 AARP-sponsored telephone survey of 1,243 people age 50 and older on their attitudes toward long-term care. The survey was conducted by International Communications Research (ICR).

## **Part IX**

### **Public Attitudes on Long-Term Care**

Respondents were asked to rate whether or not they liked various long-term care options, if they or a member of their family were to need help with everyday activities. Both agency-provided services received in an individual's home and care provided by family members and friends are strongly preferred over nursing home or other residential options. Nearly half of respondents (47 percent) strongly *dislike* the option of having care provided in a nursing home or other residential setting. Among the *preferred* options, the preference for family and friends to provide care is somewhat stronger: 48 percent of respondents strongly like this option, while 38 percent of respondents strongly like an agency-provided services option.

**Figure IX-1**  
 Preferences for Type of Long-Term Care Provider, 1997\*



Source: ICR. "AARP Long-Term Care Excel Insert: Tabulation Report," December 3-16, 1997.

Note: Numbers do not add to 100% due to rounding.

\*Based on a survey of 1,243 persons age 50+.

These graphs represent answers to the following questions:  
 "If you or a member of your family had a disability and needed help with everyday activities such as bathing, dressing, cooking, and shopping, would you like:

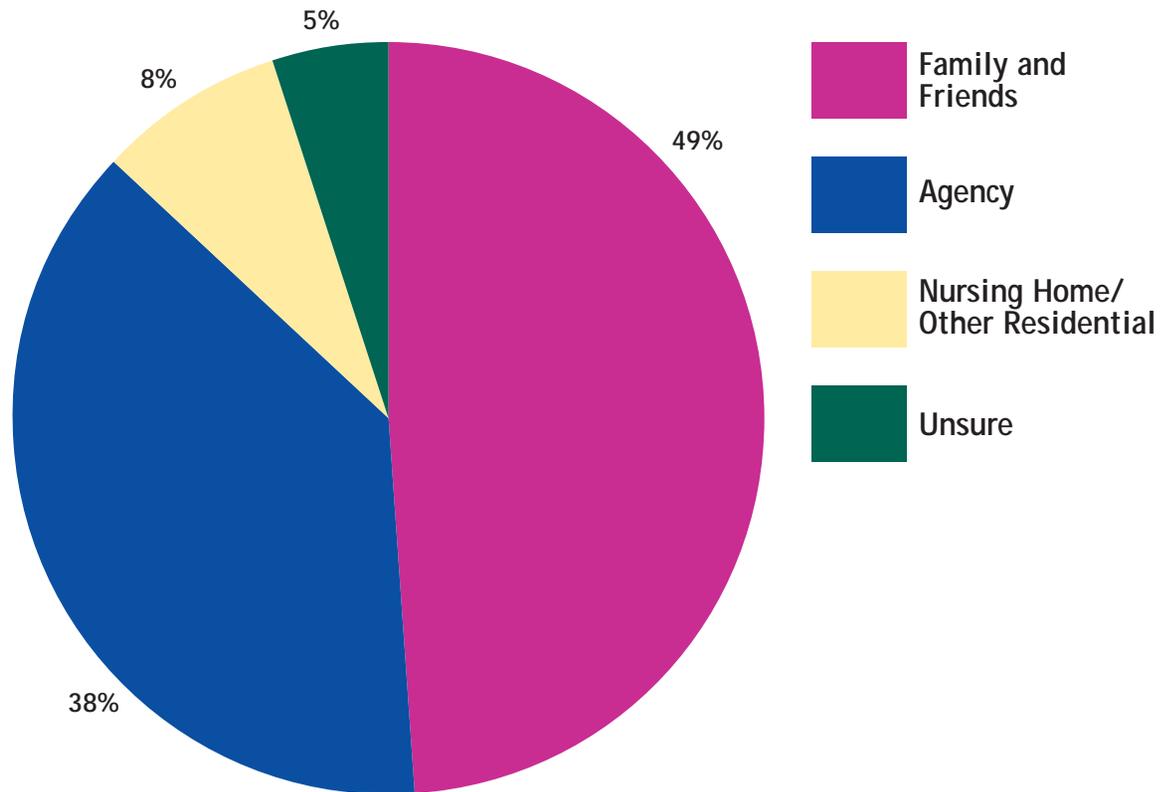
...to have family and friends provide all the care at home?

...to have services provided at home by an agency?

...to have care provided in a nursing home or other residential setting?"

## Figure IX-2

### Distribution of First Choice in Long-Term Care Provider, 1997\*



When respondents were asked to express their *first* choice for receiving care, the preference for home-based options became even stronger. Nearly half of respondents prefer help from family or friends, 38 percent view agency-provided services as their first choice, and only 8 percent consider nursing homes or other residential options as a first choice.

Source: ICR. "AARP Long-Term Care Excel Insert: Tabulation Report," December 3-16, 1997.

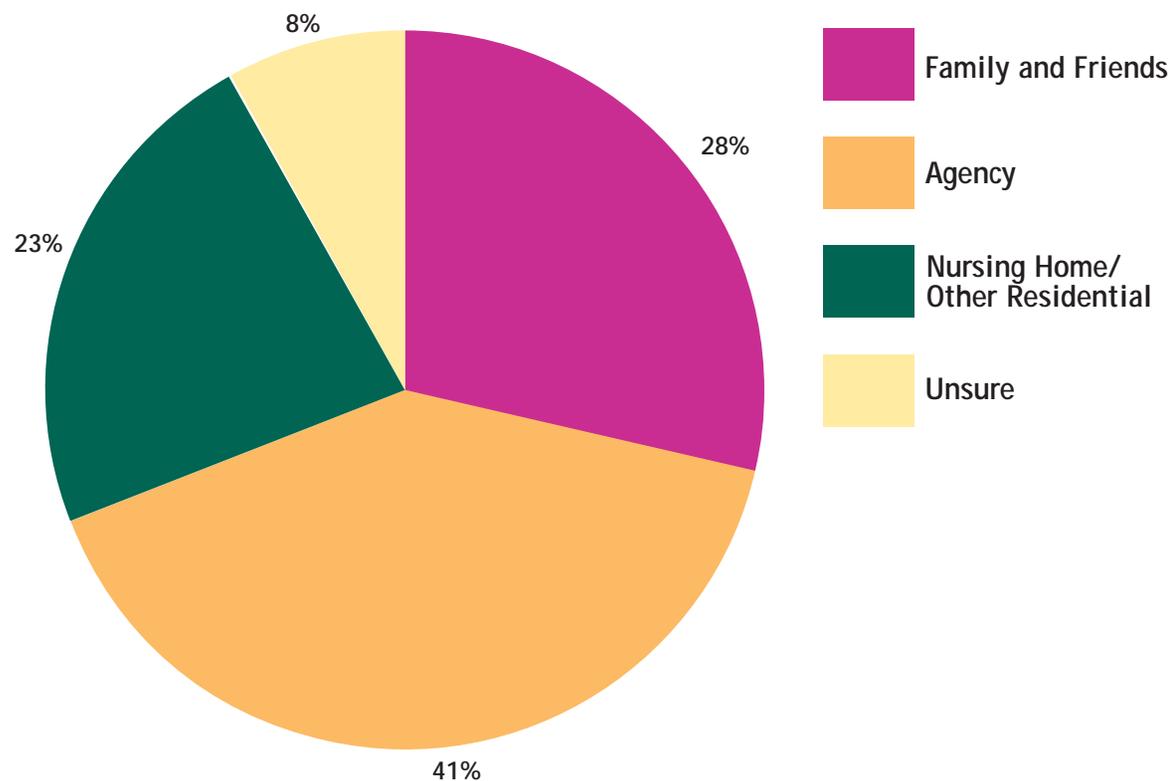
\*Based on a survey of 1,243 persons age 50+.

This graph represents answers to the following question,

"Thinking of the choices you liked most, and considering all aspects, what would be your FIRST choice for receiving care if you or a member of your family needed help with everyday activities?"

Most long-term care is provided informally by family members and friends. But as an individual's disabilities increase, the demands associated with keeping a loved one at home can become overwhelming. Respondents were asked to rate their first choice for receiving care for themselves or a family member, if that person needed help 24 hours a day. Even under this scenario, receiving care in a nursing home or other residential setting is the first choice of the fewest respondents; however, the preference shifts to agency-provided care delivered at home over family and friends providing care at home.

**Figure IX-3**  
Distribution of First Choice in 24-Hour per Day Long-Term Care Provider, 1997\*



Source: ICR. "AARP Long-Term Care Excel Insert: Tabulation Report," December 3-16, 1997.

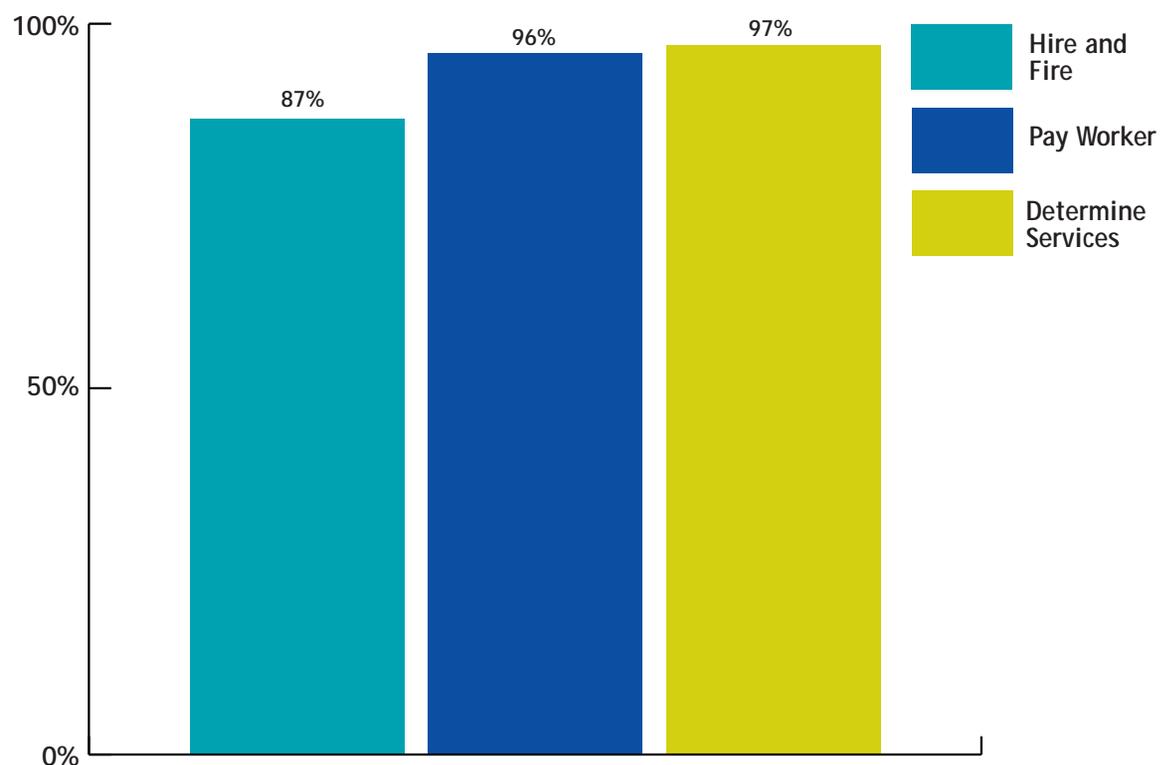
\*Based on a survey of 1,243 persons age 50+.

This graph represents answers to the following question,

"Suppose you or a member of your family had a disability and needed care 24 hours a day (rather than just help with everyday activities), what would be your FIRST choice for receiving 24-hour-a-day care?"

## Figure IX-4

Percent of Respondents Who Are Willing to Perform Various Functions, 1997\*



There is a growing interest in allowing people who receive publicly-funded long-term care services to exercise more choice and autonomy in the receipt of their care. The concept of consumer-directed care allows people with disabilities to bypass established care management systems that, traditionally, have authorized and arranged for services. Instead, people with disabilities are given the option of hiring their own home care worker and deciding for themselves what services they need.

Respondents were asked if they would prefer a program that would let them manage their own home care services rather than receive services managed by an agency. More than three-fourths (76 percent) prefer a consumer-directed home care program. This figure illustrates the percentage of respondents reporting that they would be willing to perform various functions.

Source: ICR. "AARP Long-Term Care Excel Insert: Tabulation Report," December 3-16, 1997.

\*Based on a survey of 958 respondents age 50+ who preferred self-managed home care services.

This graph represents answers to the following questions,

"1. Would you be willing to hire and fire your own home care worker yourself?"

"2. Would you be willing to pay your own homw care worker yourself, assumeing you receive money everymonth for this purpose?"

"3. Would you be willing to decide for yourself what services you receive?"

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### Introduction

This chartbook attempts to portray data in a simple and easy-to-understand format. In doing so, detailed descriptions of the sources of data used to generate the charts were not included in the text that accompanies the graphs. However, many factors in the way that disability is defined will affect the number of people who are judged to have disabilities. These differences can be quite large. The following factors can affect estimates of functional disability based on ADLs and IADLs:

- types and numbers of ADLs and IADLs used;
- definition of disability (e.g., receives help, has difficulty);
- duration of disability;
- wording of the items;
- order of the items; and
- selection of the sample.

This technical appendix addresses many of these definitional issues, provides more detail about the sources of data used and, where appropriate, describes the methods used to generate data.

### **ICR. “AARP Long Term Care EXCEL Insert: Tabulation Report”**

AARP contracted with ICR to include several questions on two of its regularly-conducted EXCEL surveys. The AARP survey questions were asked on EXCELS between December 3 and December 16, 1997, with a national sample of 1,243 persons age 50 and older. The survey asked respondents questions about their preferences for care arrangements in case of disability, if they or a member of their family had a disability and needed help with everyday activities such as bathing, dressing, cooking, and shopping. Questions ranged from type of provider preferred to whether respondents would prefer a program allowing them to manage their own home care services, over home care services managed by an agency. Respondents who preferred self-directed care were then asked about their willingness to perform various functions, such as hiring and firing their home care worker, or deciding what home care services they would receive.

EXCEL is a national twice-weekly telephone omnibus service. Each EXCEL survey consists of a minimum of 1,000 interviews,  $\frac{1}{2}$  with men and  $\frac{1}{2}$  with women. EXCEL uses a fully-replicated, stratified, single stage random-digit-dialing sample of telephone households. Sample telephone numbers are computer generated and loaded into on-line sample files accessed directly by ICR's computer system. Within each sample household, one adult respondent is randomly selected using a computerized procedure based on the "Most Recent Birthday Method" of respondent selection. Interviewing for each EXCEL survey is conducted over a five-day period, encompassing both weekdays and weekends. Up to four attempts are made to a number on various days and at different time periods. The EXCEL responses provided to AARP were weighted to provide nationally representative and projectable estimates of the adult population 50 years of age and older. The weighting process takes into account the disproportionate probabilities of household selection due to the number of separate telephone lines and the probability associated with the random selection of an individual household member. Following the application of weights, the sample is post-stratified and balanced by key demographics such as age, sex, region, and education.

**The Lewin Group. Analysis of Data from the 1994 National Health Interview Survey of Disability, Phase I (NHIS-D) and the 1994 National Long-Term Care Survey (NLTC).**

**National Health Interview Survey of Disability, Phase I (NHIS-D)**

Because AARP wanted to present data on the population age 50 and older with disabilities, the primary database used for this chartbook was the NHIS-D, Phase I. The NHIS-D contains data on people of all ages who have disabilities. The household sample of the NHIS is a continuing nationwide personal interview household survey. It uses a national sample of the civilian, non-institutionalized U.S. population. The NHIS is conducted annually. The sample is composed of 36,000 to 47,000 households, including 92,000 to 125,000 persons, depending on the year. Data are available for each year from 1969 through 1994. Each year, special modules and supplementary data about particular areas of interest are included with the survey. In 1994, a module included supplementary data on disability. The sample size for the NHIS-D, Phase I was 107,469 people of all ages. Of this sample, 28,004 were above age 50 and 13,541 were above age 65.

Five ADLs and six IADLs are included in the NHIS-D and were used in the Lewin Group analysis. The ADLs used were:

- bathing or showering;
- dressing;
- eating;
- getting in and out of bed or chairs (transferring); and
- using the toilet.

IADLs considered included:

- preparing meals;
- shopping;
- managing money;
- using the telephone;
- doing heavy work around the house; and
- doing light work around the house.

The NHIS-D includes three levels of ADL/IADL disability: “has difficulty”; “receives help and/or needs supervision or cueing”; and “receives help.” The data included in this chartbook use the receives help and/or needs supervision or cueing definition. Anyone who responded that they received help on the “receives help” item or responded that they needed supervision or cueing was classified as being impaired under this definition. A recode variable included in the survey was used to accomplish this goal.

With regard to the duration of disability, the NHIS-D contains data on people whose disabilities are of any duration. A later question asks whether disability in ADLs/IADLs is expected to last 12 months or longer. Because of its late placement in the survey, there are a substantial number of missing data on the “12 months or longer” question. Concerns about the adequacy of cell sizes for data analysis led us to use responses for disability of any duration in this chartbook. This decision could result in the inclusion of some individuals whose disabilities are not long-term. However, we also were concerned that the “12 month” duration criterion could be overly restrictive, given that disability that is expected to last for three months or longer is more generally accepted by researchers as constituting a long-term need for services.

The Lewin Group selected ADLs and IADLs and definitions of disability that are similar to those used in most of the other literature on functional disability. Generally, the Lewin Group found their estimates of the number of people with ADL impairments to be similar to estimates derived from other surveys, such as the National Long-Term Care Survey, and the Survey of Income and Program Participation. However, estimates of the number of people with IADL impairments differ substantially across surveys. The Lewin Group found that one of the crucial differences in these estimates is whether heavy housework is included in the survey.

### **National Long-Term Care Survey (NLTC)**

In several areas, data from the NHIS-D were supplemented with data from the NLTC to provide a more precise level of detail. In particular, the NLTC was used to supplement data on caregivers and cognitive impairment.

The NLTC includes data on people with chronic disabilities (disability that lasted, or was expected to last, at least 90 days). The NLTC was designed to provide information on the community-residing and institutionalized Medicare populations age 65 and older with disabilities. Data were collected in 1982, 1984, 1989, and 1994. The survey consists of (1) a screening interview to determine the impairment status of the sample person; (2) a detailed community interview for all non-institutionalized persons determined to be impaired in the 1989 or the current survey; (3) an abbreviated community interview for persons determined to be unimpaired; and (4) a detailed institutional interview for persons in institutions. The size of the community sample in 1994 was 5,000 to 6,000 persons, while the size of the institutional sample in 1994 was 1,300.

### **Caregivers**

The Helper file in the NLTC asks detailed questions about individuals providing assistance with ADLs and IADLs. The NLTC asks for the following information for each individual who provides assistance to the individual with disabilities (information is coded for up to eight helpers):

- whether the helper provides assistance with any ADL;
- whether the helper provides assistance with any IADL;
- with which ADLs and IADLs the helper provides assistance;

- relationship of the helper to the person with disabilities;
- number of days per week the helper provides help;
- number of hours per week the helper helps with ADLs;
- number of hours per week the helper helps with IADLs;
- whether the helper is paid to help; and
- the payment source.

Information was summed across all helpers to obtain estimates of the number of helpers and types of help they provide. Thus, estimates reflect all helpers assisting with ADLs or IADLs, not just the primary caregivers.

### **Estimates of Cognitive Impairment.**

The Lewin Group estimated the prevalence of cognitive impairment among people age 50 and older, using data from the 1994 NHIS-D and the NLCTS. The NLCTS measures cognitive impairment in several ways. However, while it contains the most detailed measures of cognitive impairment, it does not include the population under age 65. Although the NHIS-D does not contain a standardized test measuring cognitive impairment, such as a mental status or cognitive function questionnaire, it contains a number of other measures of cognitive impairment. These variables capture both severe cognitive impairment, such as the presence of Alzheimer's and other senility disorders, as well as more moderate cognitive impairments, such as the presence of confusion or difficulty concentrating. The 1994 NHIS, including the disability and the aging supplements, contains items that can identify persons with cognitive impairments across all ages.

A factor analysis was conducted on these measures of cognitive impairment to determine if the variables could be summarized using just one scale. This analysis revealed only one construct, supporting a summarization across the cognitive impairment measures. The variables were summarized to establish two levels of cognitive impairment: severe and moderate. Individuals were classified as having severe cognitive impairment if they:

- had a diagnosis of Alzheimer's disease or another dementia-related disorder; or
- had someone to stay nearby to help with one or more ADLs *and* scored as being cognitively impaired on at least one other measure of cognitive impairment.

Individuals not classified as having severe cognitive impairment, while being impaired on other measures of cognitive impairment, were defined as having moderate cognitive impairments. Measures that were used to capture those with moderate cognitive impairments included having trouble concentrating long enough to complete everyday tasks, having serious difficulty learning how to do things that most people their age are able to learn, and being frequently confused, disoriented, or forgetful.

The NLTCs contains detailed information on the cognitive functioning of persons age 65 and older. The Lewin Group benchmarked two of the measures of cognitive impairment available in the NHIS-D with measures included in the NLTCs. This comparison included both examining prevalence rates for variables that are similar across both surveys (cross-survey variables) and examining the relationship between the cross-survey variable and two other methods of assessing cognitive impairment.

#### **Cross-Survey Measures**

In order to compare findings across surveys, The Lewin Group constructed new variables so that cognitive impairment was defined similarly in each of the two surveys. They made comparisons using the following two indicators of cognitive impairment:

- **Alzheimer's:** Because the NHIS-D measure of Alzheimer's disease addresses both Alzheimer's and senility, the separate measures of Alzheimer's and senility were combined in the NLTCs to produce estimates that could be compared.
- **Confusion:** Four NLTCs measures of confusion were combined in order to match the NHIS-D definition of confusion (frequently confused, disoriented, or forgetful). Three survey questions designed to measure confusion and the interviewer observation that the individual was confused (CONREPT) were included. The NLTCs items asked of the respondent are as follows: (1) loses their way and cannot find the way back, (2) forgets to do important things, such as eating, taking medicine, or paying bills, or (3) takes items belonging to others without meaning to do so. Individuals are classified as being impaired if they or a proxy report being impaired on any of these items.

#### **Other Measures**

Prevalence rates for the cross-survey variables were then compared with rates resulting from definitions used by: (1) William Spector (1991) in "Cognitive Impairment and Disruptive Behaviors Among Community-Based Elderly Persons: Implications for Long-

Term Care,” *The Gerontologist* 31(2),51-59; and (2) Beth Jackson (1997) in “New Research: Implications for Product Design and Pricing,” paper presented at the 12th Annual Private Long-Term Care Insurance Conference, November 5, 1997, San Diego, CA. The Spector/Jackson definition classifies individuals as being cognitively impaired if they meet one of the following criteria:

- Scores indicating moderate or severe impairment (four or more errors) on the Short Portable Mental Status Questionnaire.
- Affirmative responses to items addressing Alzheimer’s, mental retardation, and senility.

The Lewin Group also used Jackson’s second classification of cognitive impairment: cognitive impairment with evidence of need for care. This definition classifies individuals as having cognitive impairment with evidence of need for care if they both meet the criteria set out above, and are impaired on one or more ADL, or have one or more behavior problem (wandering, frequent temper tantrums, or compulsive stealing), or are impaired on one or more cognitive IADL (money management, medication management, or telephoning).

The level of missing data in the NLTCs complicates analysis of this survey. Although the percentage of persons with missing data is below one percent for some variables of interest, approximately 10 percent of persons designated to receive the mental status questionnaire (non-proxies) have no data for the series of questions. Duke University’s Center for Demographic Studies is aware of this problem and notes that because the cognitive functioning section was administered at the end of the survey, there may have been high rates of attrition due to fatigue. The Alzheimer’s and senility variables also have a high percentage of missing values: up to 35 percent of the sample given these questions (proxies) are missing data.

This level of missing data compromises the validity of many of the cognitive impairment estimates derived from the NLTCs. Jackson (1997) produced two estimates of cognitive impairment that varied only in how missing data was apportioned. The 18 percent difference between these estimates demonstrates the unreliability caused by missing data (1,451,000 versus 1,230,000 cognitively impaired individuals, depending on how individuals with missing data were classified).

There are enormous complexities involved in quantifying cognitive impairment. The specific criteria used can result in different persons being classified as cognitively impaired. Further investigation needs to be conducted to assess the implications of using one criterion over another, but such investigations were beyond the scope of this project.

### **Projections of the Number of Persons by Disability Level**

The Lewin Group projected the number of people age 65 and over that will be living in the community with disabilities to the year 2050. Projections were based on U.S. Census Bureau projections of the population by age and sex. Census Bureau projections were adjusted to remove individuals residing in nursing facilities. To accomplish this, prevalence rates of nursing home use by age and sex were derived from the 1995 National Nursing Home Survey and applied to the Census Bureau projections. This method assumes that nursing facility prevalence rates will remain stable until 2050. The Lewin Group chose to keep nursing facility use flat because trends that may explain nursing facility use are inconsistent. For example, nursing facility occupancy rates appear to have declined in the first half of the 1990s. Greater availability of home and community-based alternatives to nursing facilities could continue this trend. However, the low fertility of the baby boom generation may counteract this trend. Baby boomers will have fewer potential informal caregivers and, therefore, may be more likely to rely on nursing facilities.

To generate the number of persons in the community by disability level, The Lewin Group applied the distribution of disability for each sub-category derived from its analysis of the 1994 NHIS-D to the Census Bureau projections that they modified to remove individuals in institutions. This methodology assumes that prevalence of disability will remain constant into the future. Recent research by Manton (1997) and his colleagues suggests that disability rates have been declining. At the time this analysis was done, The Lewin Group did not consider the trends observed by Manton in these projections for two reasons:

- other researchers had questioned whether these trends were real or a result of inaccuracies associated with assessing ADL/IADL impairment; and
- trends occurring over the past decade may not continue in the future.

## **Reliability of the Estimates**

Estimates based on fewer than 30 records were deemed to be unreliable, as they are likely to have high standard errors and are, therefore, subject to considerable variability. No estimates based on fewer than 30 records were included in this chartbook.

The standard error is the most commonly used measure of the precision of an estimate. Statistical analysis packages such as SUDAAN can be used to calculate standard errors from national surveys like the NHIS-D and the NLTCs, which have complex sample designs that must be accounted for in the calculation of the standard error. SUDAAN analyses of selected tabulations from the NHIS-D indicate that cell counts of about 25 records are generally associated with standard errors of less than 20 percent of the mean, a reasonable threshold for the purposes of these tabulations. A more conservative threshold of 30 records was applied to estimates from both the NHIS-D and the NLTCs.

## **National Health Expenditures**

The Health Care Financing Administration's report on National Health Expenditures presents data on the history of health care delivered (hospital care, physician services, nursing home care, etc.) in the United States through spending for health care services and the sources of funding for that care (private health insurance, Medicare, Medicaid, out-of-pocket spending, etc.) from 1960 through 1996. Data presented on expenditures for home health care and nursing home care are based only on free-standing agencies and facilities (and do not include hospital-affiliated agencies or hospital-based nursing homes). Data were published in the HCFA Review (see citation for Levit).

## **National Home and Hospice Care Survey**

The National Center for Health Statistics (NCHS) established the National Home and Hospice Care Survey (NHHCS) in 1992. Information collected through the NHHCS includes national baseline data on the characteristics of hospices and home health agencies in relation to the patients they serve and the type of staff they employ. Information also is collected on Medicare and Medicaid certification, on charges to patients by hospice and home health agencies, and on sources of payment for services. Information about patients' functional status and diagnosis while receiving home and hospice care is collected.

The data used in this publication are from the 1994 and 1996 surveys. The National Center for Health Statistics' 1994 NHHCS sample of current patients and discharges age 65 years and over was used for beneficiary characteristics. The 1994 sample contained 1,510 agencies. The data used focused on personal help provided by home health care agencies in relation to ADLs and IADLs. It did not include help provided by other sources. Data on agency characteristics were derived from the 1996 survey, which included 1,200 agencies selected from a universe of 16,700 agencies classified as agencies providing home health and hospice care. All data used in this chartbook were previously published in NCHS Advance Data Numbers 274, 279, and 297. Full citations appear in the reference list.

### **National Nursing Home Survey**

The 1995 National Nursing Home Survey (NNHS) collected baseline statistics about nursing homes, their services, and residents. Data produced are from two perspectives: that of the recipient of services and that of the provider of services. Data about the facilities include basic characteristics such as size, ownership, Medicare/Medicaid certification, and services provided. Data about the residents include basic demographics, marital status, place of residence prior to admission, health status and services received. Information was collected from a number of sources in each sampled nursing home, including the administrator, accounting department, staff members, and medical records. No residents were interviewed directly. All data used in this chartbook were previously published in NCHS Advance Data Numbers 280 and 289. Full citations for Advance Data appear in the reference list.

The sampling frame for the 1995 NNHS was the 1991 National Health Provider Inventory (NHPI) as updated by the Agency Reporting System to include nursing facilities that were either missed in the 1991 NHPI or that began operation after the 1991 Inventory was completed. The NNHS and the NHPI are segments of the long-term care component of the National Health Care Survey. The universe of facilities for the 1995 NNHS included nursing and related care homes in the continental United States that had three or more beds, were staffed for use by residents, and routinely provided nursing and personal care services. The frame for the sample selection contained 17,500

nursing homes from which 1,500 facilities were sampled. Estimates of nursing facility characteristics are based on 1,409 responding nursing homes and 8,056 of their current residents. (See Advance Data Number 280.) Estimates of the characteristics of elderly nursing home residents are based on current residents who were age 65 and older at the time of admission to the nursing home, and are based on responses for 7,165 current residents age 65 and over. (See Advance Data Number 289.)

### **U.S. Bureau of the Census, Current Population Reports**

The U.S. Bureau of the Census uses six sets of data to generate population projections using a cohort-component model. These data include a base-year population, projected fertility rates, projected survival rates, future net immigration statistics, 1990 inflation/deflation rates, and an estimated Armed Forces overseas population. The most difficult aspect of producing these population projections involves deriving the base-year starting points and rates. Each data set is organized into 16 different race/ethnic/sex matrices, with each matrix containing a cell for each year of age from 0 to 100 and over. The sixteen matrices are the four races – White; Black; American Indian, Eskimo, and Aleut; Asian and Pacific Islander – by Hispanic origin (Hispanic and Not Hispanic) and sex. The sum of all cells in all 16 matrices equals the total population. Census data used in this report were obtained from the “Statistical Abstract of the United States: 1997.”

AARP, celebrating 40 years of service to Americans of all ages, is the nation's leading organization for people age 50 and older. It serves their needs and interests through information and education, advocacy, and community services which are provided by a network of local chapters and experienced volunteers throughout the country. The organization also offers members a wide range of special benefits and services, including *Modern Maturity* magazine and the monthly *Bulletin*.



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