100TH CONGRESS
2d Session

SENATE

REPT. 100-291
Volume 3

DEVELOPMENTS IN AGING: 1987
VOLUME 3

THE LONG-TERM CARE CHALLENGE

A REPORT

OF THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

PURSUANT TO

S. RES. 80, SEC. 19, JANUARY 28, 1987

Resolution Authorizing a Study of the Problems of the Aged and Aging

FEBRUARY 29, 1988.—Ordered to be printed

100TH CONGRESS
2d Session

SENATE

REPT. 100-291
Volume 3

DEVELOPMENTS IN AGING: 1987
VOLUME 3

THE LONG-TERM CARE CHALLENGE

A REPORT

OF THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

PURSUANT TO

S. RES. 80, SEC. 19, JANUARY 28, 1987

Resolution Authorizing a Study of the Problems of the Aged and Aging

FEBRUARY 29, 1988.—Ordered to be printed

U.S. GOVERNMENT PRINTING OFFICE

83-347 WASHINGTON : 1988

SPECIAL COMMITTEE ON AGING

JOHN MELCHER, Montana, *Chairman*

JOHN GLENN, Ohio	JOHN HEINZ, Pennsylvania
LAWTON CHILES, Florida	WILLIAM S. COHEN, Maine
DAVID PRYOR, Arkansas	LARRY PRESSLER, South Dakota
BILL BRADLEY, New Jersey	CHARLES E. GRASSLEY, Iowa
QUENTIN N. BURDICK, North Dakota	PETE WILSON, California
J. BENNETT JOHNSTON, Louisiana	PETE V. DOMENICI, New Mexico
JOHN B. BREAUX, Louisiana	JOHN H. CHAFEE, Rhode Island
RICHARD SHELBY, Alabama	DAVE DURENBERGER, Minnesota
HARRY REID, Nevada	ALAN K. SIMPSON, Wyoming

MAX I. RICHTMAN, *Staff Director*
G. LAWRENCE ATKINS, *Minority Staff Director*
CHRISTINE DRAYTON, *Chief Clerk*

LETTER OF TRANSMITTAL

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC, February 29, 1988.

Hon. GEORGE BUSH,
President, U.S. Senate,
Washington, DC.

DEAR MR. PRESIDENT: Under authority of Senate Resolution 80, agreed to January 28, 1987, I am submitting to you the annual report of the Senate Special Committee on Aging, Developments in Aging: 1987, volume 3.

Senate Resolution 4, the Committee Systems Reorganization Amendments of 1977, authorizes the Special Committee on Aging "to conduct a continuing study of any and all matters pertaining to problems and opportunities of older people, including, but not limited to, problems and opportunities of maintaining health, of assuring adequate income, of finding employment, of engaging in productive and rewarding activity, of securing proper housing and when necessary, of obtaining care and assistance." Senate Resolution 4 also requires that the results of these studies and recommendations be reported to the Senate annually.

This report describes actions during 1987 by the Congress, the administration, and the Senate Special Committee on Aging which are significant to our Nation's older citizens. It also summarizes and analyzes the Federal policies and programs that are of the most continuing importance for older persons, their families, and for those who hope to become older Americans in the future.

On behalf of the members of the committee and its staff, I am pleased to transmit this report to you.

Sincerely,

JOHN MELCHER, *Chairman.*

CONTENTS

	Page
Introduction	1
Section 1: Facts and Figures	5
A. The Need	5
B. The Impact of Chronic Illness and Disability	8
C. The Elderly Long-Term Care Population	10
D. Informal/Formal Caregiving: The Myth of Family Abandonment	18
E. Can the Elderly Afford Long-Term Care?	26
F. Federal Expenditures	30
Section 2: Long-Term Care Services	33
A. Nursing Homes	33
B. Home and Community-Based Services	41
C. Long-Term Care Services for Veterans	48
Section 3: New Developments in Long-Term Care Policy	55
A. Developments in Legislation	55
B. Future Directions	61
C. Conclusion	67

List of Charts and Tables

SECTION 1

Chart 1—Population 55 Years and Over By Age: 1900–2050	6
Chart 2—The Aging of the Veteran Population: 1980–2020	7
Chart 3—Number of Persons Needing Long-Term Care: 1980–2040	8
Chart 4—The Elderly Disabled Population: Community vs. Nursing Home Residence	11
Chart 5—The Elderly Disabled Population: Age Distribution (Community and Nursing Home Residents)	13
Chart 6—The Elderly Long-Term Care Population: Marital Status and Sex Distribution (Community and Nursing Home Residents)	15
Chart 7—The Elderly Disabled Population: Percent With Severe Limitation in Daily Activity (Community and Nursing Home Residents)	16
Chart 8—Nursing Home Residents By Living Arrangements Prior to Admission: 1985	17
Chart 9—Who Provides Care? Caregivers and Their Relationship to Elderly Care Recipients	20
Chart 10—Who Provides Care? Percent of Caregiving Days By Relationship to the Caregiver	21
Chart 11—Who Provides Care? Distribution of Caregivers By Age	23
Chart 12—Tasks Performed By Caregivers	25
Chart 13—Out-Of-Pocket Health Costs for Persons With Over $2,000 in Expenditures: 1980	27
Chart 14—Nursing Home Costs By Source of Payment: 1980 vs. 1987	28
Chart 15—Community-Based Long-Term Care Costs By Source of Payment	32
Table 1—Risk of Death of Persons 65 and Over—1984	9
Table 2—Tracking the Community Elderly Over a 2-Year Period, 1982–84	10
Table 3—Characteristics of the Disabled Elderly Living in the Community and in Institutions	14
Table 4—Major Characteristics of Caregivers by Relationship of Caregiver to Disabled Person	21–22
Table 5—Caregiver Commitment by Relationship of Caregiver to Disabled Person	24
Table 6—Nursing Home Payment, 1984 Long-Term Care Survey	31

SECTION 2

Table 1—Nursing Home Care—Trends and Costs	50
Table 2—VA Domiciliary Care—Trends and Costs	50

100TH CONGRESS
2d Session

SENATE

REPT. 100-291
Volume 3

DEVELOPMENTS IN AGING: 1987—VOLUME 3 THE LONG-TERM CARE CHALLENGE

FEBRUARY 29, 1988.—Ordered to be printed

Mr. MELCHER, from the Special Committee on Aging, submitted the following

REPORT

[Pursuant to S. Res. 80, 100th Cong.]

INTRODUCTION

Today, and well into the next century, the provision and financing of long-term care is, and will be, one of the major health policy issues facing older Americans and their children, the Federal Government, the States, insurers, health care providers, and aging advocates. There are five primary reasons why this is the case.

First, the driving force behind the increasingly louder calls for action on the long-term care issue is the fact that the United States is facing an unprecedented demographic change. The elderly population, with its high demand for long-term care services, has increased more rapdily than the rest of the population for most of this century. This trend will continue to the point that, by the year 2020, when the baby boom has reached retirement age, the 65-plus population is expected to double.

Second, life expectancy has advanced dramatically in this century, adding, on average, more years of disability to life. Death before age 65 is the exception rather than the rule in the 1980's, while in the early part of the century, the majority of persons did not reach the mid-60's. Today's 65-year-olds can expect to live to an average age of 82. But the irony of improved longevity is that not only have more healthy years been added to life, but more unhealthy years have also been added. Marked by a greater likelihood of chronic illness and disability, these later years are generating, and will continue to generate, a growing demand for long-term care services.

Third, other than the Medicaid Program, there is very little protection against the costs of long-term health care. Older Americans, who are chronically ill, are discovering that unless they are eligible for Medicaid (qualifying for it only after "spending-down" their financial resources on health care), their long-term health care costs are not covered. According to a 1987 Brookings Institute study, of the two-thirds of Medicare beneficiaries who own Medigap policies, only 3 percent have long-term care policies. The tragic reality is that many elderly are forced to spend all their income and assets on long-term care or transfer their assets to others in order to qualify for long-term care under Medicaid.

Fourth, many older Americans cannot afford long-term care. Many elderly find that the expense of such care quickly leads them down the road to poverty. According to a recent analysis of the 1982–84 Long-Term Care Survey, one out of three disabled elderly who spend any time in a nursing home end up impoverished.

Fifth, to date, no legislation has passed the Congress which would significantly address the long-term care issue. While vitally-needed to remedy shortfalls in acute (short-term) health care coverage, the catastrophic health care legislation (expected to be enacted in 1988) does not include provisions that would provide comprehensive protection from the catastrophic costs of long-term care. Nor can private long-term care insurance be counted on to fully resolve this crisis. According to a 1987 Brookings Institute study, moderately comprehensive private nursing home insurance may be affordable by, at most, 26 to 45 percent of the elderly population by 2018 and long-term care insurance will account for not more than 12 percent of total nursing home expenditures. (Although an improvement on current coverage, this 12 percent would reduce Medicaid expenditures by only 2 to 5 percent.) In addition, while touted by some as a solution to the long-term care problem, other private sector approaches such as home equity conversion, life-care communities, and social health maintenance organizations, protect only a small portion of those in need of long-term care services.

Volume III of Developments in Aging is designed to provide basic facts and figures for use by policymakers, researchers, and others engaged in the quest for a solution to the gap in long-term care for the elderly. It represents a compilation of the most recent information available on the issue. For the purposes of this report, long-term care refers to a wide range of services for persons who, because of chronic illness or disability, need personal assistance in caring for themselves over an extended period of time. Long-term care services may be medical, health-related, or social. These services may range from low intensity, for persons with conditions such as arthritis, to high intensity for persons with diseases, such as cancer.

The first section of this volume reports some major new findings which highlight important aspects of the long-term care population. Two of these findings have particular significance for long-term care policy. The first, that one in three elderly who spend any time in a nursing home end up in poverty, highlights the plight that many elderly and their families face when they are in need of long-term care. This fact supports a recent analyses reported by the House Aging Committee.

The second finding dispels a common myth about aging—if once disabled, always disabled. The truth is that one in five elderly with severe disability and one in four with moderate disability actually improve within a 2-year period. This fact points out the importance of appropriate rehabilitative, rather than "custodial" services for many disabled elderly.

In addition to major findings and facts about the long-term care population, the first section also covers the major characteristics of caregivers to the disabled elderly. Non-paid, family caregivers provide the lion's share of long-term noninstitutionalized care, only 5 percent of care is provided by formal (paid) caregivers.

The first section of this report draws heavily from the work of Korbin Liu of the Urban Institute, Kenneth Manton of Duke University, and Robin Stone, National Center for Health Statistics Research. The Committee is grateful for their assistance.

The second section of the report reviews the development and current state of long-term care services in the United States. Specifically, the review focuses on the provision in financing of nursing home and home and community-based services. Also included is a summary of the services and programs the VA is trying to provide to meet the long-term care needs of an elderly veterans' population that is aging even more rapidly than the general population.

The third and final section details new developments in long-term care policy. Significant legislative intitatives, that received favorable consideration by the Congress in 1987, made notable progress toward addressing long-term care quality and access issues and these are summarized in this section. These measures include the Omnibus Budget Reconciliation Act, and the Older Americans Act Amendments of 1987. Equally important, however, notable shortcomings of this legislation are also highlighted. In addition, the potential and limitations of private sector initiatives, such as long-term care insurance are outlined. Last, this section describes the focus of present research and training initiatives and needs.

Section 1

FACTS AND FIGURES

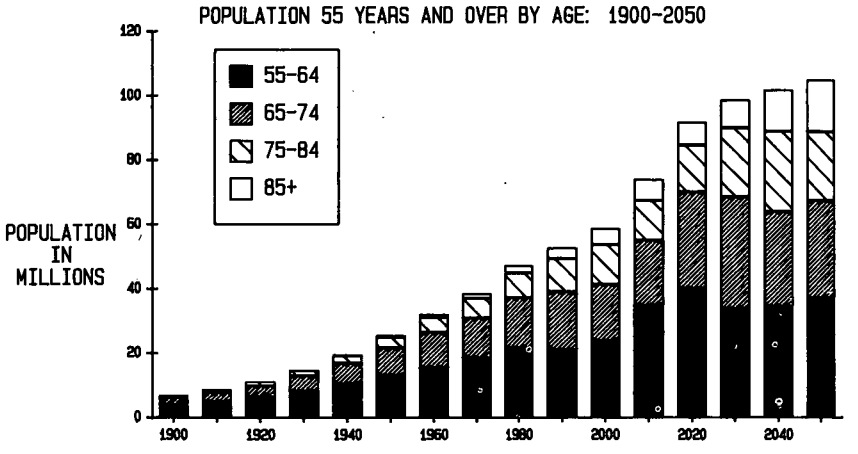
A. THE NEED

1. The Aging of the Population

As individuals live longer they become more susceptible to developing medical conditions that require long-term care services. The older population, with its high demand for these services, has increased far more rapidly than the rest of the population for most of this century. In the last two decades alone, the 65-plus population grew by 56 percent while the under-65 population increased by only 19 percent. This type of demographic change—often referred to as the graying of America—is unprecedented.

This century's dramatic increase in the number and proportion of older persons is reflected in statistics prepared by the U.S. Census Bureau. In 1986, 21 percent of the population was 55 or older (51.4 million Americans) and 12 percent (29.2 million Americans) were age 65 or older. Between 1985 and 2020, the 65-plus population is expected to more than double. At that time, one in six Americans will be 65 or older and by 2030 one in five will be elderly. (See Chart 1.) This phenomenon is the result of the aging of the baby boom.

CHART 1

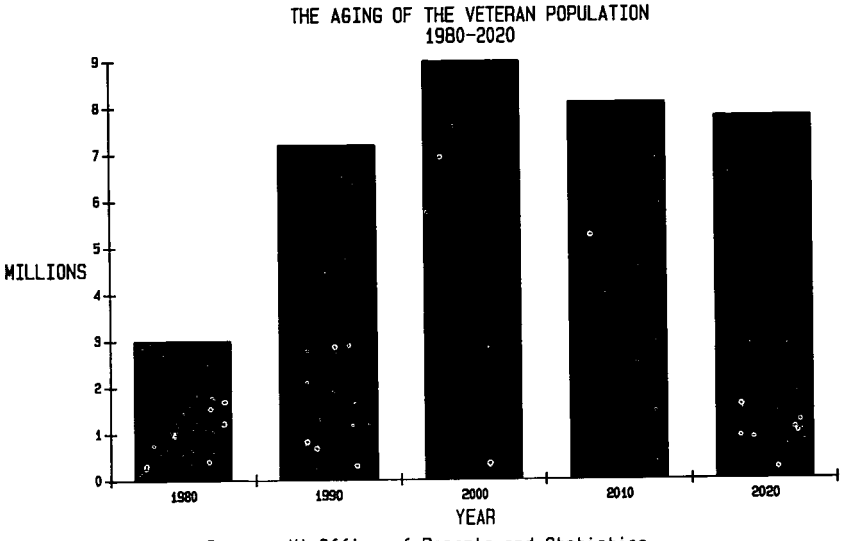


SOURCE: U.S. Bureau of the Census, Current Population Reports, Series P-25, No. 952
U.S. Census of the Population, 1890-1980

The age group with the greatest need for long-term care services, those 85 and over, is growing especially rapidly. Nearly one-fourth of those who were age 65 in 1980 could expect to survive to at least age 90. In 1900, there were 123,000 people age 85 and over compared to 2.8 million people in 1986 and by the turn of the century we can expect that there will be almost 5 million. About 22 percent of the oldest-old population live in nursing homes and another 20 percent living in the community are in need of long-term care services.

The aging of the population is having great impact on specific segments of society. For example, the numbers of veterans who will turn 65 or older—the age at which veterans become eligible for VA health care, regardless of income—far outpaces those projected for the general population. The increasing size of the elderly veteran age group is expected to peak in the year 2000, at least 20 years before this same phenomenon is forecast for the general population (Chart 2).

CHART 2



Source: VA Office of Reports and Statistics, March, 1983

Veterans of World War II account for most of this demographic surge in aging veterans. In the mid-1990's, virtually all veterans of this war will have reached age 65, with the vast majority over 70 years of age. By the turn of the century, veterans of the Korean War will swell the ranks of veterans in this age group to an all time high of 9 million.[1] Although this trend begins to decline after this point, the demand for VA long-term care will continue to rise as these veterans age and their medical needs increase.

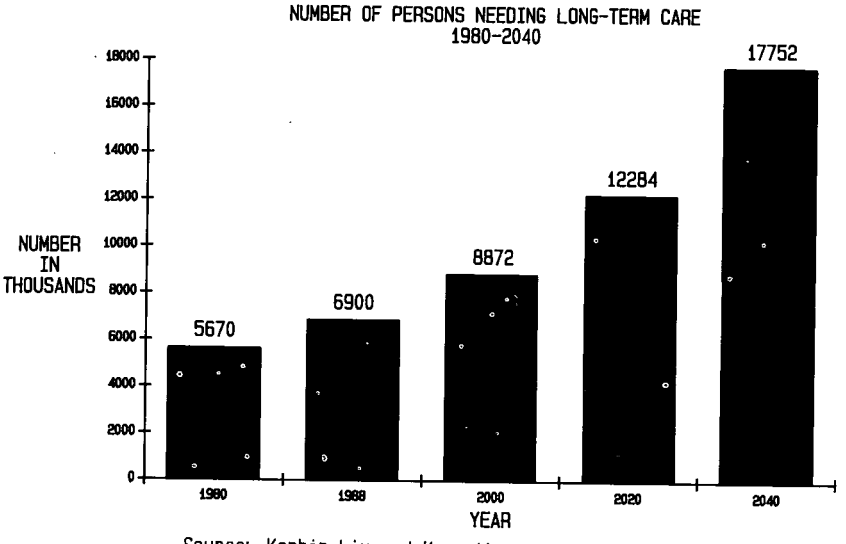
In response, the VA is placing an increasing emphasis on the provision of long-term care services. To the extent the VA meets the challenge, an aging veteran population may help determine how successfully this same problem is later addressed in the general population.

2. The Demand for Long-Term Care

In 1988, about one-quarter—6.9 million—of the elderly will need long-term care services. By the turn of the century, the number in need will increase to almost 9 million. By 2040, the aging of the baby boom population is expected to swell the long-term care population to 18 million. (See Chart 3.)

[1] U.S. Veterans Administration, Caring for the Older Veteran, Washington, DC, U.S. Government Printing Office, 1984.

CHART 3



Source: Korbin Liu and Kenneth Manton, Current Estimates and Projections, 1987

The number of Americans whose lives are indirectly affected by the long-term care crisis is even greater. According to a nationwide poll conducted in 1987, 60 percent of the respondents had had some experience in their own families or through close friends with the need for long-term care.[2]

Despite the tremendous and growing demand for long-term care, many people in need of such care do not receive it.[3] For example, only those who are dying (and are therefore eligible for hospice services) or live in poverty (and are therefore eligible for Medicaid) are protected against its cost. The U.S. House Committee on Aging estimated that 200 million Americans of all ages are underinsured against long-term care costs.[4]

B. THE IMPACT OF CHRONIC ILLNESS AND DISABILITY

The major determiner of need for long-term care is the presence of a chronic condition which results in disability. More than four out of five persons 65 and over have at least one chronic condition, while multiple chronic conditions also are common in the elderly.

Two factors have contributed to the increasing number of elderly with chronic illnesses. First, chronic conditions have replaced acute conditions as the major health problem of the elderly. Second, there has been a change in the pattern of wellness within an indi-

[2] R.L. Associates, "The American Public Views Long Term Care", October 1987.
[3] House Select Committee on Aging, "Long Term Care and Personal Impoverishment: Seven in Ten Elderly Living Alone Are at Risk," October 1987.
[4] Ibid.

vidual's lifetime. As individuals grow older, acute conditions become less frequent and the chance of developing a chronic condition increases.

The leading chronic conditions for the elderly in 1985 were arthritis and hypertensive disease, heart conditions and hearing impairments. In most cases, the rates for these diseases are much higher for the elderly population than for younger persons. For instance, the likelihood of suffering from arthritis is 76 percent higher for those 65 and over than for those age 45 to 64; the likelihood of hypertension is 60 percent higher for the older age group.[5]

According to results of the 1984 long-term care survey, a high level of disability resulting from chronic conditions is strongly linked to a high risk of mortality. There is a 4.5-fold difference in the risk of dying between elderly persons living in the community with severe impairment and those with no functional disability. (See Table 1.) The link between great disability and death is so strong that the severely impaired elderly are four times as likely to die within a 2-year period than to enter a nursing home.[6]

TABLE 1.—RISK OF DEATH OF PERSONS 65 AND OVER—1984

Disability status	Percent dying over a 2-year period
Not disabled	8
Mildly disabled[1]	21
Moderately disabled[1]	24
Severely disabled[1]	37
Institutionalized[1]	41

[1] Mildly disabled =1—2ADL's, moderately disabled =3—4 ADL's, severely disabled =5—6 ADL's; ADL=activities of daily living.

Source: Manton, Kenneth G., Planning Long-Term Care for Heterogeneous Older Populations, forthcoming in Annual Review of Gerontology and Geriatrics, Springer Publishing.

Recent analysis of the 1982-84 Long-Term Care Survey has shattered a common myth about disability and aging—if once disabled, always disabled. According to the analysis, over a 2-year period a large proportion of those who were chronically disabled improved significantly. (See Table 2.) For example, 22 percent of persons with severe disability and 24 percent of persons with moderate disability improved over the 2-year period. (Those with moderate disability were limited in two or three major activities of daily living and those with severe disability were limited in five to six.) This finding points out the importance of rehabilitative and supportive services for the disabled elderly.

[5] National Center for Health Statistics, "Current Estimates from the National Health Interview Survey, United States, 1986", Vital and Health Statistics Series 10, No. 164 (October 1987).

[6] Source: Manton, Kenneth G., "Planning Long-Term Care for Heterogeneous Older Populations", forthcoming in Annual Review of Gerontology and Geriatrics, Springer Publishing.

TABLE 2.—TRACKING THE COMMUNITY ELDERLY OVER A 2-YEAR PERIOD, 1982–84[1]

Disability status		Percent
1982	1984	
Not disabled	Remain not disabled	82
Severely disabled	Improved	22
Moderately disabled	Improved	24
Slightly disabled	Improved	18

[1] (Average =77 in 1982.)

Source: Manton, Kenneth G., "Planning Long-Term Care for Heterogeneous Older Populations", forthcoming in Annual Review of Gerontology and Geriatrics, Springer Publishing.

Another myth dispelled by the recent analysis is that females have a greater risk of disability than males. In fact, females had a slightly lower risk of becoming chronically disabled over a 2-year period. For instance, for those who were not disabled in 1982, 89 percent of the females and 86 percent of the males were free of disability in 1984. In the past, greater rates of disability for females have been based on data describing one point in time (cross-sectional), not longitudinal data. The higher rates of disability based on cross-sectional data have reflected the fact that females live longer with disability than males. In other words, males who become disabled die much sooner, on average, than their female counterparts who remain in the community or enter nursing homes.

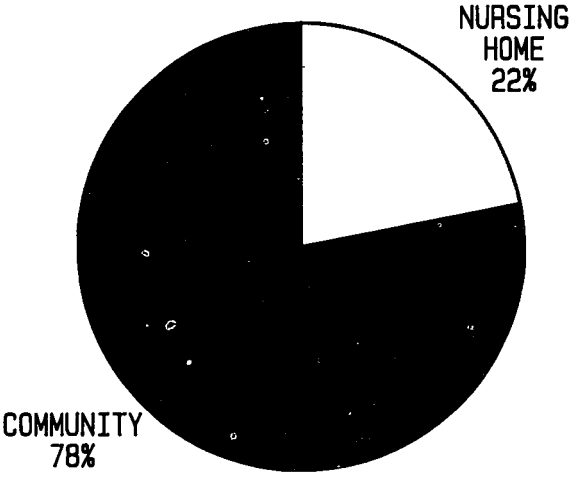
C. THE ELDERLY LONG-TERM CARE POPULATION

1. Overview

The great majority of long-term care recipients remain in their own homes and are cared for in their communities. An estimated four out of five elderly with long-term care needs live in the community. Only one in five live in nursing homes. (See Chart 4.)

CHART 4

THE ELDERLY DISABLED POPULATION
COMMUNITY VS. NURSING HOME RESIDENCE



Source: Korbin Liu and Kenneth Manton, Long-Term Care: Current Estimates and Projections, 1987

There is great diversity in the types and degrees of services required by the elderly in need of long-term care. For example, persons with degenerative joint problems such as arthritis generally require stable, low intensity services while persons with hip fractures may require high levels of rehabilitative care for longer periods of time with good chances of recovery. On the other hand, persons with degenerative neurological conditions, such as Alzheimer's disease, inevitably require permanent, high levels of care, and others with acute, lethal conditions such as cancer, require high levels of care for long period of time.[7]

[7] Ibid.

2. The Elderly Nursing Home Population

At age 65, individuals face about a 5 percent risk of entering a nursing home over the course of a year and a 43 percent risk of entering a nursing home during the rest of their lives.[8]

In 1985, approximately 1.4 million persons age 65 and older were in nursing homes, representing about 5 percent of all elderly.[9] The number of elderly residents in nursing homes increased 17 percent from 1977 to 1985. However, it is interesting to note that the proportion of nursing home residents did not increase over this time period.

It is expected that the nursing home population will grow rapidly over the next decades, primarily because of the growth of the older population. The Administration on Aging projects that between 1985 and 2000, the number of people in nursing homes will increase from 1.3 to 2 million and will more than double again to 4.5 million by 2040.[10]

One of the common misconceptions about nursing home care is that residents do not return to the community but remain institutionalized for the remainder of their lives. The facts are that the majority of persons entering a nursing home do not remain there. Seventy-five percent of those entering a nursing home stay less than 1 year and one-third to one-half of all entrants to nursing homes stay less than 3 months.[11]

Residents 85 and over comprise the largest group in nursing homes (45 percent), followed by those age 74 to 85 and 65 to 74 (Table 3 and Chart 5). The rate of nursing home use increases from 1 percent of those age 65 to 74, to 6 percent for those 75 to 84 and to 22 percent of those 85 and over.

---

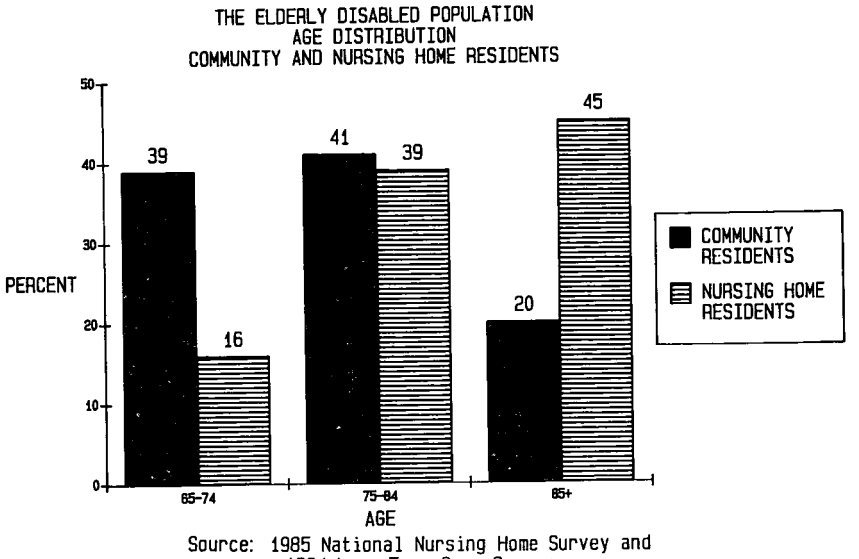
[8] Liu, K. and K.G. Manton, "The Characteristics and Utilization Pattern of an Admission Cohort of Nursing Home Patients," The Gerontologist, February 1983; Department of Health and Human Services Task Force on Long Term Care Policies, Report to Congress and the Secretary, 1987.

[9] Unless otherwise noted, data in the section on the elderly nursing home population are from the 1985 National Nursing Home Survey.

[10] U.S. Senate Special Committee on Aging, Aging America: Trends and Projections, 1987-88.

[11] Cohen, Marc, Eileen Tell and Stanley Wallack, "The Lifetime Risks, Costs of Nursing Home Care Among the Elderly", Medical Care, vol. 24, No. 12, December 1986.

CHART 5



Source: 1985 National Nursing Home Survey and 1984 Long-Term Care Survey

The 85 and over population accounted for three-fourths of the growth in nursing home residents over an 8-year period ending in 1985.[12] The proportion of elderly residents who were aged 85 years and over increased from 40 percent to 45 percent during this time period.

The increase in the numbers of oldest-old in nursing homes has contributed to a nursing home population that is increasingly dependent. In 1985, a larger proportion of elderly residents required assistance or had difficulty with bathing (91 vs. 89 percent), using the toilet room (63 vs. 55 percent), continence (55 vs. 47 percent) and eating (40 vs. 34 percent) than in 1977 when the previous survey was conducted. The proportion requiring assistance in dressing remained the same at 78 percent.

[12] Hing, Esther, "Use of Nursing Homes by the Elderly" Preliminary Data from the 1985 National Nursing Home Survey, No. 135, May 14, 1987.

TABLE 3.—CHARACTERISTICS OF THE DISABLED ELDERLY LIVING IN THE COMMUNITY AND IN INSTITUTIONS

[In percent]

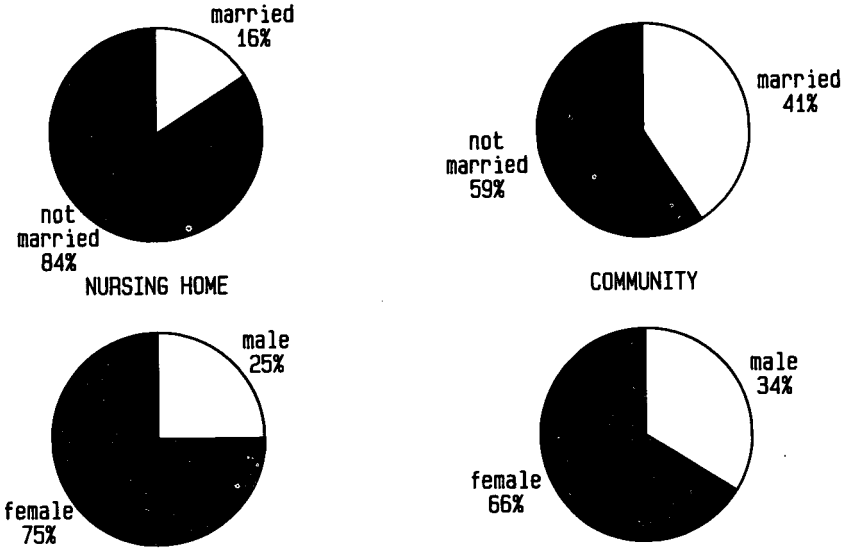
	Nursing home residents (1985) (N=1,315,800)	Disabled community residents (1984) (N=5,343,571)
Age:		
65 to 74	16	39
75 to 84	39	41
85-plus	45	20
Sex.		
Male	25	34
Female	75	66
Marital status:		
Married	16	41
Not married	84	59
Limited in:		
Bathing	91	50
Dressing	78	23
Toileting	63	28
Mobility	63	44
Eating	40	12
Severely limited	50	15

Source: Liu, K. and K. Manton, Long-Term Care: Current Estimates and Projections.

Nursing home residents are predominantly female. (See Chart 6.) Seventy-five percent of nursing home residents are women. In turn, the increase of nursing home use with age is greater for females than males. One in four women 85 and over resided in nursing homes in 1985, compared with one in seven men the same age.

CHART 6

THE ELDERLY LONG-TERM CARE POPULATION
MARITAL STATUS AND SEX DISTRIBUTION
COMMUNITY AND NURSING HOME RESIDENTS



Source: 1985 National Nursing Home Survey and
1984 Long-Term Care Survey

Nursing home residents are also predominantly white. Ninety-three percent of nursing home residents are white, while only 6 percent are black and less than 1 percent were of other races. And, in 1985, 5 percent of the elderly white population were in nursing homes compared with 4 and 2 percent of black persons and other races. The proportion of blacks using nursing homes has actually gone down from 4 to 2 percent from 1978 to 1985. Lower rates of nursing home use by this group and people of other races may result from greater informal support from family and friends than among white populations.

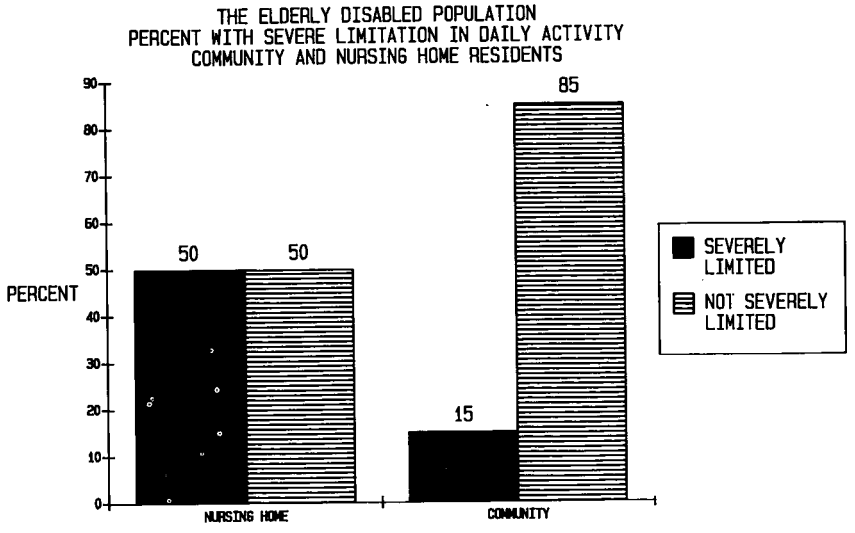
3. Risk Factors of Institutionalization

Two major risk factors of institutionalization are degree of disability and the lack of a family member to provide help when it is needed. (See Table 3.) For example, elderly disabled nursing home residents are about twice as likely as the disabled elderly living in the community to be limited in the major daily activities of bathing, dressing, toileting, and eating.[13] And 50 percent of all elderly disabled persons living in nursing homes have severe limitations

[13] Unless otherwise noted, data in the section on risk factors and institutionalization are from the 1985 National Nursing Home Survey and 1984 Long-Term Care Survey.

(five to six daily activity limitations) compared to 15 percent of disabled elderly community residents. (See Chart 7.)

CHART 7



Source: 1985 National Nursing Home Survey and 1984 Long-Term Care Survey

Similarly, studies have shown that factors indicating the lack of a family member to provide help are significant predictors of nursing home placement.[14] For example, 84 percent of the elderly in nursing homes are not married compared to 59 percent of disabled community residents. (See Chart 6.) In turn, 63 percent of nursing home residents have children compared to 81 percent of all elderly people in the community.

Another major risk factor for institutionalization is deteriorating cognitive functioning. In 1985, 63 percent of elderly nursing home residents were disoriented or memory impaired to such a degree that activities of daily living were impaired every day.

Other common factors leading to institutionalization include the following:

Age.—Forty-five percent of nursing home residents are age 85 or older compared to 20 percent of the disabled elderly living in the community.

Sex.—The lifetime risk of institutionalization for women at age 65 has been estimated at 52 percent and that for men at 30 percent.[15] Seventy-five percent of nursing home residents are women compared to 66 percent of disabled elderly community

[14] Thomas, K. and A. Wister, "Living Arrangements of Older Women: The Ethnic Dimension," Journal of Marriage and the Family, 76, 1984.

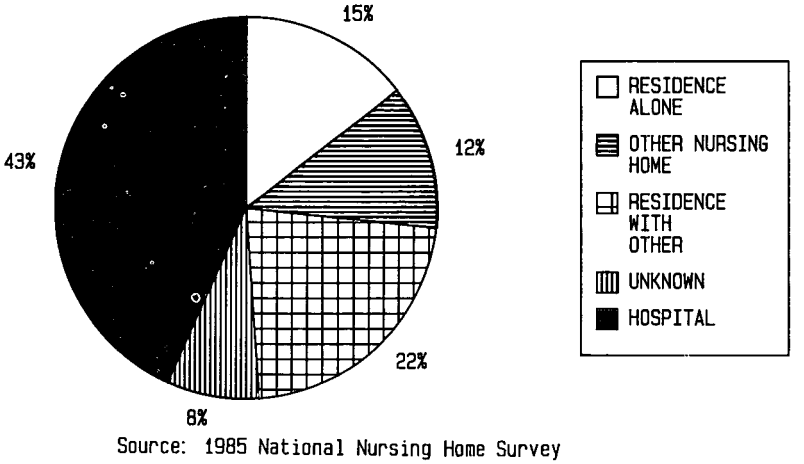
[15] Cohen, Marc, Eileen Tell and Stanley Wallack, "The Lifetime Risks and Costs of Nursing Home Use Among the Elderly," Medical Care, Vol. 24, No. 12, December 1986.

residents. In addition, 6 percent of elderly females are nursing home residents compared to 3 percent of elderly males. The greater utilization of nursing homes by elderly women than men is a reflection of women's greater longevity.

Time spent in a hospital or other facility: Fifty-seven percent of nursing home residents transfer from another health facility. (See Chart 8.) The most common facility is a short-stay hospital (30 percent). The proportion of elderly residents admitted from short-stay hospitals increased from 34 to 39 percent from 1977 to 1985 when the last two national nursing home surveys were conducted. This may be a reflection, in part, of the effects of the early release by hospitals of patients in need of long-term care under the Medicare prospective payment system.

CHART 8

NURSING HOME RESIDENTS BY LIVING ARRANGEMENTS PRIOR TO ADMISSION
1985



Source: 1985 National Nursing Home Survey

4. Elderly Disabled Persons Living in the Community

In 1984, there were 5.3 million elderly disabled persons living in the community.[16] There were 2.8 million in need of extensive services due to severe disability. Rough estimates for 1988 are that 54.7 million elderly community residents currently need long-term care, 3 million of which are in need of extensive services.[17]

Elderly disabled persons living in the community are more than twice as likely to be among the young-old (age 65 to 74) and mar-

[16] Unless otherwise noted, data in the section on the elderly disabled living in the community are from the 1984 Long-Term Care Survey.

[17] Based on the 1984 Long-Term Care Survey and U.S. Census Bureau estimates of the population.

ried than their counterparts in nursing homes. (See Table 3.) As mentioned earlier, they are also less likely to be limited in the major daily activities of bathing, dressing, toileting, and eating or to be severely limited. However, it is important to note that one out of seven elderly disabled persons living in the community are severely limited and in need of extensive long-term care services.

As would be expected, the majority of elderly disabled persons living in the community are women. Older women outnumber older men two to one in this group. Impaired blacks have higher rates than whites for remaining in the community. According to data from the 1984 Long-Term Care Survey, 29 percent of the non-institutionalized elderly who were black or of other races were functionally impaired for at least 3 months, compared with 19 percent of white persons.[18]

The presence of caregivers unsually enables the disabled elderly to remain in the community and avoid institutionalization. The following section provides details on informal and formal caregiving.

D. INFORMAL/FORMAL CAREGIVING: THE MYTH OF FAMILY ABANDONMENT

1. The Myth of Family Abandonment

The provision of care by family members plays a major role in helping the disabled elderly remain in the community.[19] Elderly persons with family members to assist them tend to enter nursing homes at a much higher level impairment than do those without such help.[20]

Although persistent, the myth of abandonment of the elderly by the family is not supported by the facts. Rather, studies reveal that a majority of elderly persons, including those living alone, maintain close contact with their families. In 1984, four out of five aged persons who lived alone and had children were in contact with a child, in person or by telephone, at least once a week, according to the National Center for Health Statistics. More specifically, 23 percent saw a child daily, 20 percent saw him or her more than once a week, and 40 percent at least once a week. Another 16 percent saw a child at least once a month. Most of the others polled saw their child several times during the year. When asked how quickly one or more of their children could get there if needed, 50 percent had at least one child who could get there in a matter of minutes. Only 3 percent of those who lived alone and had one child or more said they never saw a child or saw them less than once a year. Of the 11 percent who lived alone and had no living children or siblings, 27 percent had recently seen a relative and 51 percent had visited with a friend or neighbor. In addition, 38 percent had talked on the

---

[18] 1982 Long-Term Care Survey.

[19] Unless other noted, data in the section on Informal/Formal Caregiving were prepared by Robin Stone, National Center for Health Services Research, and are from the 1982 Long-Term Care Survey/Survey of Caregivers.

[20] Branch, L.G., and Jette, A.M., "A Prospective Study of Long-Term Care Institutionalization Among the Aged," American Journal of Public Health, 23, 1982; Butler, L.H., and Newacheck, D.W., "Health and Social Factors Relevant to Long-Term Care Policy," Policy Options in Long-Term Care, University of Chicago Press, 1981.

telephone with a relative and 57 percent had a telephone conversation with a friend or neighbor.[21]

2. Informal Caregiving

The lion's share of long-term care is provided by family and friends (informal caregiving). Approximately 75 percent of the disabled elderly who live outside of an institution rely solely on informal care. Only 5 percent of such care is on a paid basis.[22]

3. Formal Caregiving: A Last Resort

For most families, formal or paid caregiving is a last resort. Only 5 percent of community-based long-term care recipients receive all their care from paid sources. In fact, severely disabled elderly persons living with spouses tend to obtain formal services only after the disabled spouse become incontinent. Among those living with children, the use of a formal caregiver is generally precipitated by the need for extensive supervision.[23]

4. Caregiving: A Woman's Issue

The majority of primary caregivers are either wives or adult daughters. (See Chart 9.) Approximately 72 percent of caregivers to the disabled elderly are women. (See Table 4.) Twenty-nine percent of caregivers are daughters and 23 percent are wives. Only 9 percent are sons and 13 percent are husbands. Daughters and sons-in-laws, grandchildren, siblings, other relatives, friends and other unpaid helpers make up the remainder. Proximity to the elderly person in need of assistance and lack of competing demands appear to determine who is the primary caregivers.[24]

---

[21] Kovar, M.G., "Aging in the Eighties, Age 65 and Over and Living Alone, Contacts with Family, Friends and Neighbors", NCHS Advance Data, No. 116, May 9, 1986.

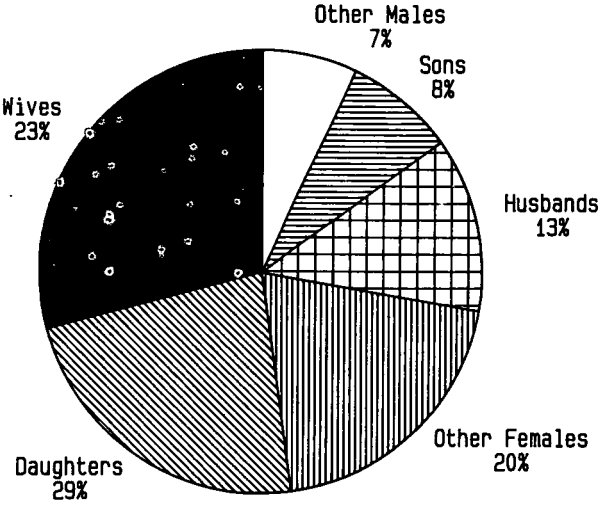
[22] 1982 Long-Term Care Survey.

[23] Soldo, B.J., and K.G. Manton, "Health Status and Service Needs of the Oldest-Old: Current Patterns and Future Trends", Milbank Memorial Fund Quarterly, 63, 1985.

[24] Subcommittee on Human Services of the House Select Committee on Aging, Exploding the Myths: Caregiving in America, January 1987.

CHART 9

WHO PROVIDES CARE?
CAREGIVERS AND THEIR RELATIONSHIP TO ELDERLY CARE RECIPIENTS



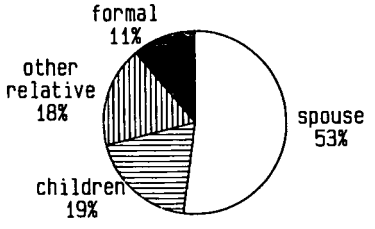
Note: Caregiver population includes primary and secondary caregivers.

Source: 1982 Long-Term Care Survey/
Survey of Caregivers

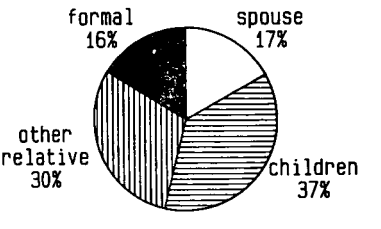
Caregiving follows a pattern that differs for men and women. This is at least partially due to the fact that wives generally outlive their husbands. For elderly men, the primary caregiver is most often a wife, followed by adult children, other relatives and formal (paid) sources of care. However, for elderly women, the order in these groupings is first, children, followed by relatives, husbands, and formal care. (See Chart 10.)

CHART 10

WHO PROVIDES CARE?
PERCENT OF CAREGIVING DAYS
BY RELATIONSHIP TO THE CAREGIVER



PROVIDING CARE TO
DISABLED MALES



PROVIDING CARE TO
DISABLED FEMALES

Source: 1982 Long-Term Care Survey/
Survey of Caregivers

Note: Percents may not add to 100 due to rounding.

TABLE 4.—MAJOR CHARACTERISTICS OF CAREGIVERS BY RELATIONSHIP OF CAREGIVER TO DISABLED PERSON

Type of commitment	All persons	Relationship to disabled person					
		Female			Male		
		Spouse	Child	Other	Spouse	Child	Other
Population (thousands)	2,201	500	637	438	282	186	158
Percent	100	23	29	20	13	9	7
	PERCENTAGE DISTRIBUTION						
Type of caregiver:							
Primary caregiver only	33	60	23	18	55	11	13
Primary caregiver with informal help	29	29	36	26	26	29	10
Primary caregiver with informal and formal help	10	9	11	7	16	8	4
Secondary caregiver	29	2	30	50	3	52	74
Age in years:							
14 to 44	22	2	24	40	1	36	45
45 to 64	41	25	63	35	8	56	36
65 to 74	25	48	13	18	49	8	17
75-plus	10	25	4	7	42	1	2
Mean age	57	69	52	50	73	49	45
Racial background:							
White	80	85	78	71	89	79	74
Other	21	15	22	29	11	22	26

TABLE 4.—MAJOR CHARACTERISTICS OF CAREGIVERS BY RELATIONSHIP OF CAREGIVER TO DISABLED PERSON—Continued

Type of commitment	All persons	Relationship to disabled person					
		Female			Male		
		Spouse	Child	Other	Spouse	Child	Other
Living arrangements:							
Lives with disabled person	74	99	61	54	97	61	73
Lives separately from disabled person	26	1	39	46	1	39	27
Family income:							
Poor/near poor	32	37	27	38	30	24	28
Low/middle income	57	59	57	50	63	61	58
High income	10	4	14	10	7	11	12
Marital status:							
Married	70	99	56	51	100	53	49
Widowed	8	1	14	15	0	0	8
Divorced/separated	9	0	16	10	0	20	8
Never married	13	0	13	23	0	27	36
Number of children less than 18 years of age in household:							
None	79	94	76	63	95	76	62
1	10	3	11	15	4	12	16
2	7	2	9	13	2	8	9
3 or more	4	0	5	8	0	4	13
Employment status:							
Working	31	10	44	33	12	55	46
Quit work to become caregiver	9	14	12	3	11	5	1
Not working for other reasons	60	76	45	64	76	40	54
Health status:							
Excellent	24	17	25	31	17	23	39
Good	43	39	44	47	33	48	47
Fair or poor	33	44	32	23	50	29	15

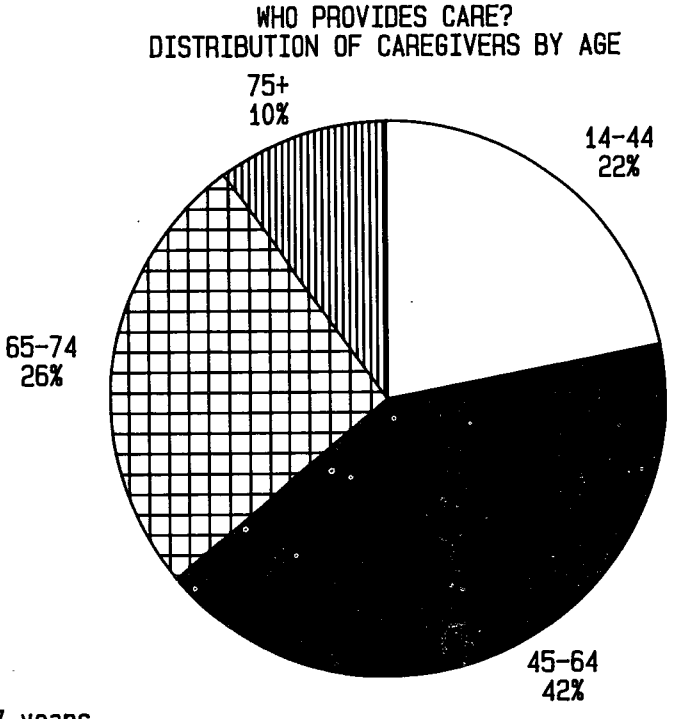
Source: 1982 National Long-Term Care Survey/Survey of Caregivers.

Women provide significantly higher levels of overall assistance than men. They are much more likely than men to attend to the personal hygiene needs of the elderly person, such as bathing, dressing, and toileting, and to engage in household tasks and the preparation of meals. Male caregivers typically provide transportation and help the older person with home repairs and financial management.

5. Characteristics of Caregivers

The majority of caregivers are middle-aged or young-old. (See Chart 11.) The average age of the informal caregiver is 57. However, 25 percent are 65 to 74 and 10 percent are 75 or older. Approximately 70 percent of all caregivers are married. About 31 percent hold down jobs, representing a source of income and a competing demand for the caregiver's time. Roughly the same percentage—32 percent—of caregivers are poor or near-poor, while 57 percent have low or middle incomes. (See Table 4.)

CHART 11



Mean age is 57 years.

Source: 1982 Long-Term Care Survey
Survey of Caregivers

While a quarter of caregivers state that they are in excellent health, one-third report that their health is fair or poor. When compared to non-caregivers of similar age, by their own assessment, caregivers are in poorer health. In 1982, one-third of female caregivers aged 45 to 64 assessed their overall health as being fair or poor, as compared to slightly more than one-fifth of female non-caregivers, in the same age group.

The majority—74 percent—of caregivers live with the disabled family member or friend. Of these live-in caregivers, 61 percent are sons and daughters. Apparently deteriorating health of the elderly person is a key factor in the decision to live together. In fact, 38 percent of caregiving daughters and 33 percent of the caregiving sons indicate that they would not live with their parents were their assistance not required. Furthermore, about 8 percent of informal caregivers who do not live with the disabled relatives or friend report having moved in order to be closer to the home of the elderly person in need of assistance.

6. Degree of Caregiver Involvement

Virtually all spousal caregivers provide daily assistance to their elderly disabled wife or husband. (See Table 5.) Close to 75 percent of daughters and 71 percent of sons devote part of each day to caregiving activities for an ailing parent. On the average, caregivers spend approximately 4 hours per day on such tasks.

TABLE 5.—CAREGIVER COMMITMENT BY RELATIONSHIP OF CAREGIVER TO DISABLED PERSON

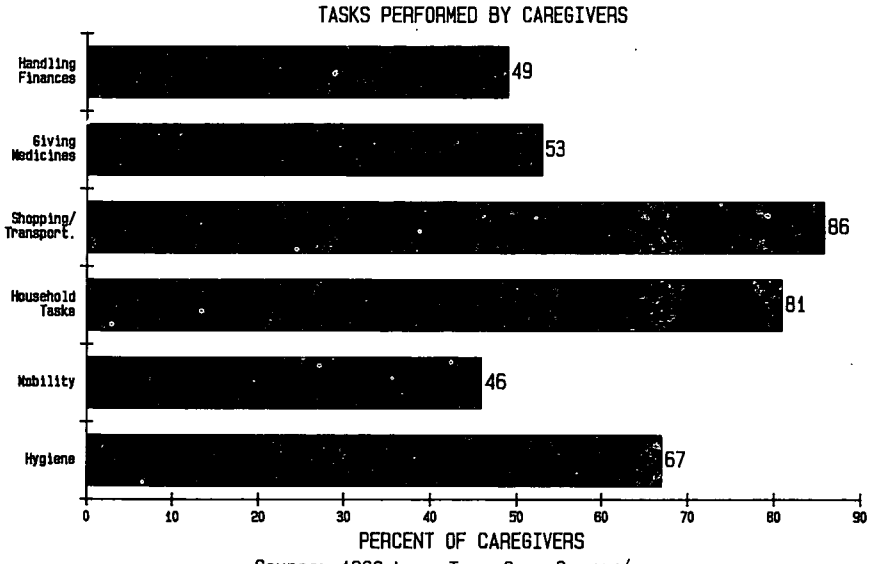
Type of commitment	All persons	Relationship to disabled person					
		Female			Male		
		Spouse	Child	Other	Spouse	Child	Other
Population (thousands)	2,201	500	637	438	282	186	158
Percent	100	23	29	20	13	9	7
	Percentage distribution						
Length of caregiving:							
Less than 1 year	18	19	20	18	15	16	12
1 to 4 years	44	44	45	43	49	38	42
5 years or more	20	25	19	15	24	19	19
No longer giving care	16	11	14	23	9	24	25
Number of caregiver days per week:							
1 to 3 days	14	2	20	25	2	19	18
4 to 6 days	6	1	7	10	1	10	7
7 days	80	97	73	64	97	71	75
Number of extra hours per day spent on caregiving:							
None	4	7	4	3	4	5	5
1 to 2 hours	42	38	41	44	35	50	57
3 to 4 hours	25	26	27	27	24	22	19
5 hours or more	25	25	27	22	33	21	16
Mean hours	4	4	4	4	5	4	3
	Percent citing each task						
Caregiver tasks:							
Hygiene	67	79	69	66	70	54	38
Mobility	46	41	44	44	55	54	48
Administration of medication	53	61	57	48	53	48	33
Household tasks	81	74	87	82	89	74	66
Shopping and/or transportation	86	77	91	84	89	94	86
Handling finance	49	58	59	35	42	51	29

Source: 1982 National Long-Term Care Survey/Survey of Caregivers.

The duration of caregiving ranges from less than 1 year to 43 years. For most, caregiving duties extend from 1 to 4 years. About one-fifth of all caregivers provide care for 5 years or more.

Caregivers perform a number of services, ranging from occasional errands to around-the-clock care. Over 85 percent of caregivers shop or provide transportation. (See Chart 12.) Four out of five perform one or more household chores, 50 percent handle finances and 53 percent administer medication and/or change bandages. Two-thirds also assist in providing basic personal care functions such as eating, bathing, dressing, or toileting. Just under 50 percent assist their elderly relative or friend in getting in and out of bed or moving around inside the house. In addition, caregivers also serve as links to services for the disabled elderly.

CHART 12



Source: 1982 Long-Term Care Survey/ Survey of Caregivers

Husbands and wives, in particular, report that caregiving is a major contribution to their self-worth. Approximately two out of three caregivers also view their disabled relative or friend as a source of company.

7. The Changing Supply of Informal Caregiving

Demographic trends affect the availability of informal caregivers. As a result of the low birth rate during the Depression years, in the 1980's, there are fewer children to tend to the needs of elderly parents than in previous periods. However, parents of the baby boom generation will have a relatively greater number of children available to care for them. In turn, when the baby boom generation becomes elderly, a lower birth rate among this group means fewer children to assist them in later years. This may have implications for the future supply and demand of formal long-term care services.

The steady increase in the rate of divorce over the past 30 years will also affect the future pool of caregivers. The divorced older person who does not remarry will be without a spouse to turn to for help if it is needed. In addition, the increased participation of women in the labor force may prevent them from taking on caregiver duties in coming years. In 1987, more than 56 percent of all women age 16 and over held down jobs. However, in 1960, only 38

percent of women held down jobs.[25] Should the trend or more women entering the labor market continue, it may become even more difficult for families to provide the type and level of care needed by the elderly.

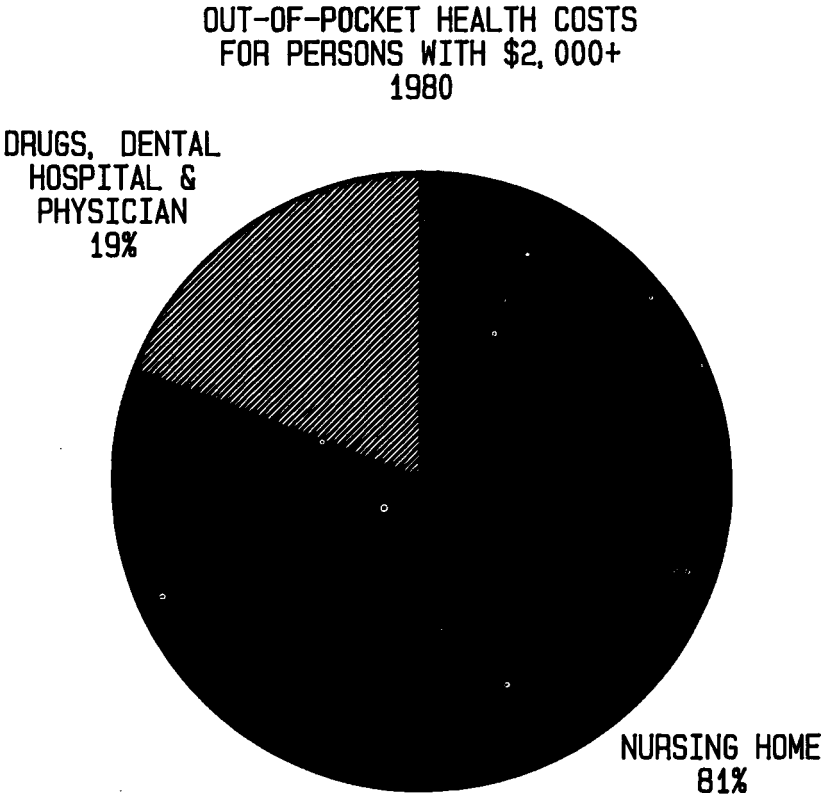
E. CAN THE ELDERLY AFFORD LONG-TERM CARE?

1. Long-Term Care Costs

Long-term care is the major catastrophic health care expense of older Americans. For example, nursing home stays account for over 80 percent of the expenses incurred by those older persons who experienced very high out-of-pocket costs for health care (over $2,000 per year). (See Chart 13.) A recent nationwide poll found that 90 percent of Americans agreed that having a family member who needs long-term care would be financially devastating for most working and middle-income families. And by a four to one ratio, poll respondents felt that nursing home costs would be "impossible to pay" or would constitute a major sacrifice.[26]

[25] U.S. Bureau of Labor Statistics.
[26] Long-Term Care '88, 1987.

CHART 13



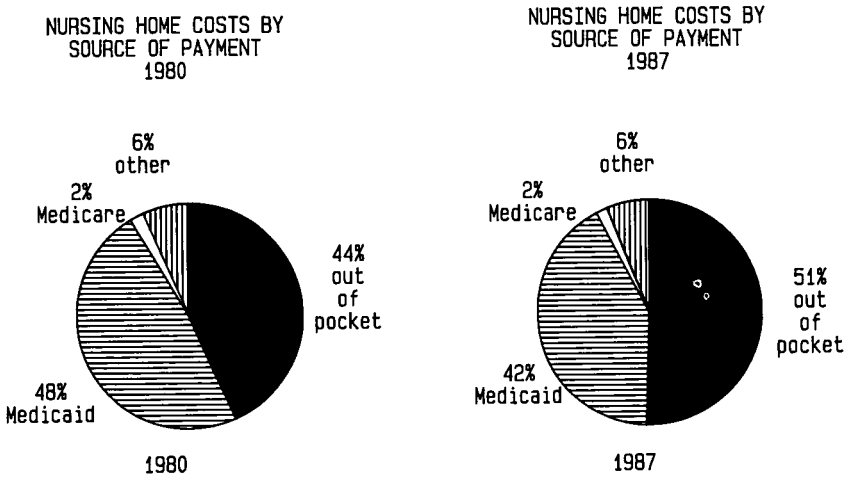
Source: Thomas Rice and Jan Gabel
Health Affairs, Fall, 1986

The costs of nursing home or home health care are often astronomical. While the median family income of the elderly is about $20,000, the cost of care in a nursing home is now around $25,000 per year. In some States, nursing homes are running $35,000 a year. The cost of around-the-clock home health care can be equally prohibitive, running as high as $70,000 per year. It has been projected that about one-half of the approximately 1.2 million elderly persons who will be admitted to nursing homes in 1988 will have out-of-pocket expenses greater than $5,000 for their stay and over 10 percent will have personal expenses over $50,000.[27]

[27] R.L. Associates, "The American Public Views Long-Term Care," October 1987.

Contrary to what many Americans assume, Medicare does not cover the cost of long-term care for its 31 million beneficiaries. Older Americans pay about half (51 percent) of their nursing home bills out of their own pockets. (See Chart 14.) Between 1980 and 1987 alone, the proportion of health care costs that are paid out-of-pocket have risen by about 8 percent.

CHART 14



Source: Health Care Financing Administration
Office of the Actuary

Note: Percents may not add to 100 due to rounding.

2. The Economic Status of the Elderly

Since the 1960's, the economic status of the elderly has risen and poverty has declined. For example, the poverty rate among those 65 and older was halved from 28.5 percent in 1966 to 14.6 percent in 1974. During the same time period, the median family income of persons over 65 grew from $12,311 to $16,682 (in comparative 1986 dollars). The real income of the elderly continued to rise slowly during the remainder of the 1970's and 1980's. In 1986, the median family income of the elderly was $19,922 and the poverty rate was 12.8 percent.[28]

Although some view this improvement as the elimination of economic problems facing the elderly, this is not the case. In fact, elderly persons are more likely than other adults to be poor or near-poor. In 1986, 15.5 percent of persons aged 65 or older were "near-poor" compared to 8.4 percent of nonelderly adults.

[28] 1987 Current Population Survey. Prepared by the Congressional Research Service.

The elderly are not a homogeneous group. Factors such as race, age, family composition and disability all play a role in determining differences in personal resources. For example, the risk of poverty increases with age. The age group which is the most likely to need long-term care, the 85-plus population, is one of the poorest groups in the country. In 1986, 18 percent of the individuals in this age group lived in poverty.

Moreover, a large proportion of these elderly who are in need of costly long-term care services, have very low incomes. In 1982, 46 percent of elderly females and 31 percent of elderly males who are functionally impaired and living in the community had family incomes of less than $7,000. And 61 percent of functionally impaired black persons had incomes of less than $7,000. This figure was 37 percent for elderly impaired whites.[29]

3. Impoverishment

One of the major policy concerns regarding long-term care is the high number of the elderly who become impoverished as a result of trying to meet their long-term care needs. According to a preliminary analysis of the 1982 and 1984 Long-Term Care Surveys, one in three elderly who spend any time in a nursing home will end up poor (become eligible for Medicaid).[30] These statistics support similar analyses. For nursing home residents, there is a four-to-five-fold risk of becoming impoverished compared to those who require such care but remain in the community. While the likelihood of becoming impoverished is 31 percent for those who spend any time in a nursing home, it is 7 percent for those disabled elderly living in the community. According to the analysis, for those nursing home residents who become impoverished, 43 percent become poor within 6 months and 58 percent in 1 year.

According to a recent study by the House Select Committee on Aging, using data from the 1984 Current Population Survey, after only 13 weeks in a nursing home, 7 in 10 elderly living alone found their income spent down to the Federal poverty level. (See Chart 7.) Within 1 year, over 90 percent of the elderly nursing home residents were impoverished. It took only 6 weeks to reach this point for elderly persons living alone with incomes between 125 and 200 percent of the poverty level. The picture for married couples was only slightly less tragic. After either spouse has spent only 6 months in a nursing home, over 50 percent of the elderly couples were impoverished. (See Chart 9.)

When income and assets are both considered, the picture is still bleak, according to the committee study. After only 13 weeks in a nursing home, 48 percent of the elderly living alone were impoverished. Within 1 year, 7 in 10 elderly living alone had depleted both their income and assets. For married couples, over one-half of the couples had been reduced to poverty status after 1 year in a nursing home.

---

[29] Macken, C., "A Profile of Functionally Impaired Elderly Living in the Community," Health Care Financing Review, vol. 7, No. 4.

[30] Liu, Korbin and Kenneth G. Manton; "The Effect of Transitions Between Community and Nursing Homes on Medicaid Eligibility."

The risk of impoverishment is also great when extensive home health care is required. Using conservative estimates for the cost of home health care—$43 per day or $15,000 per year—the committee report determined that close to 90 percent of the elderly living alone and two-thirds of couples living alone would be impoverished by the end of 1 year of 7-day-a-week home care. When both income and financial assets are considered, over 60 percent of the elderly living alone would have exhausted their financial resources in this time period. Over 80 percent of the elderly living alone and 33 percent of elderly couples would be poor after 1 year of 5-day-a-week home care.

F. FEDERAL EXPENDITURES

Public (Federal, State, and local) long-term care expenditures now account for 0.45 percent of the gross national product.[31] The majority of these expenses are for nursing home care. Nursing home care is the second largest health care expenditure (after hospitals) for the elderly and the largest source of personal expenditures. Aggregate expenditures for nursing homes were $41.6 billion in 1987.

Medicaid is the major source of public financing for nursing home care, accounting for 87 percent of all publicly funded nursing home care. In 1987, Medicaid's share of total nursing home expenditures was $13.3 billion or 42 percent. (See Chart 14.) In that year, $600 million, or less than 2 percent, was provided by Medicare and private health insurance covered $400 million or less then 1 percent of all nursing home costs.

According to the Health Care Financing Administration, half of the Nation's nursing home bill is paid for by the elderly or by others on their behalf. In 1987, direct patient payments amounted to $21.1 billion or 51 percent of all expenditures. The proportion of nursing home costs paid out-of-pocket has increased significantly from 44 percent in 1980 to 51 percent in 1987. During the same time period, the proportion of nursing home costs financed by Medicaid has decreased, from 48 percent in 1980 to 42 percent today. The proportional decrease in Medicaid's spending for nursing homes has not received much attention in light of the increase in actual nursing home expenditures under Medicaid, up from $9.8 billion in 1980 to $17.3 billion today.

It is important to note that there is some discrepancy in estimates of source of payment for nursing home care. According to a recent analysis of the 1982 and 1984 Long-Term Care Survey, 62 percent of nursing home residents were currently being covered by Medicaid at the time of the 1984 Survey. This figure is significantly higher than others commonly seen in the literature such as that mentioned above which are based solely on payment source at admission to nursing homes. According to the analysis, about half of nursing home residents report self as the source of payment, while children contribute to the cost of between 7 and 8 percent of residents. (See Table 6.)

---

[31] Wiener, Joshua M., "We Can Run, But We Can't Hide: Financing Options for Long-Term Care," testimony presented before the Budget Committee, U.S. House of Representatives, Oct. 1, 1987.

TABLE 6.—*Nursing home payment, 1984 long-term care survey*

Payment source	*Percent*
Self	51
Spouse	2
Children	7
Insurance	2
Medicare	13
Medicaid	62

Note.—Individuals may report more than one source of payments.

Source: Liu, Korbin and Kenneth Manton, The Effect of Transitions Between Community and Nursing Homes on Medicaid Eligibility, Urban Institute, November, 1987.

Medicaid is more likely to be the primary source of payment of nursing home care for the "growing-old," women and minorities. According to results of the 1985 National Nursing Home Survey, Medicaid was the primary payment source for 45 percent of residents age 65 to 74, compared to 39 percent of those 75 to 84 and 85 and over.

The lower income levels of females and blacks are reflected in their reliance on Medicaid. In 1985, 42 percent of elderly nursing home female residents relied on Medicaid as their primary payment source, compared to 36 percent of elderly males. And elderly black nursing home residents are twice as likely as whites to use Medicaid as the primary source of payment. In the same year, Medicaid was the primary source of payment for 70 percent of black nursing home residents compared to 38 percent of elderly white residents. Conversely, elderly white residents are more likely to use their own income or family support to pay the major portion of the nursing home bills. Fifty percent of white nursing home residents pay the majority of all their bills out of their pockets compared to 17 percent of black residents.

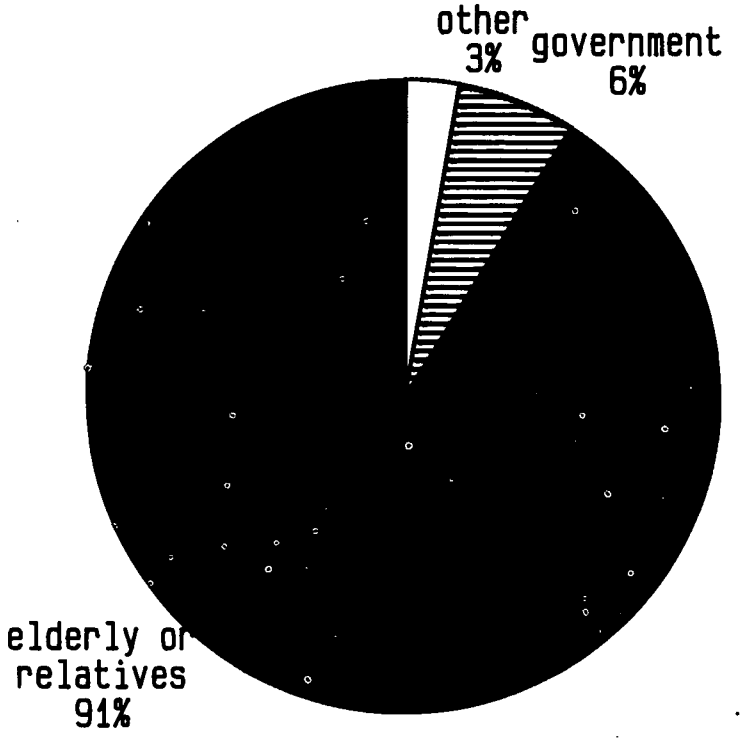
Nursing home expenditures are expected to triple by the year 2000 to $129 billion. The Health Care Financing Administration predicts that at that time private health insurance will begin to pick up a greater share of the costs (5 percent), while direct patient payments will account for 53 percent and Medicaid's share will drop to 35 percent.

Only 25 percent of paid long-term care in the community is financed through government sources.[32] This is a reflection of the fact that 91 percent of all community-based long-term care is provided by the elderly or their relatives. (See Chart 15.)

[32] Liu, Korbin, Kenneth G. Manton, and Barbara Marzetta Liu, "Home Care Expenses for the Disabled Elderly," Health Care Financing Review, vol. 7, No. 2 (winter 1985).

CHART 15

COMMUNITY-BASED LONG-TERM CARE COSTS BY SOURCE OF PAYMENT



Note: Other includes helping organizations.

Source: 1982 Long-Term Care Survey

Section 2

LONG-TERM CARE SERVICES

A. NURSING HOMES

1. History

At the turn of the century, nursing homes were virtually unknown in the United States. There was little demand for the type of specialized services a nursing home could provide. "Aging" (in the sense of a social phenomenon) and retirement as we know it today were unheard of at that time. For example, in 1900, only about 1 in 25 Americans were age 65 or older. Most continued to work or conduct their lives in the same manner as long as they were able, and those that needed care usually received it from friends or family members. Only the most poor and isolated became public wards as residents of an almshouse or poorfarm.

Events over the next 30 years, however, dramatically altered these conditions. Not only did the elderly population begin to grow, but societal changes—such as industrialization, increased mobility in the population, and smaller families—made it increasingly difficult for families to meet their traditional responsibilities in caring for aging relatives. Consequently, the numbers of frail elderly without any private means of assistance began to grow.

Several States began to develop programs to provide cash assistance payments for needy older persons with no personal means of support. By the middle of 1931, 18 States had established various programs of "old-age assistance," or "old-age relief." These programs expanded slowly until the Depression stopped their growth completely. States then began to look to the Federal Government for financial support for these programs.

In 1935, Congress enacted the Social Security Act, making it possible for the States to receive Federal matching funds for the purpose of making noninstitutional cash assistance grants to various categories of needy people. Title I of the Act included a provision of some importance to the development of the nursing home system in the United States. This provision prohibited the Federal Government from making any assistance payments to persons residing in "public institutions." The purpose of this stipulation was to discourage the State from using the poorhouse system as a means for dealing with the problems of aged dependency.

As a result, the use of private facilities as a means of caring for the frail elderly began. Homes that began as room-and-board facilities gradually took on the responsibilities of meeting the health and personal needs of their aged residents. Thus, many of today's nursing homes have their origins as small private boarding homes for older people.

2. Characteristics of the Population

In 1985, approximately 1.4 million older persons were residents of nursing homes, which represents about 5 percent of the total elderly population. The Administration on Aging projects that between 1985 and 2000, the number of people in nursing homes will increase from 1.3 million to 2 million, and will more than double again to 4.5 million by 2040.

The nursing home population is varied—some residents require rehabilitative care of short duration as a result of an acute illness, while others are severely disabled and require extensive and continuous care for months or years. Analysis of nursing home utilization has found a high degree of variance in the length-of-stay among nursing home residents. The majority of persons entering a nursing home (75 percent) stay less than 1 year, and one-third to one-half of all entrants stay less than 3 months. About one-fourth of all persons entering a nursing home stay beyond 1 year, and relatively few (14 percent to 17 percent) stay more than 3 years.[1] For more detailed information on the elderly nursing home population, please see Section 1.

3. Medicare

Medicare is a Federal health insurance program with a uniform eligibility and benefit structure throughout the United States. The program covers most individuals entitled to Social Security benefits, persons under age 65 entitled to Federal disability benefits, and certain individuals with end-stage renal disease. Coverage is available to individuals without regard to their income or assets.

Medicare's coverage is focused primarily on acute rather than long-term care, particularly hospital and surgical care and accompanying periods of recovery. To the extent that Medicare covers any long-term services, it does so only where a need for skilled care can be demonstrated. The current Medicare skilled nursing facility (SNF) benefit is limited to 100 days of services in a year following a hospital stay of at least 3 days, subject to a daily copayment after the 20th day. For those persons receiving SNF benefits in 1984, Medicare covered an average of 27 days of care. While the House and Senate-passed versions of the catastrophic legislation expand the number of days covered under the SNF benefit and eliminate the prior hospitalization requirement, the focus of the benefit on acute, rehabilitative care is unchanged.

Medicare expenditures for long-term care generally have been small. In fiscal year 1986, Medicare benefit payments for SNF care were only $607 million,[2] less than 2 percent of total public and private spending for nursing home care and less than 1 percent of total Medicare spending. According to the Health Care Financing Administration (HCFA), the number of patients admitted to Medicare SNF's has increased since the advent of the Prospective Payment System (PPS) in fiscal year 1984. Between 1983 and 1984, the number of covered admissions rose from 308,000 to 332,000, an in-

[1] Cohen, Marc, Eileen Tell, and Stanley Wallack. "The Lifetime Risks and Costs of Nursing Home Use Among the Elderly." Medical Care, v. 24, No. 12, December 1986. p. 1169.

[2] Health Care Financing Administration, Office of the Actuary.

crease of 7.7 percent. However, the total number of covered days of care declined from 9.1 million to 8.9 million during the same time period, a decrease of 2.2 percent. The average number of covered days of care per discharge dropped by almost 3 days, or 8.9 percent, from 29.2 days in 1983 to 26.6 days in 1984.[3] Although expenditures for the SNF benefit increased during that time in absolute terms, the rate of increase was lower in the post-PPS period than in the pre-PPS period.

Many believe that the Medicare SNF benefit has been the target of arbitrary denials by the various fiscal intermediaries (FI's) in recent years. Fiscal intermediaries are private insurance companies that contract with HCFA to administer the Medicare Program. The FI's base their coverage determinations on existing law and regulations, as well as on HCFA manuals. Because the law and the manuals are very broad, they are subject to widely varying interpretations. According to the American Association of Retired Persons, the regional variation in denials of SNF claims ranges from 9.8 percent in the Denver region to 41.5 percent in the Boston region. Medicare denied 31.8 percent of all SNF claims in fiscal year 1986, compared to 1.8 percent of all hospital claims and 6 percent of all home health claims. HCFA issued a new set of guidelines, effective April 1, 1988, that clarify the SNF benefit and are designed to provide better guidelines to FI's and providers.

4. Medicaid

The Medicaid Program is a Federal-State matching program providing medical assistance for certain low-income persons. Each State administers its own program and, subject to Federal guidelines, determines eligibility and scope of benefits. Each State also determines the payment rate for services provided to Medicaid recipients. The Federal Government's share of medical expenses is tied to a formula based on the per capita income of the State. At minimum, the Federal Government will pay 50 percent of the costs of medical care; this amount ranges up to 78 percent in the lower per capita income States.

Although most older Americans are not eligible for Medicaid, it nonetheless has become the primary source of public funds for nursing home care. Approximately 89 percent of all public expenditures for nursing home care are paid by Medicaid and 48 percent of all nursing home residents are Medicaid beneficiaries.

State Medicaid programs are required by Federal law to cover the categorically needy, that is, all persons receiving assistance under the Aid to Families with Dependent Children (AFDC) program and most people receiving assistance under the Supplemental Security Income (SSI) program. States also may cover persons who would be eligible for cash assistance, except when they are residents in medical institutions, such as SNF's or intermediate care facilities (ICF's).

In addition, States may, at their discretion, cover the medically needy, that is, persons whose income and resources are large

[3] Office of Research and Demonstrations, Health Care Financing Administration. Report to Congress: "Impact of the Medicare Hospital Prospective Payment System, 1985 Annual Report." August 1987, p. 6.19-20.

enough to cover daily living expenses, according to income levels set by the State, but are not large enough to pay for medical care. If the income and resources of the medically needy individual are above a State-prescribed level, the individual must first incur a certain amount of medical expenses which lowers the income to the medically needy levels (that is, the spend-down requirement). Thirty-two States and jurisdictions have medically needy programs that can cover the elderly. As a result of State variations such as these, persons with identical circumstances may be eligible to receive Medicaid benefits in one State, but not in another. Further, individuals within the same State with similar incomes may not be equally eligible for benefits because of welfare rules.

Medicaid expenditures for nursing home care in 1987 are estimated to be approximately $17.3 billion, up from $16 billion in 1986.[4] Medicaid financed 87 percent of Federal spending and 42 percent of total nursing home expenditures. To illustrate the extent to which Medicaid finances nursing home care, 21.8 million people received Medicaid benefits in fiscal year 1985. Of that number 2.5 percent received SNF care, and 3.8 percent received ICF services. Yet, of fiscal year 1985 vendor payments, 13.5 percent were for SNF care and 17.4 percent were for ICF services.[5]

Medicaid expenditures have been growing rapidly since 1972, and expenditures for nursing home care are the largest and fastest growing component if ICF's for the mentally retarded are included. Increasing numbers of elderly nursing home residents account for a portion of this growth, but the costs of nursing home care have grown at twice the rate of beneficiary growth. For example, the number of ICF residents (nonmentally-retarded) grew by 3.9 percent between fiscal year 1984 and 1985, while the cost per resident grew by 7.7 percent, nearly twice the growth rate.[6] The growth in costs for SNF benefits is even more dramatic: The number of recipients actually declined by 2.2 percent during this period while costs per resident rose by 7.7 percent.

Because Medicaid expenditures consume 10 to 15 percent of State budgets, many States are seeking to control the growth of their nursing home population and their obligated Medicaid expenditures. As many as 26 States made changes in nursing home reimbursement policies to reduce costs in 1981 and 1982, and most States now use a form of prospective reimbursement. Other initiatives used to contain Medicaid nursing home expenditures include limits on the number of Medicaid-licensed beds, pre-admission screening programs, and a greater emphasis on home and community-based care.

5. Out-of-Pocket Expenditures

While the cost of long-term care represents an increasing share of Federal and State budgets, relatively few older Americans have access to publicly financed services. The cost of nursing home care

[4] Division of National Cost Estimates, Office of the Actuary, Health Care Financing Administration. National Health Expenditures, 1986–2000. Health Care Financing Review, summer, 1987, vol. 8, No. 4, p. 13.
[5] Ibid.
[6] Congressional Budget Office, 1987.

and home and community-based care often falls on individuals and their families.

Older persons and their families pay for more than one-half of the costs of nursing home care. The proportion of total nursing home costs paid out-of-pocket has increased by about 20 percent from 1975 to 1985. During that same period, the portion of nursing home costs paid by Medicaid has decreased. As mentioned above, while the amount that Medicaid pays for nursing home care has been increasing (306 percent between 1975 and 1985), the amount paid out-of-pocket has been increasing at a faster rate—420 percent between 1975 and 1985.[7]

The price of a year in a nursing home ranges from $12,000 to $50,000; the cost at even the lower end of this range is beyond the resources of most older Americans. Thus, many elderly people must spend their entire savings before they become eligible for Medicaid soon after they enter a nursing home. Currently, between one-quarter and two-thirds of the patients who enter nursing homes as private paying patients subsequently spend down their resources before they become eligible for Medicaid.

6. Differences in States' Medicaid Programs

Each State designs and administers its Medicaid programs within broad Federal guidelines. As a result, there is significant variation among States with regard to eligibility requirements, benefits provided, and provider reimbursement policies. Because Medicaid programs are so complex, there is not a sizable body of data and research available on the differences among the various States' programs. Further, the information that is available focuses on the programs in general, rather than on differences in specific aspects of the various programs (such as nursing home services or the effects of eligibility requirements on those 65 and older).

All Medicaid programs are required by Federal law to provide SNF benefits. The services must be needed on a daily basis, and must be provided in an inpatient facility. Fourteen States impose no limits on SNF services, and 22 States require prior authorization for payment, with 7 of the 22 requiring periodic reauthorization (generally, authorization means approval for payment by an administrative body, although there is no constant usage of the term across States). Twenty States impose other limits on SNF services such as restrictions on private rooms, SNF services outside the State, specific services, bed reservations when on leave or in another facility.[8]

In fiscal year 1985, the nationwide simple average Medicaid daily SNF reimbursement rate was $51.73, with rates ranging from a low of $30.31 in Arkansas to a high of $92.90 in New York. The national simple average Medicaid payment per patient day was $41.01. The lower rate reflects mandatory patient contributions, primarily from the Social Security and pension income of the recipient. These

[7] Varner, Theresa, "Catastrophic Health Care Costs for Older Americans," American Association of Retired Persons, Public Policy Institute, Publication No. 8702, June 1987.

[8] Health Care Financing Administration, Health Care Financing Program Statistics: "Analysis of State Medicaid Program Characteristics, 1986" (Baltimore: U.S. Department of Health and Human Services, 1987), p. 31.

simple nationwide averages, however, can be deceptive given the enormous interstate differences in payment rate per recipient.

Total days of care in fiscal year 1985 ranged from a low of 10,000 in New Hampshire to a high of 22,417,000 in California. Some ancillary services are included in the SNF payment rate, although this also varies widely among States. Most States include nonlegend drugs and medical supplies, and about one-half the States include physical or occupational therapy. Very few include prescription drugs in the per diem rate.[9]

Intermediate care facility services are optional, although all States include this service in their benefit packages. These services must be provided in a facility, and those eligible are those who do not require hospital or SNF care, but whose mental or physical condition requires services that are above the level of board and care. Eighteen States place no limits on ICF services, 22 States require prior authorization for ICF services, and 6 of the 22 require periodic reauthorization. Other limits, similar to those discussed earlier under the SNF benefit, are imposed by 14 States.

Again, as with the SNF benefit, there are tremendous interstate differences with regard to rates per patient day and payments per patient day. Excluding Alaska and Hawaii, average Medicaid allowable ICF rates per patient day for fiscal year 1985 ranged from a low of $28.75 in Arkansas to a high of $61.18 in New York, with an average rate of $41.65. The national simple average Medicaid payment per patient day was $30.33. Total days of care ranged from a low of 58,000 in Wyoming to a high of 17,471,000 in Texas. The five largest ICF programs in terms of total days of care were Illinois, Indiana, Michigan, Pennsylvania and Texas. Patterns of inclusion of various ancillary services were similar to those for SNF's.[10]

There is also a wide disparity among various States with regard to numbers of Medicaid-certified nursing home beds, training and staffing requirements, etc. For example, the number of nursing home beds in 1983 per thousand elderly ranged from 89.4 in Wisconsin to 22 in Arizona.[11] The number of nursing hours required in a Medicaid-certified SNF facility per resident day ranges from 3.2–4.0 in Hawaii to zero in 7 States which have no requirements (those States are Arkansas, Kentucky, North Dakota, Nebraska, New Mexico, Washington, and West Virginia). Thirty-four States have no requirements for the training of nurse aides in nursing homes, although California, Missouri, Illinois, and Maine require from 150–120 hours of training.[12]

7. Medicaid Eligibility and Spend-down

A particularly important concern over the past few years has been the issue of Medicaid spend-down for nursing home care. To become eligible for Medicaid coverage, persons must either be poor

[9] Ibid.
[10] Ibid.
[11] Erdman, Karen and Sidney M. Wolfe, M.D., "Poor Health Care for Poor Americans: A Ranking of State Medicaid Programs" (Washington, DC: Public Citizen Health Research Group, 1987), p. 81.
[12] Ibid.

or spend-down their income to the eligibility level of their State's Medicaid Program. While there is a great deal of variability among States' Medicaid programs and income eligibility levels, nursing home residents—and often their spouses—must impoverish themselves before they become eligible for Medicaid coverage. According to the Department of Health and Human Services, about one-half of the persons receiving Medicaid coverage for their nursing home care became eligible after they entered the nursing home. As mentioned earlier, a preliminary analysis of the 1982 and 1984 Long-Term Care Surveys found that 1 in 3 elderly persons who spend any time in a nursing home will end up poor, and become eligible for Medicaid.

Moreover, a recent report from the House Select Committee on Aging revealed that 7 in 10 elderly persons living alone (and 9 million of the 27 million noninstitutionalized elderly in this country live alone) are impoverished after 13 weeks in a nursing home.[13] Within 1 year of entering a nursing home, more than 90 percent of these elderly are impoverished. Based on income, a person older than 65, living alone, with an annual income between $9,700 and $15,000 (between 200 percent and 300 percent of the poverty level) would be impoverished after only 17 weeks, on average, in a nursing home. The same older person with an income between $6,000 and $10,000 (between 125 percent and 200 percent of the poverty level) would be impoverished, on average, after only 6 weeks in a nursing home.

While the picture is somewhat brighter for elderly couples, more than one-half of the couples are impoverished after one spouse has spent only one-half year in a nursing home. Most often, it is the wife who remains in the community, and she often is left with little or no money with which to meet her own health and other needs.

Generally, when determining Medicaid eligibility, income (such as Social Security checks, pensions and interest from investments) is attributed to the person whose name is on the instrument conveying the funds. In the case of Social Security, the amount attributed to each spouse is the individual's share of the couple's benefit. Therefore, if the couple's pension check is made out to the husband, all of that income is considered his for the purpose of determining Medicaid eligibility. Because the current generation of women whose husbands are at risk of needing nursing home care typically did not work outside the home, they likely have very little income other than their husband's.

The attribution of resources such as certificates of deposit and savings accounts is done similarly. If the resources are held solely by the institutionalized spouse, they are attributed to him or her for purposes of determining Medicaid eligibility. If they are in both spouses' names, they are still attributed to the institutionalized spouse. Medicaid eligibility can be denied to individuals who transferred resources for less than fair market value within 2 years of applying for Medicaid.

---

[13] U.S. Congress, House Select Committee on Aging, "Long-Term Care and Personal Impoverishment: Seven in Ten Elderly Living Alone Are at Risk," Committee print, 100th Cong., 1st sess., Washington, DC, U.S. Government Printing Office, 1987.

Once an institutionalized spouse has been determined Medicaid-eligible, some of his monthly income is reserved for the use of his spouse. When combined with the community spouse's income (if one exists) it allows a maintenance needs level. Under current regulations, the maintenance needs level may not exceed the highest of the SSI, State supplementation, or "medically needy" standards in the State. According to a survey taken by the American Association of Retired Persons in March 1987, maintenance needs levels vary widely from State to State—from a high of $632 in Alaska to zero in Oklahoma. Thus, in a State with a maintenance needs level of $350, if the community spouse's monthly income is equal to $150, the contribution from the institutionalized spouse would be $200.

Both the Senate- and the House-passed versions of the catastrophic health insurance legislation (H.R. 2470) contained provisions to address the issue of spousal impoverishment. These bills are discussed in Chapter 4.

8. Nursing Home Quality of Care

Quality of care in nursing homes has been an item of concern and interest to the elderly and their advocates for a number of years. Several investigations and studies, including a 2-year investigation (completed in 1986) by the Senate Special Committee on Aging, a report by the Institute of Medicine, and most recently a report commissioned from the General Accounting Office by Senator John Heinz, have found that thousands of frail elderly citizens live in nursing homes which fail to provide care adequate to meet even their most basic health and safety needs. Legislation finally was passed in 1987 to implement many of the recommendations of the various studies and aging advocacy organizations. The Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203) contains extensive nursing home quality care provisions that will take effect over the next 2½ years. This legislation will be outlined in greater detail in Chapter 4.

In 1983, in response to congressional concern about controversial nursing home regulations proposed by HCFA, the administration commissioned a study from the Institute of Medicine (IoM) of the National Academy of Sciences. According to the contract, this study was to "serve as a basis for adjusting Federal (and State) policies and regulations governing the certification of nursing homes so as to make those policies and regulations as appropriate and effective as possible." The study was begun in October 1983 and released in 1986. It concluded that the quality of care and quality of life in many nursing homes are unsatisfactory, and that a stronger Federal role is essential to improve the quality of care. The study made a number of recommendations to strengthen and improve the current Federal regulations that have been incorporated into the 1987 law. These recommendations include the elimination of the distinction between SNF's and ICF's, the use of intermediate sanctions to enforce compliance with regulations, and the strengthening of residents' rights.

Both the GAO report and the Special Committee on Aging's investigation found many of the same problems. For example, the Aging Committee disclosed that nursing home inspection reports

from HCFA revealed that in 1984, more than one-third (3,036) of the Nation's 8,852 certified SNF's failed to comply with the most essential health, safety, and quality standards of the Federal Government. About 1,000 (11 percent) of the SNF's violated three or more of these standards. GAO found that 41 percent of SNF's and 34 percent of ICF's nationwide were out of compliance during three consecutive inspections with one or more of the 126 skilled or 72 intermediate care facility requirements considered by experts to be most likely to affect patient health and safety. Penalties or sanctions to enforce compliance were found to be severely lacking.

B. HOME AND COMMUNITY-BASED SERVICES

1. History

Home and community-based long-term care services are those that assist individuals to avoid unnecessary institutionalization and maintain independence in the community. These services range from medical and therapeutic services for the treatment and management of chronic conditions to assistance with basic living services associated with shelter and meals (such as housekeeping and shopping) to personal care assistance (such as bathing, grooming, and getting out of bed). Services may be provided in the home or in other settings, such as day care centers. Providers include agencies and organizations that are paid for their services and informal care givers, usually family members, who generally provide assistance without compensation.

Home care programs were initially established in the United States around 1796 when the Boston Dispensary established a home care program primarily for the purpose of training resident physicians. This concept was revived a century and a half later by hospitals in New York City and eventually followed by other hospitals when the lesser costs of out-patient services became more attractive.

Public health nursing which emerged in the late 1800's also involved home visits. For several decades, beginning in 1909, home nursing care was offered by life insurance companies to its policy holders.

A comprehensive home care model was developed in England after World War II and in time was transplanted and adapted to the United States. Beginning in the 1950's, home nursing agencies began to augment their services with home health aides and homemakers. Further expansion of home care services, particularly home health services, began after the passage of Medicare and Medicaid, titles XVIII and XIX of the Social Security Act, in 1965.

Hospice care is a means of caring for the terminally ill and their families. The term "hospice" is derived from a medieval word for a wayside shelter for travelers on difficult journeys. St. Christopher's in London, England, founded in 1967, is the first modern-day hospice, and hospices in the United States are modeled after it. The first hospice opened here in 1974, and there are now an estimated 1,500 programs in various stages of development around the country. Most hospice care takes place in the home, and its emphasis is not on curative care, but rather on alleviating pain and improving

the quality of life for persons for whom there is no chance of a cure. Hospice models range from hospital-based programs to free-standing facilities to so-called "hospices-without-walls."

Adult day care also has European roots. The first geriatric day hospital was opened in England in 1950. By the end of the decade, the concept of the day hospital had evolved into two forms: the geriatric day hospitals and social day care centers. The adult day care center movement in the United States did not begin to grow until the early 1970's. In 1970, there were about 14 such centers, in 1987 this number had grown to over 1,200.

Respite services are those that provide family caregivers with intervals of relief from the demands of their caregiving roles and are provided in a variety of settings. Family caregivers currently provide between 70 and 80 percent of needed care for the disabled elderly in the community. Such assistance not only alleviates the stresses experienced by the caregiver but may also prevent or delay the institutionalization of an impaired elderly person. Additionally, respite is seen as a preventive measure against elder abuse.

Several European countries have been experimenting with respite care alternatives for 20 years. These include short-term placement of the disabled person in institutions or private homes and, sitting services. Respite care is a relatively new concept in the United States. A few individual States began to develop the first programs in the late 1970's. Although respite care does not have the historical evolution that home care and day care have, both of those programs include a respite component.

Case management, as it pertains to community services for the elderly, is generally defined as the development and management of an individualized plan of community-based services designed to enable frail individuals to live independently. Activities include client screening, assessment, care planning, coordination of services to carry out care plans, follow-up, and monitoring.

Social workers, clergy, community agencies, and hospital discharge planners have provided elements of case management since the mid-19th century. The first Federal involvement with case management began in 1971 when the Department of Health, Education, and Welfare funded a series of demonstration projects. The goal of the projects was to test a variety of mechanisms for integrating social and health services for clients, including information retrieval and patient tracking systems as well as case management.

Since then, case management has been utilized not only with increasing access to a broad set of long-term care services, but also within the context of limiting costs under Medicaid, and the gatekeeping function of health maintenance organizations.

2. Characteristics of the Population

Elderly persons, by virtue of their high risk of chronic illness that results in disability and functional impairment, are the primary recipients of long-term care in this country.

In 1984, there were 5.3 million elderly community residents in need of long-term care. Approximately 2.8 million of these were in need of extensive care due to severe disability. Rough estimates for 1988 are that 5.7 million elderly community residents currently

need long-term care, 3 million of which are in need of extensive services.

Elderly community residents in need of long-term care are more than twice as likely to be among the young-old (age 65 to 74) and married than their counterparts in nursing homes. As mentioned earlier, they are also less likely to be severely or moderately limited in activities of daily living and in need of extensive long-term care services.

3. Medicare

Medicare does not provide extensive support for long-term care, although it does pay for very limited amounts of community-based long-term care services, primarily through the program's home health benefit. In order to receive home health care under Medicare, the beneficiary must be under the care of a physician and be confined to his or her home. Further, the person must be in need of part-time or intermittent skilled nursing care, or physical or speech therapy. Services must be provided by a Medicare-certified home health agency according to a plan of treatment prescribed and reviewed by a physician. There is no statutory limit on the number of home health visits covered under Medicare, nor is the beneficiary liable for any cost-sharing such as deductibles or copayments for covered home health services.

Home health care has been one of the most rapidly growing Medicare benefits. However, as a percentage of total Medicare expenditures, the amount of reimbursement for home health care is small. According to HCFA, Medicare payments for home health care comprise a relatively small 3.8 percent of total program outlays. For fiscal year 1987, total reimbursements for Medicare home health services were $2.5 billion.[14]

The number of persons receiving Medicare-covered home health care increased by 12.2 percent between 1983 and 1984, from about 1.3 million to 1.5 million persons. However, the rate of growth over this time period was lower than the 13.7 percent annual rate for the period between 1980 and 1983 (the period immediately prior to the implementation of the Prospective Payment System). Between 1983 and 1984, the number of visits increased from almost 37 percent to more than 40 million. The average number of visits per person remained unchanged at 27 in that period.

There has been growing concern that the Medicare home care benefit does not provide adequate post-hospital care to many Medicare beneficiaries. Large numbers of Medicare patients who are discharged "quicker and sicker" under PPS often find post-hospital care unavailable or substandard. The stress on post-hospital services is increasing substantially.

According to many aging advocates, this problem has been exacerbated by the efforts of HCFA to reduce access to the Medicare home care benefit. Many believe that HCFA has targeted the home health benefit for continual cutbacks, lower payment levels, and narrower interpretation of the scope of the benefit. As a result, more Medicare beneficiaries need home health care at a time when

[14] Health Care Financing Administration, Office of the Actuary.

less care is available. Concerns have also been raised about the quality of home health care and the adequacy of the current oversight and monitoring system to assess quality care. Several provisions in the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203) address these issues.

Currently, Medicare beneficiaries over 85 are nearly five times more likely to receive home care services than Medicare beneficiaries aged 65-69. As the "old-old" population (those older than 85) increases, home care demand and utilization also will increase significantly.

Hospice care, which focuses on controlling the pain and other symptoms of the terminally ill rather than on curative measures, is also covered by the Medicare Program. Hospice care is provided in a home-like environment, and the whole family, rather than the patient alone, is the unit of care. Care is supervised by a team of physicians, nurses, social workers and counselors, and is provided and monitored on a round-the-clock basis, when necessary, whether provided in an institutional setting or at home. Drugs and other therapies are used to prevent or control pain, rather than to cure the disease.

In order to be eligible for the Medicare hospice benefit, a beneficiary must be certified terminally ill by his or her physician and agree to receive care from a Medicare-certified hospice program instead of standard Medicare benefits. Medicare pays the full cost of all covered services with no deductibles or copayments except for the cost of outpatient drugs and respite care, for a maximum of two 90-day periods and one 30-day period. Covered services include: Nursing and physicians' services, home health aide and homemaker services, physical therapy, and drugs, including outpatient drugs for pain relief and symptom management. The patient is responsible for 5 percent of the cost of outpatient prescription drugs, or $5.00 toward each prescription, whichever is less. For respite care, which is a short-term inpatient stay of up to 5 days designed to give temporary relief to the patient's primary caregiver, the patient is responsible for 5 percent of the cost, up to a total of $540 (in 1988).

The average Medicare beneficiary who elects the hospice benefit is 74 years of age, white, and a cancer victim who enrolls and remains for 1 to 2 months before dying. In fiscal year 1985, Medicare served 5,523 patients under the hospice benefit, at a cost of approximately $2,000 per patient.[15]

4. Medicaid

Medicaid is a combined Federal/State funding source for health care to low-income persons. It is the Federal program which primarily supports long-term care, particularly nursing home care. The home health benefits that may be reimbursed under Medicaid include part-time nursing, home health aide, and medical equipment and supplies. At the State's option, the home health benefit may also cover physical therapy, occupational therapy, speech pa-

[15] Health Care Financing, Extramural Report, Medicare Hospice Benefit Program Evaluation, U.S. Department of Health and Human Services, Health Care Financing Administration, Office of Research and Demonstrations, U.S. Government Printing Office, Washington, DC, 1987.

thology, and audiology. In addition to home health services, States may also cover as optional services personal care services, private duty nursing and case management.

Prior to 1981, Federal regulations limited Medicaid reimbursable home care services to the traditional acute care model. In practice, this meant that only those conditions of a short-term, and/or single episodic nature were covered by Medicaid. Congress, in Section 2176 of the Omnibus Budget Reconciliation Act of 1981, authorized the Secretary of the Department of Health and Human Services to expand Medicaid beyond acute care. The Secretary was given the authority to waive certain Medicaid requirements to allow States to provide a broad range of home and community-based long-term care services to individuals who otherwise would have no alternative than to receive Medicaid-financed care in a hospital, skilled nursing facility, or intermediate care facility. These home and community-based services must cost no more than institutional care. Waivers to provide these services are frequently referred to as 2176 waivers after the section in the Act which authorized them.

Prior to the implementation of the 2176 waiver program, Medicaid services available to chronically ill or disabled individuals living in the community were generally restricted to medical and medical-related services. The waiver authority acknowledges that a wide variety of nonmedical services may also be needed in order to prevent or avoid institutionalization.

The services allowed under the waivers include long-term nursing or therapy for chronic conditions, case management, personal care, homemaker and chore services, adult day health care, and respite care. Personal care comprises 40 percent of waiver expenditures for aged and disabled clients, followed by case management and homemaker services which account for 15 percent each of expenditures. The remainder of waiver expenditures for the aged and disabled provides for adult day care (5 percent), home health aide (4–5 percent), respite care (1 percent), and other nonspecified services.

In 1987, 46 States had 180 approved waiver programs in operation. However, despite the large number of these programs, waiver clients account for only 3 percent of the entire "at risk" population. Five States account for 56 percent of all aged and disabled waiver recipients: Florida, California, Illinois, New York, and Oregon.

While the Medicaid Program is the predominant Federal program supporting long-term care services, a variety of social service programs provide community-based services which often have as their primary purpose the delay or prevention of institutionalization. Foremost among these programs are the Social Services Block Grant program and the Older Americans Act. In many communities, these two programs represent an important source of services to the frail elderly and often fill gaps in services not met by either the Medicare or Medicaid programs.

5. Social Services Block Grants: Title XX of the Social Security Act

Title XX, which was added to the Social Security Act in 1975, consolidated various Federal social services programs and effectively centralized their Federal administration. In 1981, Congress created the Social Services Block Grant (SSBG) program which eliminated most of the restrictions that existed under Title XX. States were given much more discretion in determining the service population and services to be offered. The 1981 law also eliminated State reporting requirements.

Among other goals, the SSBG is designed to prevent or reduce inappropriate institutional care by providing for community-based care, and to secure referral or admission for institutional care when other forms of care are not appropriate. Through the SSBG, all 50 States provide a number of home and community-based long-term care services for diverse client groups, including children, the disabled, and the elderly.

Although the SSBG is the major social services program supported by the Federal Government, its ability to support the long-term care population is limited. Because it provides a variety of social services to a diverse population, the Title XX program has competing demands and can only provide a limited amount of care to the older population. The elimination of the reporting requirements under SSBG has made efforts to track services for the elderly difficult. According to a Department of Health and Human Services (DHHS) analysis of the States' fiscal year 1986 pre-expenditure reports, home care services—which may include homemaker, chore, and home management services—were to be provided by virtually all States; adult day care by 31 States; and adult foster care by 18 States.

A survey was conducted by the American Association of Retired Persons (AARP) in 1987 to determine the amount of SSBG funds being used for services to the elderly. The survey showed that 47 States use some portion of their SSBG funds to provide services to older persons. Forty-four of the States submitted estimates on the percentage of services allocated for the elderly. The estimates ranged from less than 1 percent up to 50 percent, with an average of 18 percent. The survey also revealed that the most frequently provided services to the elderly were home-based, adult protective, adult day care, transportation, and nutrition services.[16]

6. Older Americans Act

The Older Americans Act carries a broad mandate to improve the lives of older persons in the areas of income, emotional and physical well-being, housing, employment, social services, civic, cultural and recreational opportunities.

The purpose of Title III of the Act, which authorizes formula grants to States for services to older persons, is to foster the development of a comprehensive and coordinated service system for older persons in order to: (a) Secure and maintain maximum inde-

[16] Gaberlavage, George, "Social Services to Older Persons Under the Social Services Block Grant," Washington, DC: American Association of Retired Persons, April 1987.

pendence and dignity in a home environment for older persons capable of self-care; (b) remove individual and social barriers to economic and personal independence for older persons; and (c) provide a continuum of care for the vulnerable elderly.

Under Title III, grants are made to State agencies on aging, which in turn award funds to 670 area agencies on aging, to plan, coordinate, and advocate for a comprehensive service system for older persons. Title III supports a wide range of supportive services, as well as congregate and home-delivered nutrition services. Certain supportive services have been given priority by Congress. These priority services are access services (transportation, outreach, information and referral), legal assistance, and in-home services such as homemaker, home health aide, personal care, chore, escort and shopping services. Visiting and telephone reassurance are also considered to be in-home supportive services. Other community-based long-term care services which may be provided under Title III include case management, adult day care, and respite care. According to the Administration on Aging, the estimated number of client contacts in 1987 under Title III–B supportive services ranges from 6.3 million for transportation to almost 1 million for homemaker/home health aid services.

The Older Americans Act Amendments of 1987 (Public Law 100–175), which authorized the Act for another 4 years, created a new service program for in-home services for the frail elderly, which is discussed in greater detail in Chapter 4.

7. Providers

Providers of home and community-based care include private, nonprofit agencies; for-profit agencies; and public health and social service agencies. In certain circumstances, area agencies on aging also provide direct services, particularly case management.

However, most care, particularly home care, is provided by family and other informal caregivers. The 1982 National Long-Term Care Survey found that most of the disabled elderly received personal assistance in activities of daily living from spouses, children or other informal sources of support. Of the 4.3 million disabled elderly in the community, only 5 percent of long-term care recipients receive their care from paid sources. Relatives represented 84 percent of all caregivers for males and provided 89 percent of days of care. Relatives represented 79 percent of caregivers and provided 84 percent of days of care for older disabled females.

Estimates from this survey show that the average age of caregivers of the impaired elderly was 57 years. More than a third of caregivers were over age 65—25 percent of caregivers were aged 65–74, and 10 percent were 75 years or older. This data supports the view that the informal services are largely provided by the "young old" to the "old old." Additionally, caregiving is primarily a female responsibility. Approximately 72 percent of caregivers to the functionally impaired elderly are female.

C. LONG-TERM CARE SERVICES FOR VETERANS

1. Overview

For more than two decades, the Veterans Administration (VA) has financed the provision of long-term care to the Nation's veterans in VA medical centers and through community nursing homes and State veterans' homes. In the last several years, the VA also has furnished veterans this care in a variety of noninstitutional settings. VA noninstitutional programs include community residential care, hospital-based home care (i.e., health care services in the home of the veteran), and adult day health care.

In an effort to keep pace with a growing demand for long-term care among aging veterans, the VA has significantly expanded its services in this area. Nevertheless, many veterans who are eligible for and in need of these services continue to be turned away. In 1986, less than 20 percent of the demand among eligible veterans for VA nursing home care was met through VA operated or supported programs.[17] Although no statistical measure exists with respect to the demand for the VA's other extended care program, a shortfall in these services also can be presumed.

It is the projected demand for long-term care services in the future that poses the most significant and unprecedented challenge to the VA. Meeting the rapidly accelerating demand for these services will require enormous efforts and resources. The extent to which the VA succeeds in meeting this demand is of vital importance to the Nation's aging veterans. Moreover, as the VA will be faced with this problem well before the rest of society, its efforts also will serve as a precursor to the Nation when the same problem later confronts the general population.

2. VA Institutional Long-Term Care

(A) NURSING HOME CARE

Since 1964, the VA has been authorized to provide nursing home care in VA medical centers, community facilities on a contract basis, and State veterans' homes through a VA grant program. In 1986, approximately 79,000 veterans were treated in the programs at a total cost to the VA of over $805 million.[18]

The VA's nursing home care program, which in 1986 served 30 percent of the VA nursing home care total, is operated in 117 VA medical centers across the Nation. In addition to nursing home care, the program provides a range of other services, including rehabilitative therapy, supportive personal care, and social activities. In 1986, 23,940 veterans were treated in the program at a cost of $18,900 per veteran. Total expenditures in that year were $452 million.

The largest component in the VA's nursing home care system, which treated 52 percent of the VA's nursing home care total in 1986, is the VA community nursing home program. Participating community facilities are inspected on a monthly basis by a VA

[17] Source: Geriatric and Extended Care Programs, Veterans Administration.

[18] Unless otherwise noted, 1986 data in sections (2) and (3) are taken from the Veterans Administration. "Annual Report: 1986".

nurse or social worker for both quality of care and life conditions. In 1986, 3,400 community nursing homes served a total of 41,124 veterans at a per capita cost to the VA of $7,400. The program total was $302 million.

In 1986, approximately 18 percent of the total number of the VA nursing home care patients received nursing home care in State veterans' homes. Under a Federal-State matching grant program established in 1964, the VA has greatly contributed to the construction or expansion of State veterans' home facilities. By 1986, the VA had spent over $204 million in matching funds for these purposes.

Up to 25 percent of the costs of extended care services in State veterans' homes is provided on a per diem basis through the VA. In 1986, 13,914 veterans were served in State homes at a total per capita cost of $14,800. The VA share of the cost per veteran was $3,700 and the State share approximately $11,100. Total costs of the program were over $51 million in that year.

The large variation in per capita costs among the VA's nursing home care programs stems from a number of factors. At $18,900 per veteran, the VA-operated nursing home care program is the most expensive due in part to the greater range of health care services it provides and the medically complex setting in which it functions. Nursing home care in a VA State veterans' home, which costs $14,800 per veteran, is likewise hospital-based and therefore more costly.[19]

In addition, the high cost of the VA-operated nursing home care program is a result of the heavier reliance it places on registered nurses, rather than lesser-trained staff, particularly when compared with the community nursing home care program. In 1986, it was estimated that as little as 10 to 15 percent of the staff in community nursing homes were registered nurses, with the bulk of daily tasks performed instead by nursing assistants. The low per capita cost of $7,400 in the program thus can be tied partially to lower labor costs.[20]

As a result of the mounting number of elderly veterans in recent years, both the demand and the costs of providing nursing home care have risen at an increasing rate. (See Table 1: VA Nursing Home Care.)

[19] Source: Geriatric and Extended Care Programs, Veterans Administration.
[20] Ibid.

TABLE 1.—NURSING HOME CARE—TRENDS AND COSTS

[In thousands of dollars]

	1965	1975	1980	1984	1986
Patients:					
Total		40,113	51,337	65,627	78,978
Daily average	324	17,101	22,048	27,136	30,538
Cost	$1,271	$161,890	$358,727	$631,135	$805,548

Sources: Veterans Administration. "Annual Report: 1986."
Veterans Administration. "Caring for the Older Veteran". 1984.

(B) DOMICILIARY CARE

For veterans who are disabled by age, injury, or illness, but who do not require acute medical services or nursing home care, the VA provides health care and support services in 1 of its 16 domiciliaries or in a State veterans' home. Eligibility is limited to those veterans who have no means of support.

In 1986, of the 21,522 veterans in the program, 13,250 received domiciliary care in VA medical centers and 8,772 in State veterans' homes at a per capita cost of $7,492 and $1,510, respectively. (As the VA only pays up to 25 percent of the State veterans' home costs, the VA-operated domiciliary care is only about $1,500 more per veteran.) In that year, VA-operated domiciliary care services cost a total of $99.3 million and State domiciliary care a total of $13.6 million, totalling $112.9 million for both components of the program.

Prior to 1984, the VA's domiciliary care population had steadily declined because, according to the VA, rising numbers of aging veterans required more medically intensive VA health care services. However, since that time, the demand for domiciliary care has leveled off. (See Table 2: VA Domiciliary Care.)

TABLE 2.—VA DOMICILIARY CARE—TRENDS AND COSTS

[In thousands of dollars]

	1965	1975	1980	1984	1986
Patients:					
Total		30,550	24,966	21,579	21,522
Daily average	23,721	15,030	12,786	10,637	10,089
Cost	$39,826	$63,085	$96,596	$107,756	$112,890

Sources: Veterans Administration. "Annual Report: 1986."
Veterans Administration. "Caring for the Older Veteran". 1984.

3. VA Noninstitutional Long-Term Care

In recent years, the VA has begun to explore and expand programs which provide extended care services in noninstitutional settings. This approach is designed to maximize the independence of veterans who require such services. It also enables the VA to more effectively utilize its institutional long-term care resources by limiting them solely to those whom the VA determines as being in need of institutional care. These programs include community residential care, adult day health care, and hospital based home care.

(A) COMMUNITY RESIDENTIAL CARE

Under the VA's community residential care program, disabled or elderly veterans who are unable to live independently are provided limited personal care and supervision in a private home. Also, to qualify for this program a veteran must lack family members that are able to undertake this responsibility and be capable of basic self-care with minimal assistance. Under the program, veterans are referred to VA-approved homes that are annually inspected. VA health care professionals visit the veteran monthly in the home, while any additional medical attention is provided on an outpatient basis at a local VA medical center or clinic. Payment for the residential setting is borne by the veteran and all health care costs by the VA.

In 1986, 11,600 veterans participated in the VA's community residential program, at an average cost of $558 per month to the veteran and $870 annually to the VA. Total program costs to the VA were $10.1 million. Authorized by the Congress in 1984, this program included 3,200 residences in 1986.

(B) HOSPITAL-BASED HOME CARE

Established in 1970, the VA's hospital-based home care program is designed to enable chronically ill veterans to leave a hospital setting earlier than would otherwise be possible by making needed health care available in the home. A primary objective of the program is to preserve the unity of the veteran's family.

Under the guidance of a VA multidisciplinary health care team—comprised of doctors, nurses, social workers, dieticians, and physical therapists—the veteran's family is trained to meet the veteran's personal care needs. Members of the team also attend to the veteran's more involved health care needs.

In 1986, VA health professionals made 229,675 home visits to treat 12,138 veterans at a cost of $1,400 per veteran. In that year, program costs totalled $16.9 million.

(C) ADULT DAY HEALTH CARE

Primarily medically directed, the VA's adult day health care program also furnishes veterans social, recreational, and health education services in a congregate setting during the work day. Participants are generally elderly veterans in need of extended care services, but may also include those who are severely disabled.

Although the Congress authorized the establishment of VA adult day health care in 1983, it has grown slowly. In 1986, a total of 169 patients were treated in 9 VA medical centers. On the average, the VA expended $9,540 per veteran in that year, with a total program cost of $1.6 million.

4. VA GERIATRIC TRAINING PROGRAMS

In recognition of the aging veteran population, the VA has established a number of programs which offer geriatric training, including the Geriatric Research, Education and Clinical Centers, physician and dentist geriatric fellowships, and continuing education activities.

(A) GERIATRIC RESEARCH, EDUCATION AND CLINICAL CENTERS (GRECC'S)

Established in 1975, the GRECC program brings together research, education, and clinical specialists to advance and integrate geriatric and gerontological knowledge into the VA health care system. In 1987, centers in 10 VA medical facilities were in operation across the Nation. (An additional 15 centers have been authorized, but not yet established, due to budgetary limitations.) A total of approximately $35 million was required to operate the GRECC program in 1987.

Although all GRECC's conduct generalized aging research, each center also specializes on specific problem areas. Such research includes geriatric endocrinology, molecular biology of aging, cognitive and motor dysfunction, and immunology, as well as a collaborative project on Alzheimer's disease.

To help meet the need for geriatric specialists, the GRECC program trains practitioners, educators, and researchers. Students at the undergraduate, graduate, and post graduate levels, and other VA health care personnel acquire skills and knowledge in geriatrics at the centers.

The clinical component of the GRECC program supplements the ongoing clinical activities of the host VA medical center. Essentially, these efforts are aimed at evaluating and launching alternative models of geriatric care.

(B) PHYSICIAN AND DENTIST GERIATRIC FELLOWSHIPS

In 1978, the VA established 2-year fellowships for physicians in geriatrics to produce specialists and to develop future academic leaders in this field. With the same objectives in mind, in 1982, the VA initiated a 2-year geriatric fellowship program for dentists. By the end of 1986, 128 physicians and 15 dentists had gained geriatric expertise through these fellowships.

As a measure of the significance of the VA's physician fellowship in geriatrics, the number of graduates currently account for slightly more than half of the Nation's physicians who have completed fellowships in this specialty. The VA's geriatric fellowship for dentists represents the Nation's largest training program in this field.

In coming years, the impact of the VA's geriatric fellowship program will be increasingly evident. By the turn of the century, 578 physicians and 90 dentists are expected to have completed a VA geriatric fellowship, and by 2020, 1,378 and 140, respectively, are projected.

(C) CONTINUING EDUCATION

The VA also offers a wide range of continuing education programs related to geriatrics and gerontology. In 1986, approximately 10,000 of the VA's health care personnel and 3,000 non-VA health care workers received training in these fields through these programs. By the year 2000, the VA's continuing education activities are projected to provide specialized training in these fields to 17,500 VA and 5,000 non-VA participants annually through 2020.

5. Projected Future Demand

Like many other facets of VA health care, the increase in the demand for long-term care services is expected to accelerate in the future as a result of the growth in the aging veteran population. In 1984, both the VA [21] and the Congressional Budget Office (CBO) [22] issued reports on the extent to which VA programs must expand in coming years to accommodate this growth.

Although both reports project significant increases in the levels of VA long-term care services needed to meet future demand, the VA's projections are generally higher. While CBO projected current use rates forward to new population levels, the VA assumed a greater percentage of veterans may seek VA health care than do at present. In other words, many eligible veterans may not currently demand VA health care services due to a lack of awareness concerning eligibility, geographic isolation, or lack of availability of the desired VA health care services. These are all variables which are subject to change. Another difference between the reports is that CBO's projections stop at the year 2000, while the VA's extend to 2020. In addition, the CBO report does not project future demands for VA noninstitutional long-term care.

(a) VA institutional long-term care

In 1986, there were approximately 40,000 long-term care beds for veterans in VA medical centers, VA domiciliaries, State veterans' homes, or community nursing homes on a contract basis with the VA. According to the VA, the demand for VA institutional long-term care will continue to rise beyond the turn of the century and crest in 2010. To meet this projected demand, the 1984 VA report concluded that the number of long-term care beds must increase to between 66,000 to 93,000 by 1990, and to between 102,000 and 131,000 by the year 2000. The CBO projections for these years are lower—between 48,000 and 55,000 and between 66,000 and 72,000, respectively. By 2010, the peak year in the VA analysis, an estimated 110,000 to 140,000 long-term beds will be needed, according to the VA.

(b) VA noninstitutional long-term care

In 1984, when the VA and CBO issued their long-term care reports, the VA's inroads into the area of noninstitutional extended care were only just beginning to be made. As a result, CBO focused only on the future demand for VA institutional long-term care services. However, despite this limitation, the VA recommended that all of the VA's programs in this area be significantly expanded.

According to the VA report, the number of VA hospital-based home care programs should increase to 76 by 1990—27 more than were operating in 1986—and to 98 by the year 2000. The number of adult day health care programs should increase to 40 by 1990 and

[21] U.S. Veterans Administration. Caring for the Older Veteran. Washington, U.S. Government Printing Office, 1984.

[22] Congressional Budget Office. Veterans Administration Health Care: Planning for Future Years. 1984.

to 98 by 2000. In 1986, there were only 9 programs in operation. Finally, the VA should have community residential care programs available through all VA medical centers and outpatient clinics. In 1986, 125 VA facilities operated these programs.

6. Conclusion

Taken together, the VA's long-term care programs make up one of the Nation's largest and most significant long-term care system. Of particular importance are the VA's efforts to expand the availability and variety of such programs in noninstitutional settings.

As part of the effort to meet the growing demand for long-term care in a cost-effective way, a provision was included in S. 9, the proposed "Omnibus Veterans' Benefits and Services Act of 1987," to establish on a demonstration basis new alternatives to VA institutional care. Under this program, the VA would be required to make greater use of community resources—including homemaker, personal-care, communal or at-home nutrition, and transportation assistance services—to help maintain elderly or severely disabled veterans in their homes. The bill, which the Senate passed on December 4, 1987 as H.R. 2616, was in conference with the House in February 1988.

To keep pace with the growth in the number of older veterans, the VA can be expected to devote a larger share of its resources for long-term care services in coming years. The VA's success in meeting the challenge an aging veteran population presents will help determine how effectively the Nation subsequently addresses and copes with this same problem in the general population.

Section 3

NEW DEVELOPMENTS IN LONG-TERM CARE POLICY

A. DEVELOPMENTS IN LEGISLATION

The many issues surrounding the delivery of long-term care services received limited but notable attention in 1987, the first session of the 100th Congress. Three measures passed Congress that affect long-term care policy: The Medicare Catastrophic Loss Prevention Act of 1987 (H.R. 2470); the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203); and the Older Americans Act Amendments of 1987 (Public Law 100-175).

There were also a number of noteworthy bills that were introduced or are expected to be introduced in the 100th Congress that would address the need for protection against the costs of long-term care services. The bills that had been introduced as of this writing include: H.R. 3436 (formerly H.R. 2762) and S. 1616, the Medicare Long-Term Home Care Catastrophic Protection Act, introduced by Congressman Pepper and Senator Simon, and the Adult Day Care Act of 1987 (S. 1839), introduced by Senator Melcher. Further, Congressman Waxman, Chairman of the House Energy and Commerce Subcommittee on Health, and Senator Mitchell, Chairman of the Senate Finance Subcommittee on Health announced their intention to offer two separate bills that would significantly expand the Medicare Program to finance long-term care.

1. Catastrophic Health Care Legislation

The passage by both the Senate and the House of separate catastrophic health care bills followed many months of efforts by Congress, the administration, health care providers and consumers, and aging advocates. As of this writing, H.R. 2470 is in conference, and it is expected that a final compromise bill will be signed into law by the fall of 1988.

Both versions of the catastrophic health legislation provide minimal coverage for long-term care. This is despite the fact that for those spending more than $2,000 annually out-of-pocket for medical expenses, the cost of nursing home care absorbs more than 80 cents of every dollar spent over and above $2,000. Ironically, however, the lack of legislative action on this issue has actually succeeded in bringing the problems of financing long-term care to the forefront of health policy.

Provisions in both versions of H.R. 2470 provide no more than a starting point for addressing the issue of financing and delivering long-term care for Medicare beneficiaries. While the legislation provides for expansion of Medicare's skilled nursing facility and home health benefits, these benefits are designed to rehabilitate

beneficiaries after an acute illness—not to provide services to those needing long-term care as a result of a chronic illness. The respite coverage included in the House-passed version is the only provision in either version that provides for the actual delivery of long-term care services. This provision provides for up to 80 hours per year of in-home benefits for chronically dependent persons as a respite for caregivers.

The issue of spousal impoverishment, in which a couple must spend-down nearly all of their resources in order for the institutionalized spouse to become eligible for Medicaid coverage of nursing home care, is an important long-term care issue that was addressed in both versions of the catastrophic health care legislation. The House-passed version of the bill specifies that in determining Medicaid eligibility, half of the couple's income would be attributable to each spouse. It also provides for a one-time determination of resources, with half attributable to each spouse. The institutionalized spouse may transfer an amount equal to one-half, or $12,000, whichever is higher, to the community spouse, up to $48,000. For example, if the couple has assets worth $20,000, the institutionalized person may transfer $12,000 to his or her spouse. If they have assets worth $100,000, the institutionalized person may transfer $48,000 to the spouse. If the community spouse's share of their assets exceeds $48,000, the excess is attributed to the institutionalized spouse.

Further, this provision permits the community spouse to keep income equal to 150 percent of the poverty line plus one-half of the couple's income over that amount, not to exceed $1,500 per month. It also establishes a national policy on the transfer of assets. The Senate provision, which was offered as an amendment to the bill by Senator Mikulski and others, is similar to the House provision except that the community spouse is permitted to keep an amount equal to 122 percent of the poverty line plus one-half of the couple's income not to exceed $1,500 per month.

The other long-term care-related provisions in the catastrophic bills concern studies or research on long-term care. Both the Senate and the House bills would require the Secretary of the Department of Health and Human Services (DHHS) to evaluate and report to Congress on the various adult day care services being provided throughout the United States. Both measures also mandate studies on various options to finance long-term care. Further, both versions would establish a bipartisan congressional commission to make recommendations regarding Federal programs to provide comprehensive health care. Within 6 months of enactment, this commission would report to Congress its findings and recommendations for appropriate legislative initiatives regarding comprehensive long-term care for the elderly and disabled.

2. The Omnibus Budget Reconciliation Act of 1987

The Omnibus Budget Reconciliation Act of 1987 (OBRA 1987) addressed several shortcomings in Federal programs related to long-term care policy. The pertinent provisions concern quality care in Medicare- and Medicaid-certified nursing homes, access to quality services under the Medicare home health benefit, alternatives to

institutional care that are provided through Medicaid 2176 waivers, and the personal needs allowance for Medicaid nursing home residents.

(A) NURSING HOME QUALITY

In 1987, Senator Mitchell and Congressmen Dingell, Waxman, and Stark introduced comprehensive nursing home reform legislation (H.R. 2270, H.R. 2770, and S. 1108). These bills were based on the findings of the 1986 Institute of Medicine report, "Improving the Quality of Care in Nursing Homes," and were included in large part in OBRA 1987. These provisions were written in a manner that leaves little to interpretation, reflecting what many perceive as congressional distrust of the Health Care Financing Administration (HCFA), the Federal agency responsible for administering the legislation. (Earlier in 1987, HCFA had proposed new rules to address nursing home quality concerns, which some aging advocates believe was an attempt to illustrate that legislation was unnecessary.)

Highlights of this watershed legislation include the elimination of the distinction between skilled nursing facilities (SNF's) and intermediate care facilities (ICF's), and the strengthening of residents' rights. Staffing requirements also were changed to require that all nursing facilities participating in Medicare or Medicaid must have at least one registered nurse on duty 8 hours per day, 7 days per week, and at least one licensed nurse on duty, 24 hours per day, 7 days per week. However, nursing facilities participating in Medicaid may apply to States for waivers of these requirements under certain circumstances. All nurse aides in participating facilities must complete an approved training course (75 hours), and States must maintain a registry of individuals who have successfully completed such a course.

Survey and certification procedures which monitor quality of care in nursing homes were revamped, and each facility is subject to an unannounced "standard survey" on a statewide average of at least one per year, but no less often than every 15 months. The legislation also strengthens the enforcement process for nursing homes not in compliance by providing for intermediate sanctions such as the denial of payment for new Medicare or Medicaid admissions, civil penalties for each day of noncompliance, appointment of temporary management for the facility, and emergency authority to close the facility and transfer its residents.

(B) HOME HEALTH QUALITY AND ACCESS

Senator Bradley and others introduced legislation in the first session of the 100th Congress (S. 1762) that addressed the issue of Medicare home health quality and access. OBRA 1987 incorporates portions of the bill. The key provisions addressing access issues include requirements that HCFA provide adequate notice of changes in policies and regulations, and ensure that the practices of fiscal intermediaries and carriers are consistent and clearly understood by home health providers as well as beneficiaries. With regard to denials of claims, HCFA's fiscal intermediaries must give the home care provider and beneficiary a written explanation of any denial

of a claim for home health or SNF services, including the statutory and regulatory basis for the denial. OBRA 1987 also clarifies the homebound definition to ensure that an individual does not actually have to be bedridden to be considered homebound.

The OBRA 1987 provisions concerning home health quality require HCFA to establish a revised certification survey that focuses on the quality of patient care and the effect of that care on the patient. Employees of home care agencies, including home health aides, will be required to meet approved training standards. Further, all State agencies that certify home health agencies must collect certain information on Medicare-certified agencies, and provide for a toll-free hotline to receive complaints and answer questions with regard to home health agencies. They must also provide for a unit to investigate these complaints which will have enforcement authority and access to survey reports and consumer medical records.

(C) MEDICAID 2176 WAIVERS

OBRA 1987 also amended the Medicaid 2176 waiver program to create a new waiver authority specific to the elderly. Under this revised program, a wide range of home and community-based services, including: Homemaker, personal care, adult day care, and respite care for families, will continue to be available to persons 65 and older and for whom a determination has been made that institutionalization would be required without the waivered services. The law also revised prior law requirements pertaining to the cost-effectiveness of the waiver by incorporating new provisions which will aggregate payments for nursing home costs and home and community-based services costs and increase this amount in future years by a specified percentage.

(D) PERSONAL NEEDS ALLOWANCE

Finally, OBRA 1987 provides for a $5 increase in the amount of the monthly personal needs allowance (PNA) received by Medicaid nursing home residents. Effective July 1, 1988, the minimum PNA will be increased from $25 per month to $30 per month. Nearly 800,000 Medicaid nursing home residents depend on their PNA each month to cover a wide range of expenses, such as toiletries, laundry, and clothing, not paid for by Medicaid.

Prior to the passage of OBRA 1987, the PNA had not been increased—or even adjusted for inflation—since Congress first authorized payment in 1972. As a result, the $25 PNA is worth less than $10 in 1972 dollars. While the $5 monthly increase in the PNA will benefit many nursing home residents, there is no provision to provide for a cost-of-living-adjustment (COLA) to this allowance. This contrasts with the automatic COLA provided to recipients of Social Security and SSI benefits.

3. Older Americans Act Amendments of 1987

The Older Americans Act Amendments of 1987 include several new provisions that significantly expand certain service components under Title III to address the special needs of certain popula-

tions including the frail elderly living at home, residents of long-term care facilities.

These provisions include an authorization of funds for nonmedical in-home services for frail older persons. While in-home services have been a priority service since 1975, no separate authorization was made under prior law. The new in-home services provision, Title III-D, includes a separate authorization for homemaker and home health aides; visiting and telephone reassurance; chore maintenance; in-home respite care; adult day care as respite for families; and minor modification of home not to exceed $150 per client. The frail are defined as those having a physical or mental disability, including Alzheimer's disease or a related disorder with neurological or organic brain dysfunction, that restricts their ability to perform daily tasks or threatens their capacity to live independently.

The OAA amendments also contain several provisions to strengthen and improve the long-term care ombudsman program which has been a required program under Title III since 1978. This program works on behalf of nursing home residents and their families, investigating complaints and solving problems. Among the new OAA provisions is a requirement that States provide ombudsmen with immunity for good faith performance of duties. Further, they must provide adequate legal counsel and representation to ombudsmen if it is required. Each State must also ensure that any willful interference with the official duties of ombudsmen is unlawful, and that retaliation or reprisals against facility residents and others who complain to or cooperate with ombudsmen are unlawful.

The new law also requires States to provide for the training of all personnel in the ombudsman program (including volunteers) in Federal, State, and local laws with respect to long-term care facilities in the State, in investigative techniques, and any other areas the State deems appropriate. Further, for the first time, a separate authorization of funds for the ombudsman program is established, with an authorization of $20 million of fiscal year 1988.

4. Legislative Outlook

A number of bills have been introduced in the 100th Congress to provide expanded long-term care services to meet the chronic care needs of the elderly. Congressman Pepper and Senator Simon have introduced one of the most far-reaching long-term care bills that Congress has seen to date. The Medicare Long-Term Home Care Catastrophic Protection Act (H.R. 3436/S. 1616) would establish for the first time a long-term home care benefit under Medicare.

Under this legislation, all disabled workers, children, and elderly who need assistance with at least two of the five activities of daily living (such as eating, dressing, bathing, or getting in and out of bed), as well as technology-dependent children, would qualify for home care benefits. Since the benefit primarily is aimed at meeting long-term care needs as opposed to post-acute care needs, patients no longer would need to be homebound and in need of intermittent care for Medicare to cover home health. The cost of this initiative—estimated to be about $6 billion a year—is financed by upper

income workers and employers by eliminating the $45,000 cap on earnings that are subject to the 1.45 percent Medicare payroll tax. According to the sponsors of the legislation, only 5 percent of workers would be affected by the elimination of the cap.

It is expected that the House will vote on the Pepper bill in the spring of 1988. Because most Members of Congress support the need for some Federal legislative approach to address the long-term care issue, there appears to be a significant desire to illustrate this support, and it therefore seems likely that the House will pass H.R. 3436.

Few dispute the fact that the Pepper bill represents an important step toward providing desperately needed long-term care benefits to chronically ill persons of all ages. However, many Members of both Houses on both sides of the political fence have concerns about the possible unforeseen costs of the expanded benefits. Some cite the expansion of Medicare to cover end-stage renal disease as an example of a major program expansion in which initial cost estimates were too low. Beyond the extreme difficulty of being able to accurately estimate the number of people who would be eligible for and utilize a new long-term care benefit, other concerns that have been raised include the lack of availability of adequately trained home care providers and the lack of oversight over the home care industry.

Most advocates of the chronically ill do not deny that a new long-term care benefit would be expensive or difficult to administer. However, they respond that the obvious need for such coverage easily outweighs these concerns and that past experience of other nations illustrates that, to a great extent, these concerns can be addressed by a careful, phased-in implementation of the long-term care benefit.

With cost and administrative concerns in mind, however, it is expected that Senate action on this issue will be more deliberative. In fact, few expect any major piece of long-term care legislation, including some version of the Pepper bill, to emerge from the Senate until after the 1988 Presidential election.

There are number of other more modest, but significant legislative approaches focusing on the need for long-term care. An example of such a bill is S. 1839, the Medicare Adult Day Health Care Amendments of 1987, introduced by Senators Melcher, Bradley, and Heinz.

Adult day health care is a structured, comprehensive program that provides a variety of health, social, and related support services in a protective group setting on a less than 24-hour-care basis. Using an individually tailored plan of care for each participant, this program can help meet many of the needs of functionally impaired adults.

S. 1839 would provide up to 100 days of adult day health care a year under Medicare, with a $5 daily copayment, for medically or mentally impaired adults who otherwise would require institutional care. Services also would be available to individuals who need assistance in at least two activities of daily living, such as eating, bathing, dressing, or transferring in and out of a bed or chair. This bill would provide that a multi-disciplinary group of professionals

would provide a wide range of health and health-related services under medical supervision.

In addition to H.R. 3436/S. 1616, a number of widely varying legislative approaches have been introduced in the Senate and the House. Although these bills have made important contributions to the long-term care debate, the legislation that is likely to receive the most serious congressional attention in the 100th Congress and beyond are comprehensive long-term care bills that are expected to be introduced by Senator Mitchell, Chairman of the Senate Finance Subcommittee on Health, and Congressman Waxman, Chairman of the House Energy and Commerce Subcommittee on Health.

Although as of this writing the Mitchell and Waxman proposals are still being developed, they are both expected to advocate expanding Medicare to provide coverage for a wide range of long-term care services including nursing home, home health, and respite care. Similar to the Pepper bill, both will base eligibility on limitations in activities of daily living (ADL's) and both will have significant case management components.

The bills are expected to vary in the amount of beneficiary copayments and deductibles, the length and/or presence of an exclusionary period. The use of an exclusionary period in which the beneficiary would be liable for the costs of care for a specified period of time could act as an incentive for private insurers to enter the long-term care market, as the privately covered benefit period would be finite in length.

A number of widely varying financing approaches for a new long-term care benefit are being examined. They include: The removal of the $45,000 cap on earnings subject to the 1.45 percent Medicare payroll tax; increasing the Part B and/or catastrophic premiums; a "sin tax" on the purchase of cigarettes and alcohol; a payroll tax increase; an estate and gift tax in which a 5 percent surtax would be imposed on the transfer of assets by gift or inheritance; mandating Medicare participation (through the Medicare payroll tax) of all State and local employees who are currently not covered, and a transitional income tax surcharge on the elderly.

B. FUTURE DIRECTIONS

The future direction of long-term care policy in the United States remains uncertain. It is an issue that will undoubtedly receive increased attention in the years to come, driven by the aging of our population and growing public and private expenditures on this most catastrophic of all health care expenses. As Congress and other policymakers, health care providers, third-party payers, and the elderly and their families begin to focus on the financing and delivery of long-term care, there are several recommendations and options that will likely form the debate. The following is a discussion of the various private and public sector options being considered. Also included is an overview of on-going long-term care research and training initiatives.

1. Private Sector Involvement

Among those options is the development of incentives to foster private sector involvement in the financing of long-term care, and

further, to promote the need for long-term care insurance among the general population. The Task Force on Long-Term Health Care Policies was formed by congressional request by DHHS to examine this issue. The Task Force made several recommendations in a 1987 report to Congress designed to encourage the growth of a broad-based market for affordable long-term care policies while providing reasonable protection for consumers.

The recommendations included expansion of the market through employer-sponsored long-term care insurance, the creation of tax incentives to encourage participation by both employers and insurance companies, long-term care financing through vested pension funds, and the development of new approaches to eligibility requirements for long-term care insurance benefits. The Task Force also stressed the importance of efforts to educate the public in the need for this type of coverage, and on the often limited scope and availability of public programs that cover some of the costs of long-term care.

To date, private long-term care insurance has played a minimal role in protecting the elderly against the costs of care. In mid-1986, only about 200,000 people held private long-term care insurance. Assuming most policyholders are over 65, this represents less than 1 percent of the Nation's elderly. A number of barriers have been cited as impediments to the development of long-term care policies. Many insurers are concerned about adverse selection, in which only persons more likely to need long-term care will buy insurance for it. Induced demand—beneficiaries using more services because they have insurance and/or shifting from unpaid to paid providers for their care—is another concern. Further, many people who need long-term care will need it for the remainder of their lives, resulting in an open-ended liability for the insurance company.

Despite the problems inherent in this area, industry representatives believe that significant market development may occur in the next several years. Not only is there growing interest on the part of some insurance companies, but many States, faced with mounting Medicaid nursing home expenditures, have expressed interest in having such coverage made more widely available.

However, not even private insurers claim that the private sector will be able to meet the long-term care need in a comprehensive manner. A preliminary report from the Brookings Institution projects that by 2018, moderately comprehensive private nursing home insurance may account for only 7 percent to 12 percent of nursing home expenditures.

Another source of funds within the private sector that could be used to finance the costs of long-term care is home equity conversion loans. Three out of every four elderly persons own their own homes; 80 percent of them, mortgage free. These are often elderly suburban homeowners with low incomes and for many, their home is their only asset. Economists currently estimate that there is $630 billion of equity tied up in the houses of people older than 65 and that by 1990 it will reach $750 billion. Thus, attention has been paid in recent years to financial arrangements which would permit aged homeowners to convert part of their equity into cash without having to leave their dwellings.

There are limitations to this approach, however. The actual cash value of average home equity holdings is often over-estimated. In 1985, the median value of the homes owned by single females (those most at-risk of needing public assistance in meeting their health care costs) was under $42,000. A home equity conversion plan would yield approximately $175 per month. While this amount of money could be useful in paying for the costs of some supportive services in the home, it represents only about 8 percent of the average monthly skilled nursing facility charge. Further, for the purpose of determining Medicaid eligibility, the value of the home is not considered. Therefore, if home equity conversion plans are to be used to delay Medicaid eligibility, an older person would be impoverished to an even greater degree than under present eligibility requirements.

Despite these limitations, home equity conversion plans offer a choice to elderly persons facing costs for housing, health care, and other necessities that have grown proportionately faster than their incomes. Although relatively few elderly have been able to take advantage of these plans to date, recent legislation and growing interest in them will likely encourage greater availability.

Another private sector option for financing long-term care services for a limited but potentially growing number of elderly persons is the life care community. Life care, also called continuing care retirement communities, typically provide housing, personal care, and nursing home care, and a range of social and recreation services as well as congregate meals. Estimates on the number of life care communities range from 300 to 600, depending on the definition used. It is estimated that there are at least 90,000 persons residing in nearly 300 such facilities.

Residents enter into a contractual agreement with the community to pay an entrance fee and monthly fees in exchange for benefits and services. Entrance fees range among life care communities from approximately $40,000 to over $150,000, with monthly fees ranging from $500 to $2,000. The contract usually remains in effect for the remainder of a resident's life. Because the life care contract is intended to provide financial protection against the future costs of long-term care, it may be considered as a form of long-term care insurance.

Problems have been discovered in some communities. Some life care communities have functioned using lifespan and health projections that are not actuarially sound, as well as incorrect revenue and cost projections. Some contracts are written in such a way that if a person decides, even within a reasonable period of time, that he or she does not want to stay at the facility, the entire endowment is lost and not returned even on a pro-rated basis.

However, supporters of life care contend that there are a number of benefits associated with this concept. For example, the pooling of resources and risks may help to reduce the uncertainties of future costs of care, and there are greater opportunities for residents to maintain their health status as health care and other services are provided on a regular basis. Others believe that while life care is an option for some elderly, it is unlikely that many with low and moderate incomes would be able to afford it.

2. Public Sector Involvement

Encouraging private sector involvement, however, will not help all the elderly in need of protection against the cost of long-term care. Indeed, many older persons most in need of this type of insurance are those least able to afford it. As a result, the public sector will continue to play a vital role in the financing of long-term care. Older Americans are living longer, and as increased age means a higher incidence of chronic disorders, there will be growing numbers of elderly requiring some form of long-term care. If the Federal, State, and local governments are to be responsive to the changing long-term care needs of their aging populations, they will be expected to provide funding and services that are more comprehensive and readily available than at present.

Medicare, the Federal program designed to provide for the health care needs of Americans over age 65, provides little coverage of the costs of long-term care. Although the Medicaid Program was originally intended to provide medical care to low-income women and children, it has become the largest third-party payer of nursing home care in the United States. While the growth rate in Medicaid expenditures for nursing home care has been slowly declining over the past few years, it is still the largest and fastest growing component of the program. This discrepancy between what many believe Medicare should pay for and what Medicaid ends up paying for is what many aging advocates consider to be the fundamental problem facing the public sector in financing long-term care.

Unlike Medicare, for which all Americans over the age of 65 are eligible regardless of income, Medicaid eligibility for the elderly is income-based. In order to receive Medicaid coverage for the costs of nursing home care, an elderly nursing home resident often must spend-down his or her resources, impoverishing him or herself, as well as the spouse who remains in the community. Half of all persons who enter nursing homes use up their available savings and income within 6 months, and are then required to apply for Medicaid.

The enormous costs associated with Medicaid coverage of nursing home care, in terms of both the financial outlays and the loss of dignity that results from the impoverishment that must occur in order to receive Medicaid benefits, have forced many health policymakers to re-evaluate the Medicaid and Medicare Programs. For many, the answer lies in either expanding the Medicare and/or Medicaid Programs or developing a new Federal program to cover the costs of long-term care.

Among all the obstacles that would be encountered with this approach, the greatest is financing. Faced with intense pressure to decrease the deficit and balance the Federal budget, Congress must discover ways to finance the costs of long-term care that are self-funding and budget neutral. There are various options that are being discussed, including: Eliminating the $45,000 cap on earnings subject to the 1.45 percent Medicare payroll tax, increasing the Medicare payroll tax, a "sin tax" on cigarettes and/or liquor, and an inheritance or gift tax.

As outlined in Chapter 1, the American public would appear to be supportive of an increased Federal role in the financing of long-term care, despite the fact that it will mean an increase in tax revenues from one source or another. This has been illustrated by recent polls which have found that some 68 percent of respondents of all ages and income levels would be willing to pay increased taxes in order to have a program of long-term care for everyone over the age of 65.[1] Further, a majority of respondents (65 percent) expressed a preference for services provided at home, rather than in a nursing home, even if the costs of home care were higher.

As the Federal Government becomes more involved in the financing and delivery of long-term care, it must ensure that the programs it is supporting are providing high quality care to their recipients. It is crucial that it develop and maintain an active role in monitoring and evaluating quality of care. This presents a strong argument for the Federal Government to proceed carefully with the expansion of any long-term care program to assure that a solid foundation of oversight and quality control is established.

Unfortunately, it appears very doubtful that a consensus on how to proceed on this issue will emerge before the 100th Congress adjourns in the fall of 1988. Recognizing this, advocates of the chronically ill of all age groups have made this a high priority and are now urging Presidential candidates to put the issue of long-term care on their agendas. These groups have been encouraged by the positive responses of candidates of both parties. Regardless of what any candidate says, however, it is clear that the need for long-term care protection will not disappear and whoever is elected will be forced to deal with these complex, expensive, and challenging issues in the years to come.

3. Research and Training Initiatives

In the months ahead, growing importance will be placed on exploring alternatives to the traditional institutional bias of long-term care services. For example, a number of demonstration projects funded by the Office of Research and Demonstration at HCFA are aimed at testing the effectiveness of community-based and in-home delivery systems for long-term care services. These projects include studies on the effects of case management systems, and studies of programs such as social health maintenance organizations, which provide for the integration of social and health care services, and respite care for impaired elderly.

In 1980, DHHS initiated the National Long-Term Care Channeling Demonstration. This project has been the largest and most rigorously designed demonstration program undertaken to test whether a carefully managed approach to the provision of community-based long-term care services to frail elderly could help control overall costs and prevent or delay institutionalization.

The final results, released in May 1986, do not support the argument for case-managed community-based services solely on the basis that they substitute for institutional care or that they can

[1] American Association of Retired Persons and The Villers Foundation. The American Public Views Long-Term Care, survey conducted by R.L. Associates, Princeton, NJ, October 1987.

reduce the total costs of long-term care. The increased costs of case management and expanded community services offered by the demonstration were not offset by reduced nursing home costs. However, the project did identify a range of unmet needs as channeling increased use of community services, particularly home health aide and homemaker/personal care services. This finding supports the view among service providers that assistance with personal care and housekeeping represents the largest service need of the functionally impaired and the one area which is inadequately supported by existing programs.

Other major research issues presently receiving attention are examination of various financing mechanisms to determine possible cost saving measures, quality of care, examining the effects of Medicare's prospective payment system for inpatient hospital care on institutional and home-based care and the development of data systems and analyses.

Two important areas of research on financing mechanisms are prospective payment for nursing homes and case-mix reimbursement. Prospective payment for nursing homes would set up a system of payment for SNF's similar to that now being used for Medicare reimbursement of hospitals. Case-mix studies evaluate the resource consumption of nursing home patients with the goal of developing more appropriate financing mechanisms.

Assessment studies include analyses of various types of long-term care policies and their effects. Specific policies that are being studied include "swing beds," the Medicare hospice benefit, and various State approaches to Medicaid financing such as use of Medicaid waivers to finance community and home-based care and financial incentives for family care.

Research on the effects of the hospital prospective payment system is being focused in two areas: To determine whether costs are being shifted to nursing home and other long-term care services and whether patients are being prematurely discharged from hospitals where alternative settings may not be able to serve them adequately.

In the area of data development, focus is shifting from cross-sectional to longitudinal data. While cross-sectional studies are needed to identify important characteristics of programs and populations, the fact that cross-sectional studies only describe one point in time, has limitations. To address the problem, HCFA has funded the Long-Term Care Surveys which are presently being analyzed to identify the factors that enable the disabled elderly to remain in the community. Another important area of research is development of a computerized inventory of research on aging. Development of this project is being discussed by the National Institute on Aging (NIA) and HCFA.

Another critical aspect of the long-term care challenge relates to the growing need for increased numbers of health care professionals with training in geriatrics and gerontology. To date, the Federal Government has yet to focus significant financial support for education and training in these areas. As a result, there already exists an alarming shortage of health care and social services professionals, as well as paid professionals, with the skills and experi-

ence necessary to most effectively care for our seniors, particularly those who are chronically ill.

To prod and guide policymakers, three reports addressing this vital issue have been published in recent years. Stressing that existing resources in this area are seriously limited, a 1984 NIA report assessed both the needs of the aging population and the ways in which the Federal Government could support needed education and training in geriatrics and gerontology.[2] A 1987 DHHS report emphasized that the number of health care practitioners who are specifically prepared to serve older people will fall far short of the need in the next few decades, unless specialized geriatric training for health professionals is greatly expanded.[3] Also released in 1987, a report of the Institute of Medicine recommended that both private and public funding be marshaled to finance geriatric centers of excellence to develop future leaders in this field.[4]

C. CONCLUSION

There is a clear need for a wide range of long-term care services, as well as for protection against the often-times catastrophic costs of these services. The challenge for the future will, of course, center around how to finance long-term care. During deliberation on this issue many concerns are likely to be raised. At the top of the list are likely to be the opposing themes of reducing the budget deficit while increasing needed services to a burgeoning elderly population.

Much research is now being conducted on how best to meet the long-term care challenge. Projects such as the Brookings Institution's study on long-term care have pointed out the inadequacy of such measures as private long-term care insurance, home equity conversion and life-care communities as sweeping remedies for the challenge. As mentioned previously, a number of creative cost-saving measures are being studied such as prospective payment for nursing home reimbursement and case-mix strategies. In addition, several long-term care bills have been or will be introduced in Congress that would address the need for protection against the cost of long-term care services. It is our hope that the information contained in this report has positively contributed to the debate by providing basic facts to be used as a starting point for developing solutions to the long-term care challenge.

○

[2] National Institute on Aging. Report on Education and Training in Geriatrics and Gerontology. February 1984.

[3] U.S. Department of Health and Human Services. "Personnel for Health Needs of the Elderly Through The Year 2020." September 1987.

[4] Institute of Medicine. Report of the Institute of Medicine: "Academic Geriatrics for the Year 2000" 1987.