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## LONG-TERM CARE REPORT

Findings from Committee hearings of the 107th Congress

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PRESENTED BY THE

SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE

ONE HUNDRED AND SEVENTH CONGRESS

June 2002



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# CONTENTS

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	Page
Foreword .....	1
Jurisdiction .....	2
Committee Background .....	3
Purpose of Hearings .....	4
List of Hearings Held by the Committee .....	5
Executive Summary .....	6
Preface .....	6
Setting the Stage: A Need for Reform .....	7
Long-term Care Defined .....	8
Current Financing Unsustainable .....	8
Home and Community-Based Services .....	9
Medicaid Waivers .....	10
State Initiatives to Expand Home and Community Based Services .....	11
Disability and Aging .....	12
<i>Olmstead</i> .....	12
Caregiving .....	13
Assisted Living .....	14
Adult Day Services .....	15
Long-Term Care Insurance .....	16
Workforce Shortage .....	16
Guiding Principles .....	17
Conclusion .....	18

## APPENDIX

Figure 1 .....	19
Figure 2 .....	20
Figure 3 .....	21
Figure 4 .....	22
Figure 5 .....	23
Figure 6 .....	24
Reports Presented to Committee .....	25



## FOREWORD

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During the 107th Congress the Senate Special Committee on Aging examined the current status of long-term care in the United States and also considered proposals for potential reform. This report summarizes findings from a thirteen part series of hearings on long-term care. These findings were created to assist Members of Congress, their staffs, and the general public in understanding and responding to the growing needs of the elderly and disabled.

JOHN BREAU, *Chairman.*

## COMMITTEE JURISDICTION

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It shall be the duty of 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 or assistance.

*Source: The Congressional Standing Committee System, Congressional Research Service, Library of Congress. Report 92-707 GOV. September 14, 1992.*

A Committee is a panel of members elected or appointed to perform some service or function for its parent body. The legislative subjects and other functions are assigned to a committee by rule, precedent, resolution, or statute. In general, committees conduct investigations, make studies, issue reports and make recommendations. Select or Special Committees are established by a resolution for a special purpose and, usually, for a limited time. Most select and special committees are assigned specific investigations or studies, but are not authorized to report measures to their chambers. Within assigned areas, these functional subunits gather information; compare and evaluate legislative alternatives; identify policy problems and propose solutions; select, determine, and report measures for full chamber consideration; monitor executive branch performance (oversight); and investigate allegations of wrongdoing. While special committees have no legislative authority, they can study issues, conduct oversight of programs, and investigate reports of fraud and waste.

## COMMITTEE BACKGROUND

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The Senate Special Committee on Aging was first established in 1961 as a temporary committee. It was granted permanent status on February 1, 1977.

Throughout its existence, the Special Committee on Aging has served as a focal point in the Senate for discussion and debate on matters relating to older Americans. Often, the Committee will submit its findings and recommendations for legislation to the Senate. In addition, the Committee publishes materials of assistance to those interested in public policies which relate to the elderly.

The Committee has a long and influential history. It has called the Congress' and the nation's attention to many problems affecting older Americans. The Committee was exploring health insurance coverage of older Americans prior to the enactment of Medicare. After Medicare was enacted, the Committee reviewed its performance on an almost annual basis. The Committee has regularly reviewed pension coverage and employment opportunities for older Americans. It has conducted oversight of the administration of major programs like Social Security and Medicare. Finally, it has crusaded against frauds targeting the elderly and Federal programs on which the elderly depend.

Chairmen of the Special Committee on Aging have established an impressive tradition. Senator Frank Moss brought to light unacceptable conditions in nursing homes. Senator John Heinz reviewed Medicare's Prospective Payment System to see whether it was true the system was forcing Medicare beneficiaries to be discharged "quicker and sicker." When the statute of limitations for age discrimination in employment claims had lapsed, Senator Melcher restored the rights to 1200 individuals. Senator Pryor investigated the pricing practices for prescription drugs and changed pricing behavior of pharmaceutical companies. Senator Cohen led the way to enactment of strong health care anti-fraud legislation. Senator Grassley worked tirelessly in a number of areas protecting senior citizens. In particular, he focused his efforts in the area of enhancing the quality of care in the nation's nursing homes and other long-term care facilities. Over the years, the Committee has been in the thick of the debate on issues of central concern to older Americans.

## SENATE COMMITTEE HEARINGS

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Committee hearings afford Senators an opportunity to gather information on, and draw attention to, legislation and issues within a committee's purview, conduct oversight of programs or agencies, and investigate allegations of wrongdoing.

Hearings are committee or subcommittee meetings to receive testimony for legislative, investigative, or oversight purposes. Witnesses often include government officials, spokespersons for interested groups, experts, officials of the General Accounting Office, and members of Congress. Committees may issue subpoenas to summon reluctant witnesses. Both houses require that the vast majority of hearings be open to the media and public and, if possible, publicly announced at least a week before they begin.

Witnesses before Senate committees (except Appropriations) generally must provide a committee with a copy of their written testimony at least one day prior to their oral testimony [Rule XXVI, paragraph 4(b)]. It is common practice to request witnesses to limit their oral remarks to a brief summary of the written testimony. A question-and-answer period usually follows a witness's oral testimony. Following hearings, committees usually publish the transcripts of witness testimony and questions and answers.

A Senate rule merely urges its committees "to make every reasonable effort" to make transcripts of hearings available before floor consideration. More and more often, committees are making statements of witnesses and, less often, full transcripts of hearings, available on their websites.

Congressional committee hearings may be broadly classified into four types: legislative, oversight, investigative, and confirmation. Hearings may be held on Capitol Hill or elsewhere, perhaps a committee member's district or state or a site related to the subject of the hearing. All hearings have a similar formal purpose, to gather information for use by the committee in its activities.



## AGING COMMITTEE LIST OF HEARINGS

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June 20, 2002—*Long-Term Care Financing: Blueprints for Reform*

April 16, 2002—*Assisted Living Reexamined: Developing Policy and Practices to Ensure Quality Care*

April 10, 2002—*Offering Retirement Security to the Federal Family: A New Long-Term Care*

March 21, 2002—*Broken and Unsustainable: The Cost Crisis of Long-Term Care for Baby Boomers*

March 14, 2002—*The Economic Downturn & Its Impact on Seniors: Stretching Limited Dollars in Medicaid, Health and Senior Services*

February 27, 2002—*Patients in Peril: Critical Shortages in Geriatric Care*

February 6, 2002—*Women and Aging: Bearing the Burden of Long-Term Care*

September 24, 2001—*Long-Term Care After Olmstead: Aging and Disability Groups Seek Common Ground*

July 18, 2001—*Long-Term Care: States Grapple with Increasing Demands and Costs*

June 28, 2001—*Long-Term Care: Who Will Care for the Aging Baby Boomers?*

May 17, 2001—*Family Caregiving and the Older Americans Act: Caring for the Caregiver*

April 26, 2001—*Assisted Living in the 21st Century: Examining its Role in the Continuum of Care*

March 29, 2001—*Healthy Aging in Rural America*

### *Executive Summary*

The first wave of our nation's 77 million baby boomers will soon reach the age of 65. This group is generally described as well educated, more financially secure than their parents and willing to demand a wide array of services to meet their needs. Thanks to advances in health care and medical technology, life expectancies have increased and many Americans can expect to live well into their seventies and beyond. However, with these longer lives often comes increased prevalence of age-related disabilities.

During the 107th Congress, the Senate Special Committee on Aging devoted a series of hearings to long-term care reform. Expert testimony illustrated that the current financing mechanisms for long-term care will not be sustainable in decades to come. In fact, without significant reform, experts predict that the United States could be on the brink of a domestic financial crisis.

The current long-term care system is funded primarily by state and federal programs. More specifically, Medicaid is the primary payor of long-term care in this country. Medicaid paid for 45 percent of the \$137 billion this country spent on long-term care in FY 2000. Yet, despite the amount of money that state and federal programs are allocating to long-term care, individuals and their families still pay out-of-pocket for nearly one-third of long-term care expenses.

Though the elderly and disabled populations have indicated a preference for receiving long-term care in home and community-based settings, a federal institutional bias exists. However, new options for long-term care are emerging. Aging and disability advocates are working with the health care industry to create a "continuum of care" including such services as assisted living, adult day services and home care. Governors have creatively used the Medicaid waiver process to increase home and community-based services for the elderly and disabled.

Although financing is the cornerstone of the long-term care issue, other issues are critical in building an adequate, seamless, and effective long-term care system to meet the increasing needs of aging baby boomers. These issues include: supporting family caregivers, addressing workforce shortages, improving the quality of long-term care services and improving access to transportation and housing.

The Senate Special Committee on Aging's hearings are an effort to turn the nation's attention to a very important issue facing all of us—long-term care reform. Whether our personal experience with long-term care comes in the form of providing care for family members or friends or whether we are in need of care at some time in our lives, this issue will touch all of us. It is the Committee's hope that Congress and the nation will focus immediate attention on long-term care before the crisis occurs—and not before it is too late.

### *Preface*

Recognizing that the impending age wave of baby boomers will soon significantly increase the demand for long-term care in the coming decades, the Senate Special Committee on Aging has dedicated a series of hearings to long-term care financing and reform. Between March 2001 and June 2002, the Aging Committee held

thirteen hearings on long-term care. This paper is intended to provide a summary of the Committee's findings as a result of this series of hearings.

*Setting the Stage: A Need for Reform*

Just nine years from now, the first wave of this nation's estimated 77 million baby boomers will reach the age of 65. The boomers who will soon comprise this nation's senior population are generally described as informed and far more likely to demand services and options to meet their needs. Yet, as more of our senior population will come to expect more choices in every aspect of their lives, their options may become increasingly limited in the very near future. The confluence of the anticipated shift in demographics and limitations on state and federal resources has increased debate about the need for comprehensive long-term care reform. Experts warn that this nation's long-term care system is on the brink of a crisis situation.

Over the course of the 20th century, life expectancies have increased by more than 30 years. Thanks to advances in health care and medical technology most Americans now live well into old age. But with increasing longevity often comes increasing age-related disability. As the baby boomers begin to move into their 60s and beyond, issues surrounding financing and delivery of services to meet increased needs will become more and more significant. By 2040, the number of individuals aged 65 and older will more than double current levels. In 2000, there were four million Americans over 85, a number projected to more than triple to 14 million by 2040, and the population of Americans aged 85 and older is the group most in need of assistance with activities of daily living. (See **Fig. 1**)

As this new wave of seniors begins to experience age-related disability, our current long-term care system—funded with state and federal dollars—will not be able to support this demographic shift. According to the General Accounting Office (GAO), entitlement programs such as Medicare, Medicaid and Social Security will nearly double as a share of the nation's economy by 2035 (See **Fig. 2**). Without fundamental changes, spending on these programs could crowd out the availability of federal and state resources for other programs. Unless entitlement reforms are made, other federal priorities such as defense and education will be pitted against long-term care services.

Whereas at one time long-term care was generally only available in nursing homes and in private residences with the help of informal family caregivers, we now have an entire "continuum of care" of options, including assisted living, adult day services and home health care. Setting and services depend on many factors, including the recipient's needs and preferences; availability of formal and informal support services; and whether the individual qualifies for public assistance, has long-term care insurance and other income-related issues. Additionally, service availability can differ not only among the states, but also among local communities, as Committee hearing testimony has illustrated. The result is a "patchwork" long-term care system that is in dire need of cohesive and comprehensive reform.

### *Long-term Care Defined*

The Congressional Research Service defines long-term care as: “a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness or frailty.” One’s need for long-term care is measured by how much assistance is needed with *activities of daily living*, often referred to as “ADLs.” Examples of ADLs include: eating, dressing, bathing, toileting and transferring from a bed to a chair.

In considering any of the models of long-term care reform it is crucial to keep in mind that long-term care is a multi-dimensional issue—involving not only health care, but also the difficult issues surrounding housing, nutrition, workforce, transportation and social supports available to maintain independence.

Long-term care is not only an issue for older Americans but also for younger disabled individuals as well, and any long-term care reform proposal must account for both populations.

### *Current Financing Unsustainable*

When Medicare and Medicaid were established in 1965, they were created to cover medical and health care costs for the elderly and the poor, respectively. At that point in time, there were not nearly as many people living for as many years with age-related disability—death as a result of an acute illness was far more common than the longer term chronic illnesses we see today in later life. Today, nearly four decades later, Medicaid has become the single largest public payor of long-term care services in this country.

In 2000, national spending for long-term care was \$137 billion. Of that amount, Medicaid covered 45 percent and Medicare paid for 14 percent, with the remainder paid for out-of-pocket or via insurance coverage. These dollars are spent not only on institutional care—such as nursing home care—but also on home and community-based services. Under the Home and Community-Based Services (HCBS) waiver authority—discussed later in greater detail—states are authorized to provide services not generally covered by the Medicaid program.

Although the waiver program enables people to receive long-term care services in their homes, data shows that there is a federal institutional bias when it comes to long-term care. In FY 2000, 58.5 percent of Medicaid spending went toward nursing home care, (**See Fig. 3**), yet nursing home residents account for only one quarter of all Medicaid recipients. Some argue that it would be more cost-efficient to shift more federal funding to home and community-based services and away from institutional care. The recent U.S. Supreme Court *Olmstead v. L.C.*<sup>1</sup> decision underscores the national momentum and support for allowing aging and disabled populations to live in the least restrictive settings as long as possible.

Government projections developed by the Lewin Group for the U.S. Department of Health and Human Services find that annual expenditures for long-term care will reach \$207 billion in 2020 and \$346 billion in 2040, and could nearly quadruple in constant dollars to \$379 billion by 2050. (**See Fig. 4**) GAO long-term budget simulations illustrate the increasing constraints on federal budg-

<sup>1</sup> *Olmstead v. L.C.*, 521 U.S. 581, 119 S. Ct. 2176.

etary flexibility that will be driven by entitlement spending growth. Absent reform spending, Social Security, Medicare and Medicaid would consume nearly three-quarters of federal revenue by 2030. This will leave little room for other federal priorities such as defense and education. By 2050, total federal revenue would be insufficient to fund spending for Medicare, Medicaid, Social Security and interest payments. **(See Fig. 5)**

Medicare generally covers acute care and short-term health needs of the elderly (primarily in the form of skilled nursing and home health) and—from a long-term care perspective—is not relied upon nearly to the same extent that the Medicaid program is. In fact, although Medicaid was not originally conceived of as a program for the elderly and disabled, it has in fact become the single largest payor funding long-term care services. **(See Fig. 6)** Medicaid costs account for 20 percent of state budgets, the second largest expenditure after education. In 2001, States experienced a 10.6 percent increase in Medicaid budgets, primarily due to health care inflation rates of 13–15 percent and prescription drug inflation rates of 18 percent. Without fundamental reform, Medicaid can be expected to remain a considerable funding source of long-term care for the elderly, exacerbating the current budgetary strain. Though many Americans believe Medicaid only provides assistance to individuals with very low incomes, the reality is far different. Many individuals who are considered “middle class” are forced to “spend down”—or—deplete their income and assets to qualify for Medicaid services and receive assistance with the high costs of long-term care.

Despite the amount of money that federal and state programs are spending on long-term care, individuals and their families still pay out-of-pocket for nearly one-third of long-term care expenses. Average annual long-term care direct costs vary widely. The average cost of nursing home care reaches almost \$50,000 a year. In addition to direct costs, families and other informal providers are the primary caregivers. Often, the burdens of caregiving require that a relative or friend reduce time spent at his or her workplace, which can lead to a reduced income. Reducing time or completely leaving the workplace can also affect benefits, such as health insurance coverage. Faced with such costs, it is unsurprising that older persons and their families often deplete their own resources and are forced to turn to public assistance.

For those who have purchased long-term care insurance, discussed in greater detail later in this paper, the need for public assistance may be reduced to some extent, and may provide a good model for how public-private partnerships can help to reduce overall long-term care costs on society.

#### *Home and Community-Based Services*

While many people equate the term “long-term care” with someone who lives in a nursing home or other institutional facility, almost 80 percent of the elderly and 41 percent of severely disabled individuals live at home or in community-based settings. Many disabled persons and older persons with functional limitations or cognitive impairments choose to remain in their homes or live in supportive housing if they can receive assistance with activities of

daily living such as eating, bathing and dressing. Studies show that generally people prefer to receive long-term care services in their homes or in other community-based settings.

The heavy bias in Medicaid funding toward institutional care does not reflect this growing preference for home and community-based services. Ironically, while the disabled population and growing elderly population prefer to receive services at home or in the community, the federal government imposes a strong bias toward institutional care through existing Medicaid and Medicare laws. Of total Medicaid spending for long-term care in 2000, 72.5 percent was for institutional care and 27.5 percent for home and community-based services. Governors have expressed frustration over the fact that while it is an entitlement for seniors and the disabled to receive services in an institution, states must apply for waivers to keep people in their own homes or in their communities. Yet, experts disagree over whether or not home and community-based care is less expensive than institutional care. While the average cost of caring for a person in the home and community is much lower than in an institutional setting, the costs of transportation, housing, meals and the burden to family caregivers such as out of pocket costs and lost wages are often not taken into account in this analysis.

Governors and other witnesses also argued that money could be saved if Medicare and Medicaid dollars could be blended to avoid duplication or delay of services, which are common in the “dual eligible” (those eligible for both Medicaid and Medicare) populations. Other savings could result in using Medicaid and Medicare funding to pay for preventive care, with a goal of delaying institutionalization. To pay for expanded home and community-based services, states have taken deliberate and aggressive action to develop an array of funding sources including state and local general revenues. States also use Medicaid state plan services, Medicaid HCBS waivers and 1115 Waivers, the Social Services Block Grant and the Older Americans Act.

#### *Medicaid Waivers*

In the 1970’s, policy makers observed that payments for nursing home care had begun consuming an increased proportion of Medicaid expenditures. At that time, the only comprehensive long-term care benefit offered by Medicaid for the disabled and elderly was institutional care. Federal task forces along with research and demonstration projects attempted to identify cost-effective alternatives to institutional care. In 1981 the Medicaid Home and Community-Based Services (HCBS) waiver program was created by amending Section 1915(c) of the Social Security Act. It was intended to correct the “institutional bias” in Medicaid services.

Within long-term care, HCBS expenditures make up a growing share of the Medicaid budget as many states use waivers. Medicaid HCBS waiver expenditures have grown from \$1.2 billion in 1990 to \$12.7 billion in 2000. All states except Arizona offer 1915(c) waivers for the elderly and disabled. HCBS waivers vary largely between states, and often the demand for services available under HCBS waivers exceeds what is available. HCBS waivers are

capped so if waiver slots are filled, only nursing homes or other institutional settings are offered.

One frequent criticism of the HCBS waiver program is that while supportive housing costs are covered under the general Medicaid program, similar costs cannot be paid for through the waiver. This drastically limits what states can do without losing federal financial support.

#### *State Initiatives to Expand Home and Community Based Services*

The National Governors Association and two governors testified before the Committee and explained how the Medicaid program is often inflexible and does not provide all the necessary services to the elderly and disabled. Often, governors pool various state and local resources to provide preventive services to individuals who do not qualify for Medicaid. They believe that “early intervention” is critical to the elderly in helping them maintain independence for as long as possible either preventing or delaying institutionalization or hospitalization. Below are some issue areas and specific programs that Governors have launched to expand and increase long-term care services:

**Medicare/Medicaid Integration Program** - These projects seek to integrate Medicaid’s long-term care services with Medicare’s acute services through managed care for the dually eligible. MMIP projects are currently underway in 13 states.

**Workforce Issues** - Initiatives have been created to improve recruitment and retention in long-term care services, including grant funded programs.

**Cash and Counseling** - Consumer-directed care and family caregiver support programs are related to home health and nursing home aide shortages. The program provides people with long-term disabilities greater choice in selecting their own personal assistance workers (which may include friends and relatives.) These programs support caregivers providing ongoing long-term care assistance to family members. Counseling is provided regarding bookkeeping and services management.

**State Funded Program Innovations** - These are funded by state and/or local revenues. These programs offer a variety of long-term care services that enable individuals needing assistance to remain in their homes. Many of these programs emphasize early intervention or prevention. Many services are provided to individuals who would otherwise not qualify for means-tested services.

**State Pharmacy Assistance Programs** - Almost half of the states have pharmaceutical assistance programs in operation, and many other states are developing programs. These programs include direct subsidy or discounts, bulk or cooperative purchasing programs, drug buying pools and experimentation with Medicaid waivers.

**Partnerships for Long-Term Care** - Public-private alliances between state government and insurance companies to create long-term care insurance programs. These programs use two models: the “Dollar for Dollar” model and the “Total Assets” model. Federal law prohibits the expansion of these programs.

**Single Point of Entry Programs** - A number of states have instituted single point of entry or “no wrong door” programs designed

to assist seniors in obtaining the services they need regardless of income levels or where they first go to obtain help.

**Increasing Assisted Living/Housing for Low and Moderate Income Seniors** - Novel programs such as the “Coming Home Program” a grant-funded program designed to foster affordable assisted living for low-income seniors primarily in rural areas, are increasing access for people of all income levels.

### *Disability and Aging*

Almost 11 million Americans of all ages have a disability and require some form of assistance. Nearly 5 million are severely disabled (need assistance in at least 3 activities of daily living). More than 80 percent of the severely disabled are over age 65. Only 1.8 million of the 11 million persons with disabilities receive institutional care:

- Including 1.6 million people in nursing facilities;
- 106,000 in institutions for the mentally retarded and developmentally disabled; and
- 57,000 in state and county facilities for the mentally ill.

The probability of disability rises dramatically with age. Fifty-eight percent of people over the age of 80 have a severe disability. Demographic trends suggest that the number of disabled elderly people needing long-term care will increase between one-third and two times the current number by 2040.

A major factor in determining whether or not someone can remain in the community or needs to be transferred to an institutional setting is the availability of family to help care for the individual. Sixty percent of the disabled elderly in the community rely exclusively on their families and other unpaid sources of care. Ninety percent of long-term care for elders is provided by family members.

### *Olmstead*

In 1999, the United States Supreme Court ruled in the *Olmstead v. L.C.*<sup>2</sup> that The Americans with Disabilities Act (ADA) prohibits states from keeping people in institutions when they could be “reasonably accommodated” in less restrictive settings. The ADA requires public entities to provide services in the “most integrated setting appropriate to the needs of qualified individuals with disabilities.” The decision has led to discussion about the implications on long-term care services for the disabled and the growing numbers of baby boomers who will need services in the future. Over 200 lawsuits have been filed in the United States seeking to apply or clarify the ruling in *Olmstead*.

One of the most profound outcomes of the *Olmstead* decision is an emerging alliance between the aging and disability communities. One quarter of the nation’s elderly are likely to experience multiple disabling conditions, rendering them dependent on others for long periods of time. This will only increase once the age wave of 77 million baby boomers reaches retirement age. There is a natural overlap between these communities because both groups require similar services. Furthermore, many experts in the field are

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<sup>2</sup>Id.



now looking at long-term care services from a “lifespan” approach rather than from an aging or disabled perspective. In January 2001, the Department of Health and Human Services announced the Real Choice Systems Change grant program to facilitate state compliance with the *Olmstead* decision. These grants have prompted most states to create new coalitions or working groups of aging and disability advocates.

Implications of the Supreme Court’s *Olmstead* decision are still unfolding. Discussions regarding how to provide current and future services inevitably lead to reviews of the Medicaid program. Within federal guidelines, states have flexibility to decide who will receive long-term care services, what services are available and for what length of time. Both populations know that gaining access to a broader array of services will require a careful review of limited Medicaid dollars—upon which both populations rely. Most state aging and disability coalitions have coordinated with governors’ offices in preparing plans which provide goals and action plans for expanding home and community-based services.

Aging and disability coalitions established in the wake of *Olmstead* view chronic disabling conditions as a social problem, a functional problem and a family problem. They tend to be advocates for “consumer-directed care,” an approach to long-term care that seeks to maintain the independence of disabled and elderly persons by giving them more decision making authority in their care. Advocates believe that when consumers direct their own care they experience a better quality of life. The “Cash and Counseling” demonstration projects, sponsored by the Robert Wood Johnson Foundation are consumer-directed care projects which support this theory.

### *Caregiving*

Family caregivers are the cornerstone of our long-term care system in the U.S., providing 80 percent of all long-term care in this country. They are the “quiet heroes” who provide day-to-day care, for weeks, months—and even years for family members and friends who have chronic illnesses. Today, one in three adult Americans—over 50 million—people care for a family member or friend. Forty percent of all informal caregivers for the elderly are baby boomers.

Most older persons remain in their own homes or in the community with the support of family caregivers. Only 5 percent of older Americans who need long-term care rely exclusively on paid care, mostly in institutional settings. Sixty-five percent of seniors rely exclusively on friends and family, while 30 percent use a combination of paid caregivers and friends and/or family.

Women comprise a disproportionate share of caregiving, providing 75 percent of all caregiving for family members. The average American woman can expect to spend 17 years caring for a child and 18 years caring for an elderly parent for a total of 35 years as caregiver. Caregiving exacts heavy tolls from women as they often suffer depression, fatigue, poor health and loss of income due to their caregiving duties. One study found that on average, a worker who takes care of an older relative loses \$659,139 in lost wages, pension benefits and Social Security income.

Conversely, family caregivers provide a significant resource to the economy and long-term care system in this country. If the work of these unpaid family caregivers were replaced by paid home care providers, estimates show this could cost \$196 billion. At a time when most states are experiencing budget deficits and the Medicaid system is overburdened, state and federal governments can not assume financial responsibility for all of the people currently receiving their primary care from family members and friends. Research shows that caregivers need a variety of services to support them in their caregiving role. One such service is respite care, which primarily offers hourly or daily temporary care enabling primary caregivers to take a break from the daily routine of caregiving and temporarily relieve the stress they may experience while providing care. If properly supported, caregivers can remain in the caregiving role for longer periods of time, often delaying or preventing the need for more costly institutional care. Therefore, any support offered to informal caregivers is essential to their ability to continue functioning as caregivers for long periods of time.

Many witnesses before the Special Committee on Aging have expressed their sentiments that it is in the best interest of the government to support family caregivers. In 2000, Congress took its first step toward recognizing the significant contribution of family caregivers when it passed the National Family Caregiver Support Program, included in the reauthorization of the Older Americans Act Amendments of 2000. Grants given to states provide funding for respite care, counseling, information and training. Other House and Senate legislative initiatives include tax credits for caregivers who provide significant care to family members and tax deductions for individuals who purchase long-term care insurance.

#### *Assisted Living*

Assisted living is a relatively new residential care option for individuals who need assistance with long-term care. Whereas at one time, nursing facilities were the only residential care option for individuals needing assistance with activities of daily living, assisted living is just one of the plethora of care options now available for this nation's seniors and disabled. There are currently about 33,000 assisted living facilities in the U.S. More than 90 percent of assisted living is privately funded. Though the majority of states do have Medicaid waivers available to pay for the health care portion of the costs of assisted living, fewer than 60,000 Medicaid recipients currently reside in assisted living facilities. Unlike nursing facilities, which are closely regulated at the state and federal level, assisted living is regulated within the states.

State assisted living regulations vary greatly. What is defined as a "board and care" home in one state may be called "assisted living" in another. For the states that do use "assisted living" as a category there is not a uniform definition for what that category is. Self-accreditation by individual assisted living facilities has been viewed by some as a possible quality improvement mechanism, however, to date so few facilities have undertaken the accrediting process that it cannot be viewed as a reliable self-policing tool.

The Aging Committee has held several hearings and forums exploring quality of care issues in assisted living. Following the most

recent hearing, Committee members called upon the assisted living industry, consumer advocates, providers and other interested parties to work together to make recommendations to the Committee about how best to ensure quality in assisted living facilities. As a result, over 30 organizations are currently collaborating and will present consensus recommendations to the Committee in April 2003.

#### *Adult Day Services*

Adult day centers are a viable, cost-effective, and community-based service option that helps keep individuals at home, in the community, with family and friends for as long as possible. Recently they have become a practical and appealing part of the solution to long-term care needs.

A national study, by Partners in Caregiving: The Adult Day Services Program (a national program of The Robert Wood Johnson Foundation at the Wake Forest University School of Medicine), confirmed there are 3,493 adult day centers in the United States. These adult day centers serve individuals ranging in age from 18 to 109 with a variety of chronic conditions such as dementia, mental retardation/developmental disabilities, mental illness, HIV/AIDS, brain injury, and those who are physically disabled but cognitively intact.

Twenty-one percent of adult day centers are based on the medical model of care, 37 percent are based on social model of care (with no medical component), and 42 percent are a combination of the two which provide a vast array of services such as: therapeutic activities, social services, personal care services, meals, transportation, medication management, caregiver support groups, rehabilitation therapy, medical services, and emergency respite.

Most people attending an adult day center live in the community with an adult child or a spouse. The average length of regular center participation is two years. The number one reason for discharge from the center is placement in a residential setting, such as an assisted living facility or nursing home.

The majority of adult day centers are not-for-profit, operate under the umbrella of a large parent organization, and are open 5, 6, or 7 days a week for 8 or more hours a day. On average, adult day centers serve 25 people per day at an average cost of \$56/day, with 38 percent of all revenue coming from third-party public reimbursements (e.g., Medicaid Home and Community-Based waiver dollars) and 35 percent of revenue is from private pay. Many centers rely on grants and donations in order to continue to provide services.

Growth in this industry is evident. Twenty-six percent of all currently operating adult day centers opened only within the last five years. However, the need for this service is greater than the industry growth rate; only 1,141 out of 3141 counties currently served. Currently only 39 percent of current need is being met, however 5,444 new adult day centers are needed nationwide (1,071 in rural areas and 4,373 in urban areas).

### *Long-Term Care Insurance*

As mentioned earlier in this report, 77 million baby boomers threaten to overwhelm our nation's long-term care system. Six out of every ten Americans who reach age 65 will need long-term care services.

The average cost of one year in a nursing home is approximately \$50,000 while one year of home and community-based care averages \$20,000. Since health care insurance does not cover long-term care expenses, people must either pay out of pocket for long-term care or spend down their assets to qualify for Medicaid. With the rapid rate of health care inflation, long-term care costs are estimated to be three or four times current costs by 2030. For example, according to the American Council of Life Insurance, by 2030 a year of nursing home care could cost \$190,600 and a year of at-home care could cost \$68,000. Either way, individuals and the government face enormous expenses.

In the 1980's, long-term care insurance emerged in the insurance industry as a new product that consumers could buy to protect their assets and guarantee choice of long-term care options. Financial planners now often recommend long-term care insurance to their clients as a way to ensure financial security in retirement. While the number of policies sold in America has increased from 815,000 in 1987 to over 7 million in 2000, the product is still relatively new and only covers about 7 percent of all Americans.

Coverage is more comprehensive today than it was just a few years ago. The proportion of dual-coverage policies, those covering both institutional care and home care, grew from 37 percent in 1990 to 77 percent in 2000. Most purchasers want to ensure that a wide array of home and community-based services are available to them. Such options include: assisted living facilities, formal home care services such as nurses, home health aides, therapists, informal home care services such as non-licensed caregivers and family caregivers, adult day care, hospice care and respite care.

People are more likely to purchase long-term care insurance if it is offered by their employer. In an effort to increase the number of individuals who have long-term care insurance coverage, Congress passed the Long-Term Care Security Act (P.L. 106-265) of 2000 to provide coverage for federal employees. The federal government is the nation's largest employer. Twenty million federal employees and select family members are potentially eligible to participate in this pilot program and many hope that this program will be seen as a demonstration model for other employers. The federal government is also launching a national education campaign to inform employees about the need for long-term care. Several witnesses before the committee expressed hope that the public relations efforts for the federal employee program will result in an increased awareness of the general public about the need for long-term care insurance.

### *Workforce Shortage*

It is well-established that the number of older people in this country is continuing to grow with each passing year, while the number of individuals entering the workforce to care for this growing population is dropping. The number of health care professionals

with specific geriatric training is not keeping pace with the changing demographics. All 125 of our nation's medical schools have a pediatrics department yet only three medical schools have a geriatrics department. Many experts have recommended a significant increase in the number of specialized physicians, nurses, and other health care professionals trained in geriatrics. However, we are currently a long way from having an established cadre of trained practitioners: at the current time, Medicare supports almost 100,000 medical residency/fellowship positions but only about 300 are in geriatric medicine.

Similarly, recruitment and retention of paraprofessionals such as certified nurse aides is also a growing challenge. The Bureau of Labor Statistics estimates that in response to the rising demands of the growing number of individuals needing assistance with long-term care, that personal and home care assistance will be the fourth-fastest growing occupation by 2006, with a dramatic 84.7 percent growth rate expected. The number of jobs available for home health aides has been projected to increase by almost 75 percent while that of nursing aides will increase by more than 25 percent. Yet, while these projections indicate that demand for direct care workers will increase, factors such as rates of economic growth; purchaser ability; and availability of individuals willing to become direct care staff may drastically affect the actual number of those employed in these positions.

Furthermore, even if new positions are created they will likely be relatively low-paid, low-benefit positions. As recruitment efforts build, it will become increasingly important for providers to offer sufficient training and education to ensure that all staff are able to perform work in a manner respectful and appropriate for care recipients. The workforce challenge is being addressed at several levels, via legislative vehicles for grants to increase staffing levels and to improve quality of care in residential care facilities and home and community-based services.

### *Guiding Principles*

While many witnesses had differing suggestions for reforms to our long-term care system, there were a number of guiding principles that most witnesses did agree upon. They include the following:

- Long-term care encompasses more than health care. It comprises a variety of services that an aged and/or disabled person requires to maintain quality of life—including housing, transportation, nutrition, and social support to help maintain independent living;

- Especially in light of the *Olmstead* decision, alternatives to institutional care should continue to be expanded for all persons;

- Consumers and their families should be involved in care decisions about long-term care services;

- Home care services should support but not necessarily replace family caregiving;

- Increased access to respite services and training for family caregivers is needed to sustain their efforts and ensure that people receive care in the least restrictive setting possible;

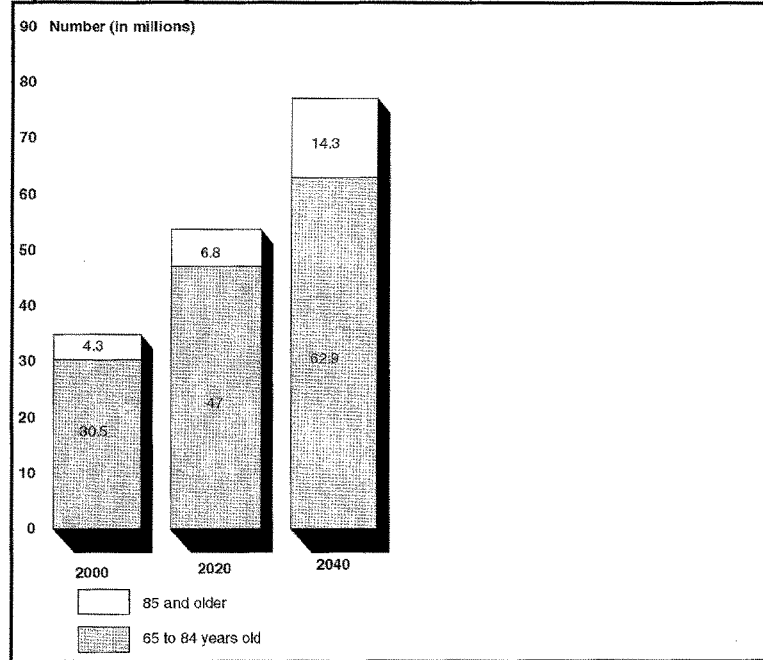
- People of all income levels should have access to long-term care services;

Just as no “one size fits all” type of care exists for individual long-term care needs, financing options must be similarly flexible;

Any long-term care system should encompass a “universal approach” and support both disabled individuals under the age of 65 as well as older Americans who may or may not also have disabilities.

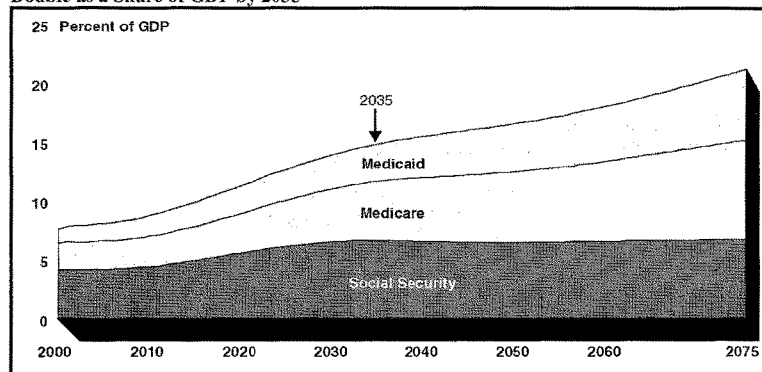
### *Conclusion*

The Committee’s hearings have helped bring to light some extremely important issues surrounding the delivery and financing of long-term care services. Thanks to the expert testimony from our witnesses and multiple reports released as a result of the Committee’s series of hearings, we have a solid base of information and awareness of the looming crisis in long-term care. Clearly, current financing mechanisms will become unsustainable in the near future and without significant reform, our nation’s 77 million baby boomers will not be able to find the wide array of affordable and high-quality long-term care options we all expect and deserve. It is the recommendation of this Committee that Congress focus immediate action on this impending crisis in American domestic policy. Congress should begin debating various proposals to reform our long-term care system before and not after the crisis occurs.

**Figure 1: Elderly Population Will More than Double by 2040**

Source: Bureau of the Census, "Projections of the Total Resident Population by 5-Year Age Groups and Sex With Special Age Categories: Middle Series," selected years 2000 to 2040 (Jan. 2000).

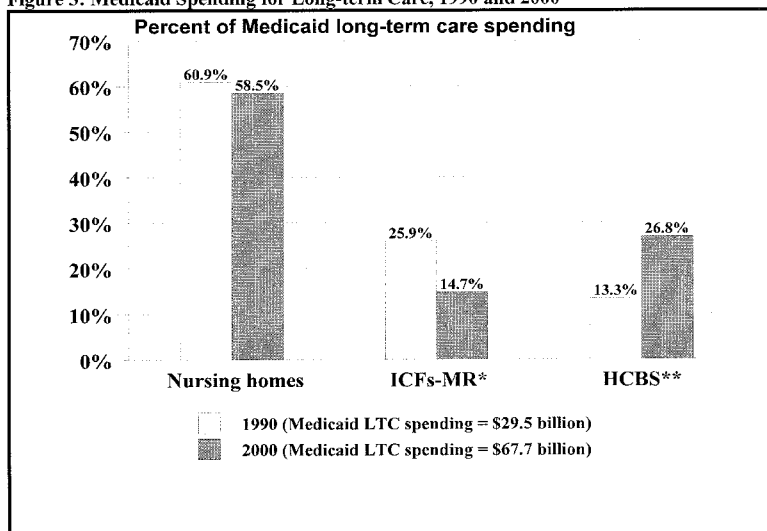
**Figure 2: Projected Federal Spending for Medicaid, Medicare, and Social Security Will Double as a Share of GDP by 2035**



Note: These estimates do not include the state share of Medicaid. Projections based on intermediate assumptions of the 2001 Old-Age, Survivors, and Disability Insurance, Hospital Insurance, and Supplementary Medical Insurance Trustees' Reports and on the Congressional Budget Office's (CBO) January 2002 long-term Medicaid projections. Source: Office of the Actuary, Centers for Medicare and Medicaid Services; the Office of the Chief Actuary, Social Security Administration; and CBO.



Figure 3: Medicaid Spending for Long-term Care, 1990 and 2000



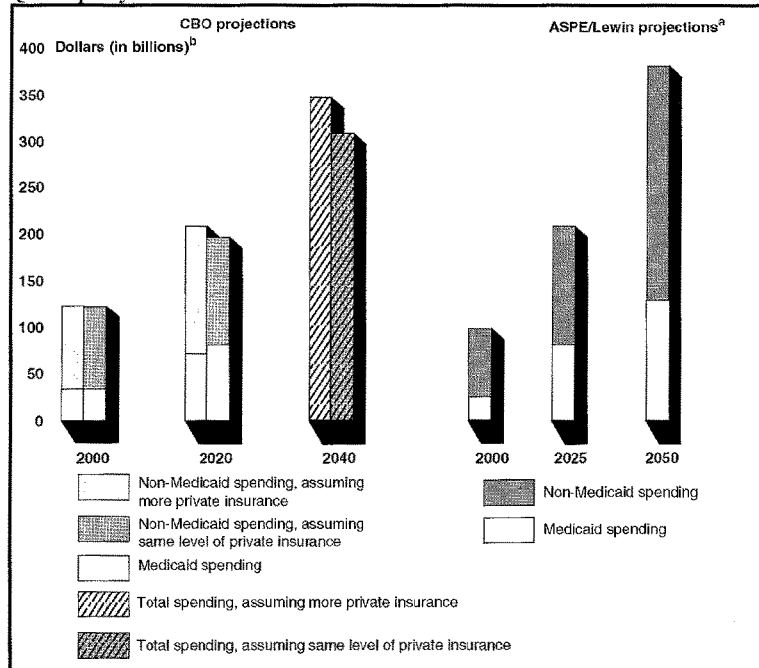
Source: CRS calculations, based on data from the Medstat Group, Inc.

Note: Percentage does not sum to 100% due to rounding

\*Intermediate care facilities for the mentally retarded.

\*\*Home & Community-Based Services.

**Figure 4: Projected Long-Term Care Expenditures for the Elderly Could Nearly Quadruple by 2050**

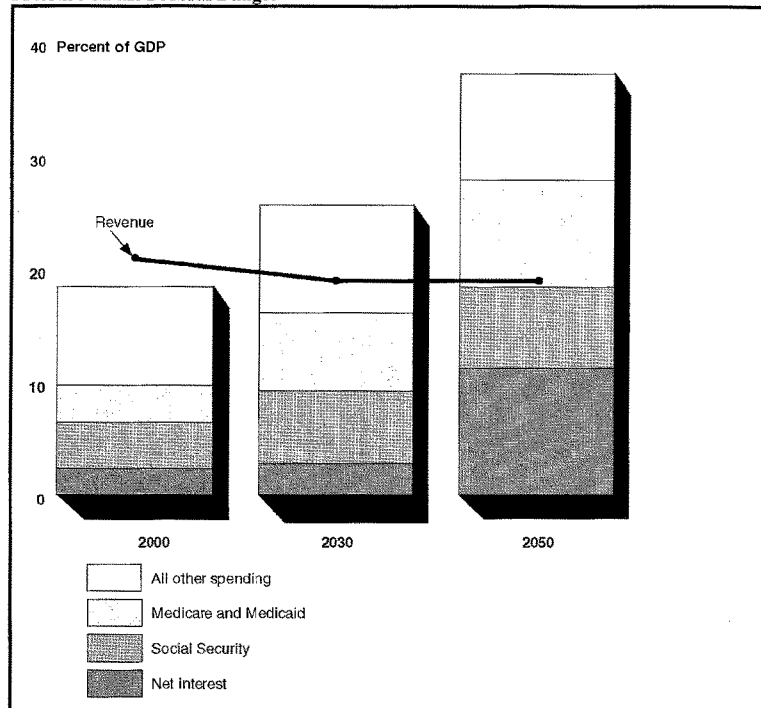


<sup>a</sup>ASPE/Lewin did not report separate estimates for different assumptions about the role of private insurance.

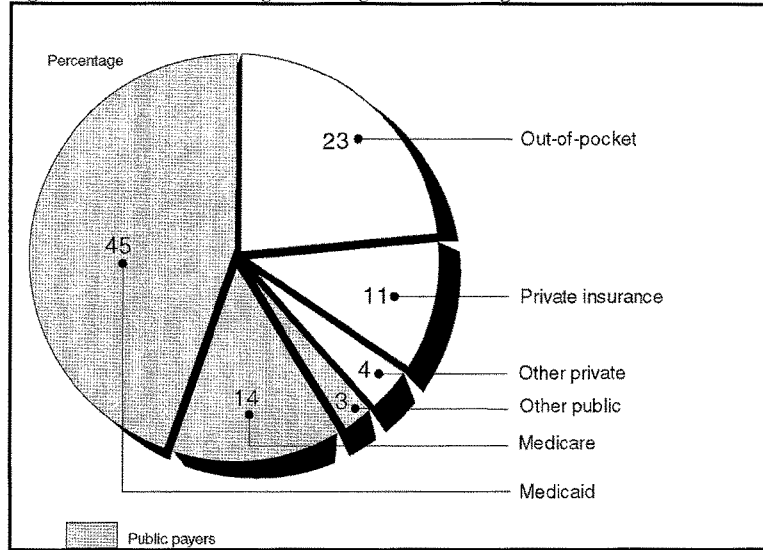
<sup>b</sup>Projections are in constant dollars.

Sources: CBO, "Projections of Expenditures for Long-Term Care Services for the Elderly" (Washington, D.C.: March 1999) and ASPE/Lewin, published in Urban Institute, "Long-Term Care: Consumers, Providers, and Financing, A Chart Book," (Washington, D.C.: March 2001), with additional information provided by ASPE on projected Medicaid spending.

**Figure 5: Medicare, Medicaid, Social Security, and Net Interest Will Put Unsustainable Pressure on the Federal Budget**



Source: GAO's January 2002 analysis. See U.S. General Accounting Office, *Budget Issues: Long-Term Fiscal Challenges*, GAO-02-467T (Washington, D.C.: February 27, 2002).

**Figure 6: Medicaid Is the Largest Funding Source for Long-Term Care**

Note: Amounts do not include unpaid care provided by family member or other informal caregivers or expenditures for nursing home and home health services provided by hospital-based entities.

Source: GAO analysis of 2000 data from the Centers for Medicare and Medicaid Services and The MEDSTAT Group.

REPORTS PRESENTED TO THE COMMITTEE

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Medical Never-Never Land: 10 Reasons Why America Is Not  
Ready for the Coming Age Boom

*By the Alliance for Aging Research*

Caring for Older Americans: Recommendations for Building a  
National Program For Graduate Nursing Education In Gerontology  
(March 2001)

*By American Academy of Nursing, Patricia D. Franklin,  
RN, MSN, CPNP*

Faces of Caregiving: Mother's Day Report (May 2001)

*By the Older Women's League*

