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LONG-TERM CARE FINANCING: BLUEPRINTS FOR REFORM

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

WASHINGTON, DC

JUNE 20, 2002

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LONG-TERM CARE FINANCING: BLUEPRINTS FOR REFORM

THURSDAY, JUNE 20, 2002

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee convened, pursuant to notice, at 9:32 a.m., in room SD–192, Dirksen Senate Office Building, Hon. John Breaux (chairman of the committee) presiding.

Present: Senators Breaux, Wyden, and Ensign.

OPENING STATEMENT OF SENATOR JOHN BREAUX

The CHAIRMAN. The Select Committee on Aging will please come to order. This morning, we have a very distinguished panel of witnesses who we are very anxious to hear. I am joined by our colleague, Senator Wyden, and other Members of the Special Committee on Aging will be with us in just a moment.

I would just point out in opening remarks that our committee has the responsibility to look ahead and see that, as a nation, we are prepared to handle the long-term care needs of the pending age wave of the 77 million baby boomers. Unfortunately, our country, arguably the strongest nation in the history of the world, still lacks a comprehensive long-term care system, and that is why this Committee on Aging has devoted 13 separate hearings in the 107th Congress to the issue of long-term care, examining what is currently available in our country, how we finance long-term care, and what we still need to do to guarantee a wide range of quality, affordable services to all disabled and elderly persons.

To capture the highlights of all the expert witnesses who have testified before our Aging Committee, we have produced a Findings Report, which I have in my hand, which members have seen and I think is available outside. This Findings Report is kind of a road map. It is a road map on how we can hopefully get from here to where we as a nation would like to be as far as providing services to our nation's seniors.

[The Findings Report follows:]

AGING COMMITTEE: HEARING FINDING SUMMARY

A REPORT

PRESENTED BY THE

SENATE SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED AND SEVENTH CONGRESS

June 2002

"This report represents findings adopted by this Committee."

U.S. Government Printing Office
Washington : 2002

FOREWORD

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 Breaux,
Chairman.

COMMITTEE JURISDICTION

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

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

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

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% 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% and Medicare paid for 14%, 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% 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.*[1]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 budgetary 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% of state budgets, the second largest expenditure after education. In 2001, States experienced a 10.6% increase in Medicaid budgets, primarily due to health care inflation rates of 13-15% and prescription drug inflation rates of 18%. 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

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[1]*Olmstead v. L.C.*, 521 U.S. 581, 119 S.Ct. 2176.

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% of the elderly and 41% 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% was for institutional care and 27.5% 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 insitutionalization 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% 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. 58% 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. 60% of the disabled elderly in the community rely exclusively on their families and other unpaid sources of care. 90% 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.*[2] 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 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.

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[2] *Id.*

Caregiving

Family caregivers are the cornerstone of our long-term care system in the U.S., providing 80% 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. 40% 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% of older Americans who need long-term care rely exclusively on paid care, mostly in institutional settings. 65% of seniors rely exclusively on friends and family, while 30% use a combination of paid caregivers and friends and/or family.

Women comprise a disproportionate share of caregiving, providing 75% 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% 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% are based on social model of care (with no medical component), and 42% 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% of all revenue coming from third-party public reimbursements (e.g., Medicaid Home and Community-Based waiver dollars) and 35% 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% 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% 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% in 1990 to 77% 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;

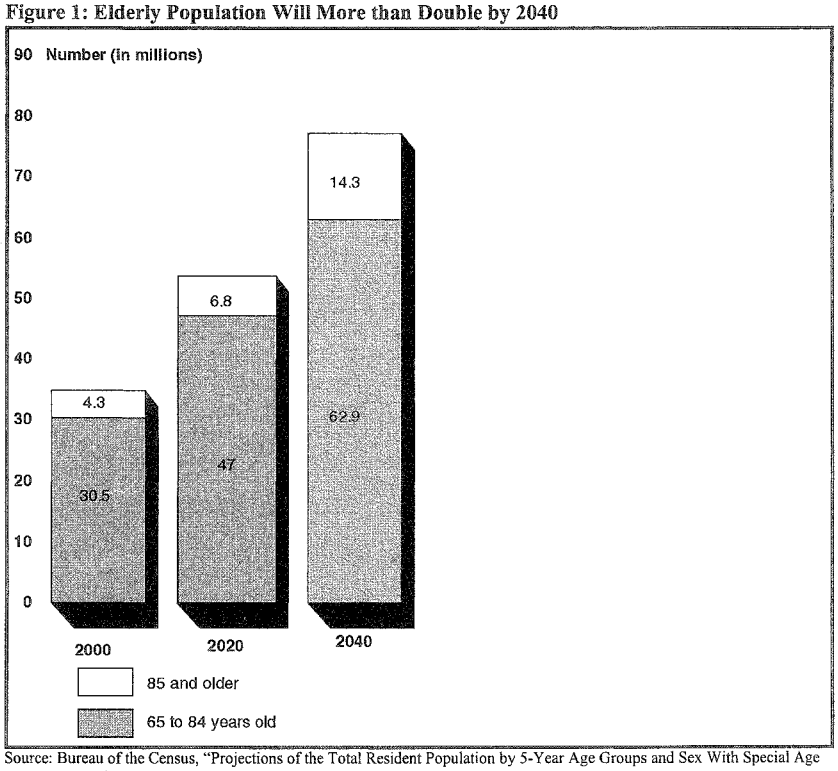
Any long-term care system should encompass a "universal approach" and support both disabled individuals under the age of 65 as well as older Americans who may or may not also have disabilities.

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

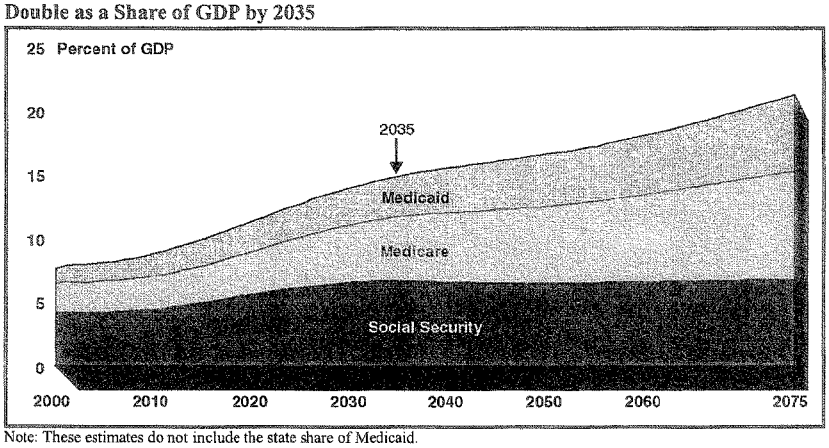
the recommendation of this Committee that Congress focus immediate action on this impending crisis in American domestic policy. Congress should begin debating various proposals to reform our long-term care system before – and not after the crisis occurs.

Figure 1: Elderly Population Will More than Double by 2040



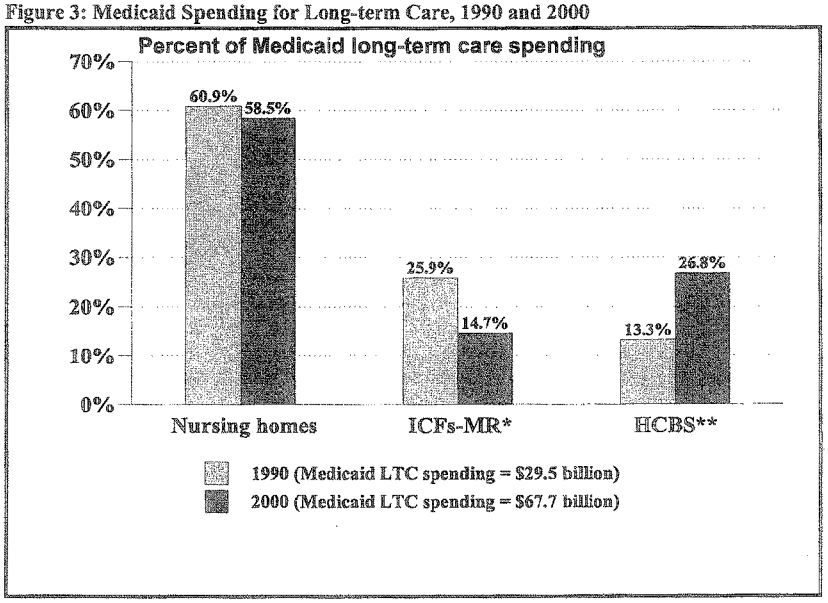
Source: Bureau of the Census, "Projections of the Total Resident Population by 5-Year Age Groups and Sex With Special Age Categories: Middle Series," selected years 2000 to 2040 (Jan. 2000).

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



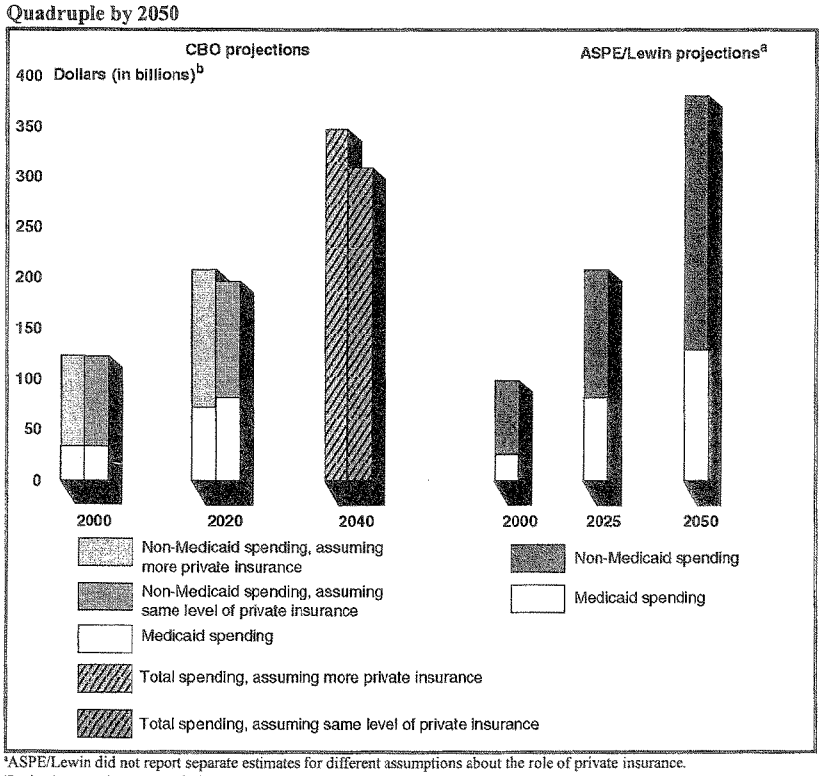
Note: These estimates do not include the state share of Medicaid.
Projections based on intermediate assumptions of the 2001 Old-Age, Survivors, and Disability Insurance, Hospital Insurance, and Supplementary Medical Insurance Trustees' Reports and on the Congressional Budget Office's (CBO) January 2002 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



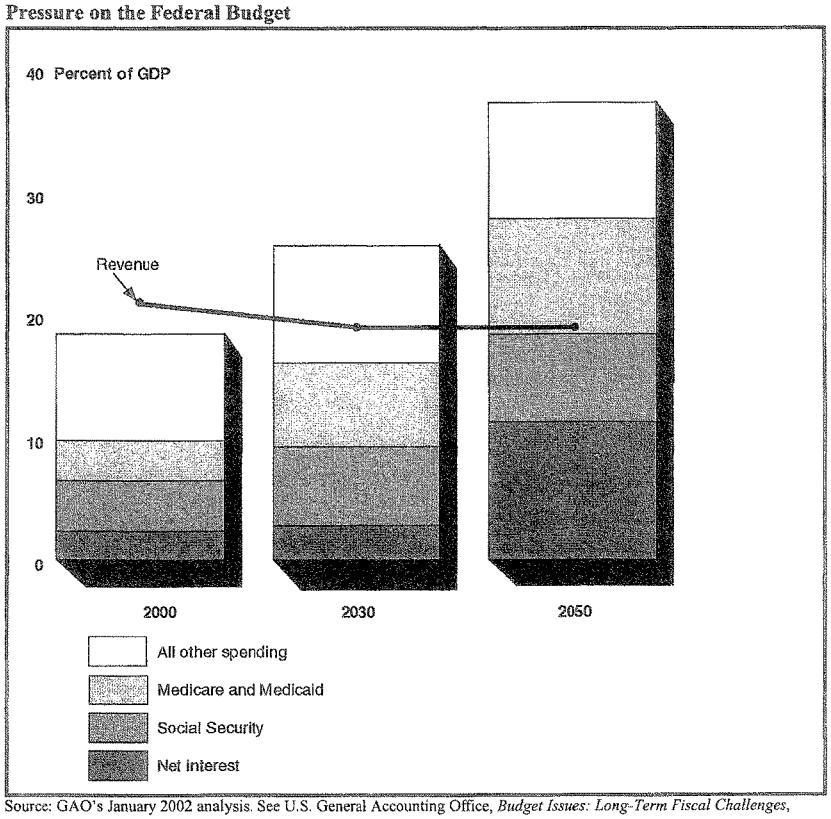
Source: CRS calculations, based on data from the Medstat Group, Inc.
Note: Percentage does not sum to 100% due to rounding
*Intermediate care facilities for the mentally retarded.
**Home & Community-Based Services.

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



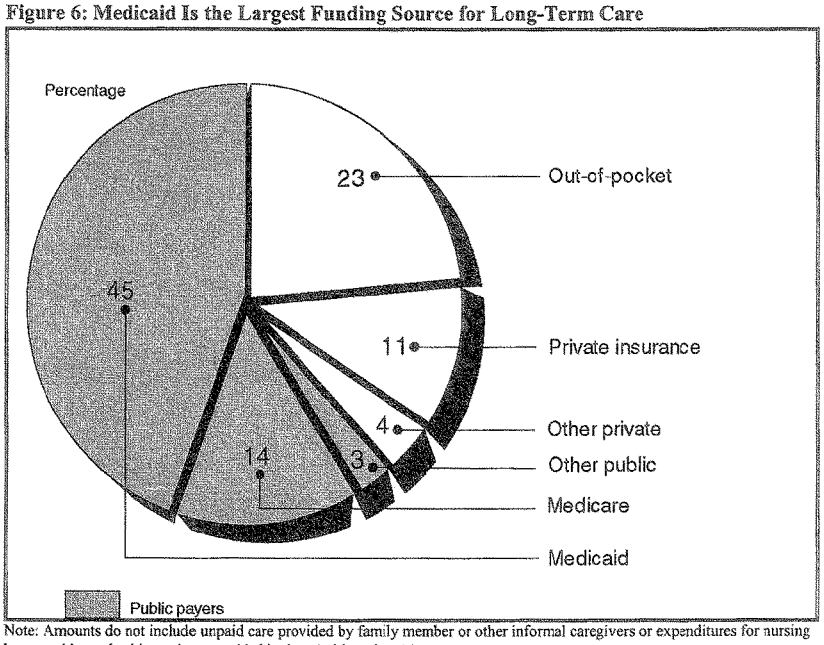
[a]ASPE/Lewin did not report separate estimates for different assumptions about the role of private insurance.
[b]Projections are in constant dollars.
Sources: CBO, "Projections of Expenditures for Long-Term Care Services for the Elderly" (Washington, D.C.: March 1999) and ASPE/Lewin, published in Urban 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

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

The CHAIRMAN. Today, we will be hearing from another group of expert witnesses who will talk about reform options to pay for a comprehensive long-term care system. Much good work has already been done and we want to take advantage of that wisdom. Other witnesses have come up with new approaches that are worthy of our time and attention, and equally important is the chance to learn what other developed countries around the world are doing to finance their long-term care service, as well.

While we have talked about this issue in terms of billions of dollars that are spent each year on services and the institutional bias that exists and the unmet need for the services that exist, what we really need to remember is that the issue of long-term care is very personal for individuals and their families and their relatives and their friends. It affects each and every one of us and our families at some point in time. It will affect all of us, if it already has not done so.

I would just like to read a short copy of a letter that I received which is really typical, unfortunately, of many of the hundreds and hundreds of letters that this committee has received from families around the country expressing their concern. This one is from a constituent of mine from Louisiana, and she says, "My name is Frances Stevenson. I am 73 years old and I live in Napoleonville, LA, with my husband, Dave. Dave is 76 years of age, is insulin-dependent diabetic who has had several mini-strokes, high blood pressure, dementia, and has had a feeding tube since May 1999 when his blood sugar elevated above 400. He wears diapers and must be bathed and changed at least twice a day. I must monitor his blood sugar at least three times a day, must bathe him in the evening, change his feeding bag daily, give medicine, insulin, and tend to his oxygen tank."

"Last May, Dave had surgery to remove his gallbladder, and at that time, he spent several days in an intensive care unit and a few more days in step-down. Home health care is allowed to come in for a few weeks at a time after each stay in the hospital and then I am on my own. My family helps me as often as they can, but each of them have jobs. My son is an Army officer stationed in Washington, DC. He gets to come home only about once a year. I have tried to get the VA to give us some aid since Dave is a World War II veteran. He served in the Marines for 5 years."

"I have been paying for an aide to come in and bathe him every morning for the last 4 years. Dave and I worked very hard throughout our whole lives and we felt that we would be all right in our later years. I can barely make ends meet with the costs of medicine, insurance, diapers, pads, bandages, a nursing aide, et cetera. The Council on Aging put Dave on a program in February, but that will end in a few weeks. He had 24-hour sessions of respite care, 34 hours of personal care, and 18 hours of sitter care."

"I want him to be cared for at home because I know that is where the best tender loving care will be given. I need home health care and someone to help with home living. Please give us some help."

I think you would agree with me that this story of one person from Louisiana is far too typical of literally hundreds, and indeed thousands of Americans throughout this country as we struggle

with the process of aging. If it is bad today, I would only point out that by the year 2040, we are projected to be spending some 75 percent of our nation's entire financial budget on Medicare, Medicaid, and Social Security. If we have problems today with about 40 million Americans over the age of 65, we can only wonder what it will be like when 77 million additional baby boomers become seniors who are going to be living a lot longer than their children would have expected.

So we have a challenge that I think is not insurmountable, but it indeed is one of the biggest issues facing us as a nation. Hopefully, this report will move us toward the process of looking at what we have done in 13 hearings and hopefully be able to come together in a bipartisan fashion to determine what some of the answers are.

I am delighted that I am joined by my two colleagues, who I will introduce in just a minute. I want to recognize a group of intern teachers that we have from Louisiana who work in our office for a short period of time to try and learn a little bit about how Congress works. Hopefully, being at our hearing today will give them a little sense of how hearings work in the U.S. Senate.

I would recognize Senator Wyden for any comments that he might have.

STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. Thank you, Mr. Chairman.

The first question, of course, that comes up when somebody talks about long-term care is can America afford such a program, particularly now with the war on terrorism, the claim on funds in a variety of areas. I think that is going to be the key question.

To me the question is not can America afford it, the question is can America afford not to do it, given this demographic tsunami that is coming. I think the answer is clearly yes. People can go through $40,000 a year easily on long-term care now. Given the population trends that you have outlined, it is obvious that the costs are just going to get worse.

So I would like to just touch very quickly on a couple of areas that I think are particularly important as we explore by way of trying to lay out a structure for new public and private partnership.

The first area that I feel very strongly about is making much more aggressive use of waivers so that programs at the State and local level can stretch the public dollars that are available for long-term care. One of the things that I am proudest of, when I came to the House after 7 years as Director of the Gray Panthers—I had a full head of hair and rugged good looks—Senator Rockefeller, who my guess is did not even know who I was, helped me with a program that really helped to start the assisted living field. It was a waiver program so that you could use Medicaid dollars that were then earmarked for nursing home care for home health care, and a number of States around the country have used it. Governor Dean is going to talk today about more aggressive use of waivers with home health and I support what the Governor is talking about, as well.

However, I think we should also look in a multi-disciplinary way at waivers. For example, I do not see any reason why we do not

allow waivers so that the VA, HUD, and Medicaid, could not team up on some innovative approaches in terms of long-term care. Those would be using existing dollars. They could come out of the State and local level. This is an area I will want to explore with our witnesses. So more aggressive use of waivers would be a top priority for public funds.

Then on the private side, where I know a number of Senators had an interest, I would like to see us allow penalty-free withdrawals from private retirement accounts for long-term care. We allow those penalty-free withdrawals for a whole lot of other stuff that America feels strongly about, like college and saving for a home and that sort of thing. I would like to see us take a look at penalty-free withdrawals from retirement plans for long-term care so that we could shore up a little bit of what is going on the private side in terms of saving for retirement.

Finally, a third area that I know Senator Rockefeller has a lot of history on, I would like to see us go back to explore the idea of a voluntary Part C of Medicare. As all you know, we have got Part A, the hospital portion, Part B, the outpatient portion. We have talked over the years sort of sporadically about a voluntary Part C of Medicare that could be designated for long-term care, where perhaps government contributions could be matched by private contributions, as well.

Your report in my view, Mr. Chairman, gives us a very good outline. I am looking forward to having a lot of people at that witness table who I have worked with over the years give their views and working with you, and Senator Ensign has had a long-term interest in this, as well, so I think we have got some bipartisan opportunities here.

The CHAIRMAN. Thank you, Senator Wyden.

Senator Ensign of Nevada?

STATEMENT OF SENATOR JOHN ENSIGN

Senator ENSIGN. Thank you, Mr. Chairman. I will keep my remarks brief. I am looking forward to hearing from the panel.

Anybody who has gone around their States—who has spent any time at all looking into this issue-realizes that there are some serious concerns not only today, but even more so into the future. I think the demographics show as the Chairman mentioned this morning, as we go into the future, that if we do not start addressing this problem now, we are going to be behind the biggest eight-ball that we could possibly imagine.

The continuum of care that is out there, and there are a lot of innovative things being done in the continuum of care, is such a big issue. This is because almost everybody is thinking about their continuum of care as they are getting older. Obviously, the closer you get and the more gray hair that you get, or the less hair, whichever the case may be—— [Laughter.]

The more that we have the fear that we may be in a situation where the care is not good. The care is something that is not only inadequate, but sometimes neglectful. There are a lot of people doing a lot of good stuff out there, but I think a lot of people, as they get older, have a big fear of the type of care that is going to be available.

So I think that this is an incredibly important issue for us. Unfortunately, we are not getting enough younger people thinking about the issue yet and I think that that is going to be one of the keys. Government has an important role in this, but the more that we can get the private sector involved and get individuals when they are younger to start saving and buying long-term care insurance—I think that that has got to be a big part of the answer.

Then as innovative ideas come forward and we figure out the best ways that we can use preventative medicine to keep people out of assisted care, the better off that we are going to be. This is because more people will be able to take care of themselves. A great example of this is the physical therapy cap. Now, there is a budgetary reason. If we do not get people back to being more on their own or maybe in a less-intensive health care situation, the more expensive it is for us and the worse their quality of life is.

So preventative medicine, to me, as part of this whole thing, has to be stressed, where we have dietitians teaching diabetics and cancer patients and heart patients how to eat better, not only how to shop for the food, how to buy the food, how to prepare the food. We have got to have physical therapists and speech therapists and occupational therapists involved in these things and then communities and non-profits involved. I think that if we look at this from a holistic approach, I think that we are all going to be better off and that is all going to be part of the solution for the future.

I appreciate the Chairman's interest in this issue. I think you need to be applauded for this because this is such an important issue.

The CHAIRMAN. Thank you, Senator Ensign.

You mentioned long-term care insurance. I would note for the first time that the Federal Employees Health Benefit Plan will be offering long-term health care insurance for the nine million Federal employees, not only Members of Congress, but also nine million others. As well, and I think that will be a very important test to see how it works. It is already available in the private sector and I think people are just becoming aware of the need for it.

We have a very distinguished panel of witnesses, as I mentioned. I will introduce them all collectively. It starts with a very distinguished colleague who has a long history of service in the health care areas. He chaired the Pepper Commission a few years back which dealt with the question of providing health insurance for the millions of Americans who are uninsured, outlining a blueprint for the future. Unfortunately, Congress has not really acted on those recommendations. We still have about 44 million Americans who have no insurance at all. We talk about Medicare not being enough. There are 44 million Americans who have nothing and that is still a problem and Senator Rockefeller was one of the leaders on that Pepper Commission.

Howard Dean will be our next witness. He is back to the Aging Committee. He has been before us on a number of occasions with his ideas and suggestions. He is testifying on behalf, really, of his own views, but also representing the National Governors Association, which has really gotten involved in this issue, and is incredibly important. We are looking forward to his testimony.

Our former colleague of this committee, as well as, and the Senate Finance Committee, David Durenberger, is back as Chairman of the Citizens for Long-Term Care Coalition, which has done outstanding work in trying to put together all of the health care groups to address this problem collectively because, really, we all have the same goal in mind. So your work in that coalition is outstanding.

Carol O'Shaughnessy will be testifying. She has been around on the Hill a number of times before this committee, and has a real expertise in health care and aging issues in particular. The work that they have done over at CRS, the Congressional Research Service, which provides us with information, has been most helpful.

Steve Chies is Vice Chairman of the American Health Care Association, which is a federation of all of the nonprofit as well as the for-profit assisted living facilities, nursing homes, residential services, et cetera, who have a major role in this area of helping us with long-term care. He also will be testifying.

I know Senator Rockefeller has a busy schedule, so Jay, if you would like to give your testimony, maybe we can ask you a few questions and you can leave. Welcome to the committee.

STATEMENT OF HON. JOHN ROCKEFELLER IV, A U.S. SENATOR FROM THE STATE OF WEST VIRGINIA

Senator ROCKEFELLER. Actually, I do not have a busy schedule, Mr. Chairman, but I am delighted that——

The CHAIRMAN. But you want to get out of here anyway? [Laughter.]

We are glad to have you.

Senator ROCKEFELLER. Thank you, Mr. Chairman, and both of your colleagues here. I am very happy to be here.

We did, in fact, and Senator Durenberger was a member of the Pepper Commission, which passed out a long-term care policy 11-to-4, and this was a very, very split commission ideologically, but not split on the concept of doing long-term care and doing it in a real and workable way.

We are delivering what I would say would be fiscally irresponsible tax cuts for the next decades. Americans throughout this country are dealing with other kinds of problems, and that is when are they going to sell their homes? When are they going to raid their savings, get rid of their retirement benefits because of long-term care problems? Families come in to take care of them, and then their assets get depleted, exhausting personal resources, having to get rid of properties in order to get people qualified for Medicaid.

So government coverage for nursing home care operates primarily and substantially through the Medicaid program, which is fraught with problems, as Governor Dean knows better than anybody, and it is the safety net for the poor, always has been, and is now grossly underfunded and States are suffering because of unwise actions on our part here in Congress.

Medicare, and everybody knows this, is not designed to do long-term care. It does lots of things, but it does not do prescription drugs and it does not do long-term care and those are probably two

of the biggest needs in the country, along with mental health coverage.

So accessing the Medicaid program, by definition, getting into it requires impoverishing yourself. We know that, but it needs to be said and said and said again. It has not changed since the late 1980's when we were dealing with this. It is still the problem of demeaning yourself and giving up what you have.

We have serious issues of quality. We are faced with a system which encourages care in institutions rather than homes. People want to stay at home. I had a mother who died from Alzheimer's and she wanted to die at home, or we wanted her to die at home. She was not sure at that point where she wanted to die, but we wanted her to die at home. That becomes an enormously emotional things within families.

It was more than 10 years ago that this bipartisan commission called the Pepper Commission issued its "Call to Action" and nothing has really changed. We had three basic concepts which we put forward. Home and community-based care should be available and they should be affordable, that is No. 1. No. 2, those who need nursing home care for short periods should have enough resources, $30,000 for a single person, $60,000 for a couple, preserved intact in order to return home, so they are not depleted entirely. That was true then, is still needed now. No one should fear impoverishment if they must end their lives in a nursing home. Now, woven throughout the recommendation is the requirement that people would have to pay some, according to their ability to do so. That seemed fair then, the same now. So I want to talk just briefly about each of those ideas.

First, a strong home care benefit was included in the Pepper Commission recommendations because people who need long-term care want to stay at home. They do not want to be in an institution. They want to stay at home. Individuals with three or more impairments—and we used to call those, and still do, measures by acts of daily living, ADL, it is a way of measuring how impaired people are—should be eligible for home care services. Our expansion did not cap the hours of service, but we did include individual budgeting caps set for each beneficiary. The trick is to encourage informal caregiving rather than to displace it, and researchers believe that a strong home health care benefit would help on this.

Today, the home health care benefit offers skilled care and possibly home health aides on a part-time or intermittent basis. Under current requirements, beneficiaries also must be confined to the home, despite the fact that many could leave home with assistance. So you get this question, if they are home, they cannot leave. So 24-hour care is not covered, nor is personal care covered, and if that is the only care a person needs, we can do a whole lot better.

Today, in fact, I am going to be introducing legislation which is the first step to improve home care, the modernization of the benefit, which allows for increased mobility out of the home. Let us not forget that the next step must be to change the home care benefit fundamentally to allow those in need to remain in the home and then to fix this bias that we have, which we are, incidentally, curing in the Veterans Administration where we have taken this on. We have made the first change in long-term care in the VA system

since the 1960's without a whole lot of fuss, not that they have implemented it, but we have changed the law and they are in the process of rules and regulations, getting people out of institutions.

Second, the Commission members recommended coverage of short stays in nursing homes regardless of income and we allowed at that time, I think, David, it was about 3 months and you did not have to pay. Income was not a factor. Most people who enter nursing homes can return home and public insurance for a 3-month stay provides the protection to do that.

At present, nursing home residents with any savings simply do not qualify for Medicaid-financed nursing home care, and under certain limited conditions, Medicare will pay some nursing home costs for Medicare beneficiaries—this is Medicare—but that is sort of the skilled nursing and rehabilitation services caveat which does not get at the basic problem.

So again, in this legislation, we are going to provide options to nursing home care under the Medicare benefit that would be payment for adult day health care. Paying for adult day care will provide a measure of respite, will reduce the bias toward institutionalization, and encourage people to stay at home. The next step, obviously, will be full coverage of a short stay in a nursing home without the condition of poverty.

Third, the Pepper Commission recommended a measure of asset protection, and I discussed that. That is the idea that one in four Americans who have to stay 3 months or longer, that you do not deplete them. They can go to the nursing home, but you allow them to keep $30,000 if they are single, $60,000 if they are a couple, keep their assets. It is so horrible, what we do to people.

In this legislation, we are going to give States the option of whether or not to pursue and sell off the homes of Medicaid recipients, and Governor Dean will probably have something to say about this. It is something that can be done in the short term. In the future, we will have to address the larger problem, as I say, of spending down to poverty.

I was going to talk about the Pepper Commission is relevant today, and you did. You basically said, Mr. Chairman, yes, they are. It is just that everything is worse. The cost of nursing homes has doubled, all the rest of it.

So I will close with a final thought. A long-term fix cannot be done without the government. That, we have to understand. We cannot ignore the government. The government is already involved. We need the Federal dollar and we need Federal leadership. The Pepper Commission concluded that Federal action is, "essential to change the nation's fundamentally flawed approach to long-term care financing." End of testimony.

The CHAIRMAN. Thank you very much, Senator Rockefeller.

[The prepared statement of Senator Rockefeller follows:]

Senator John D. Rockefeller IV
Statement Before the
Special Committee on Aging
United States Senate

Hearing on Long-Term Care Financing: Blueprints for Reform
June 20, 2002

Senators Breaux, Craig, and other members of the Committee, thank you for calling this hearing on long-term care and the elements that should make up a blueprint for reform.

I will not spend much of my time outlining the problem, as that can be done well by others. As I know from previous experience, the hard part is putting forth a solution – not a magic bullet – but a real and workable approach to attack the issue of long-term care coverage.

While we in Congress deliberate over fiscally irresponsible tax cuts for the next decade, Americans throughout the country are sorting through the really difficult choices. Choices like whether and when to sell homes, raid savings and retirement accounts, or slip below the poverty line to qualify for government help to meet desperate long-term care needs. Exhausting personal resources then precludes a return to the community, even when physical conditions allow it. States are struggling with the deleterious mandate that they sell-off the property of Medicaid beneficiaries.

Government coverage for nursing home care operates primarily -- and most substantially -- through the Medicaid program, the safety net for the poor. Despite what many Americans believe or hope, Medicare is not designed or financed to cover long-term care needs. Medicare is, in fact, the universal health care program for the elderly, which covers all health care needs, save prescription drugs and long-term care.

Accessing the Medicaid program, by definition, requires impoverishment. We also have serious issues with quality. And we are faced with a system which encourages care in an institution rather than in the home.

Today, I plan to introduce a targeted long-term care package – a first step in the direction of long-term care reform. This first step is about protecting assets, expanding home care, and modestly expanding Medicare to address the need for adult day health care.

It's been more than a decade since the Bipartisan Commission on Comprehensive Health Care, known as the Pepper Commission, sent its "Call to Action" to Congress. Bipartisan Commission recommendations became the basis for the Long Term Care Family Security Act -- it embodied three basic ideas.

Home and community-based care should be available and affordable. Those who need nursing home care for short periods would have their resources preserved intact to return home.

And no one should have to fear impoverishment if they must end their lives in a nursing home. Woven throughout the recommendations is the requirement that people would contribute to the costs of care, subject to their ability to pay.

I want to briefly talk about each of these ideas, describe why more needs to be done, and offer a first step that can and should be taken.

First, a strong home care benefit was included in the Pepper Commission recommendations, because people who need long-term care want to stay at home. It's just that simple. Individuals with three or more impairments would be eligible for home care services. This expansion did not cap the hours of service but did include individual budgets. The trick is to encourage informal caregiving rather than displace it, and researchers believe that a strong home care benefit would bolster such care.

Today, the home care benefit offers skilled care and possibly home health aides on a part-time or intermittent basis. Beneficiaries also must be confined to the home, despite the fact that many could leave the home with assistance. Twenty-four hour care is not covered, nor is personal care, if that's the only care a person needs. We can do better.

A first step to improve home care, in my view, is a modernization of the benefit which allows for increased mobility out of the home. Let us not forget that the next step must be to change the home care benefit fundamentally to allow those in need to remain in the home and to fix the bias towards institutionalizing the elderly.

Second, Commission Members recommended coverage of short stays in nursing homes regardless of income. Most people who enter nursing homes return home, and public insurance for a three month stay provides the protection to do so. At present, nursing home residents with any savings simply do not qualify for Medicaid-financed nursing home care. Under certain limited conditions, Medicare will pay some nursing home costs for Medicare beneficiaries who require skilled nursing or rehabilitation services.

We can begin to provide options to nursing home care under the Medicare benefit, such as the payment for adult day health care. Doing so would provide a measure of respite and will reduce the bias towards institutionalizing those who can -- with the right circumstances -- stay at home. The next step will be full coverage of a short-stay in a nursing home without the condition of poverty.

And third, the Pepper Commission recommended a measure of asset protection against nursing home care for the one in four Americans who will need to stay longer than three months. After all, nursing home care has the dubious distinction of wiping out the financial assets of many of those in need. Homes would be excluded from the asset test for eligibility and asset limits would be raised to $30,000 for individuals and $60,000 for couples, so that almost all the elderly will have their life savings protected.

The goal of asset protection, as presented by the Pepper Commission, sounds strikingly similar to recent efforts to abolish the tax on wealth. Indeed, long-term care financing remains the last bastion of taxes on estates -- not huge million dollar estates, but the savings of average Americans.

Giving states relief from the mandate that they must pursue and sell-off the estates of Medicaid beneficiaries is another first step. In the short-term, we can provide states with the option of whether or not to do so. In the future, we must address the spending down to poverty.

Are the Commissions' recommendations relevant today? The numbers show that they are more relevant today then they were a decade ago. Compared to the early 90s, the population of Americans over age 65 increased by 12 percent. And most importantly, the number of those with the highest chance of needing long-term care -- those 85 years and older -- has also increased since 1990. People are living longer. More elderly live alone today. And more and more women – the natural caregivers – are working outside of the home. We all know that baby boomers will soon reach age 65, but they are dealing with their parents long-term care troubles now. The average cost of a month in a nursing home has gone from $2,500 a month in 1990 to $4,600 a month today. Clearly, more needs to be done, not less.

There are few issues that are as challenging as providing a solution for the long-term care problem. I learned this lesson from chairing the Pepper Commission. The recommendations received significant bipartisan support but died in Congress. Later, recession led to a debate about how to provide health care coverage to millions of uninsured Americans. Today, the rising cost of prescription drugs -- and the fact that everyone needs medications -- calls out for prescription drug coverage.

The former staff director for the Pepper Commission has said, "On offense long-term care is a weak political issue; on defense, it's a powerhouse." If true reform is to be done, which it absolutely needs to be, we need to design a better offense. Reforming the long-term care system must return to the agenda. The needs are just too great.

I'll close with a final thought. A long-term fix cannot be done without Government. We cannot ignore that Government is already involved. We need the Federal dollar, and we need Federal leadership. The Pepper Commission concluded that federal action is essential to change the nation's fundamentally flawed approach to long-term care financing.

As we wrote in the "Call to Action," all Americans would benefit from a new public program, for it provides everyone peace of mind in the face of long-term care needs. I thank you for the opportunity to testify, and I pledge to work with you to find real, workable solutions.

Demographic Changes and Increases
Since the Pepper Commission Recommendations

Beneficiaries & Their Caregivers	1990	2000	Percent Change
Persons age 65 or older[1]	31.2 million	35 million	12% increase
Persons age 85 or older[1]	3.1 million	4.2 million	38% increase
Persons living alone[2]	22.9 million	26.7 million	17% increase
Percent of females in the labor force[3]	57.5%	60.2%	4.7% increase

Costs	1990	2000	Percent Change
Total annual US expenditures in nursing home care[4]	$52.7 billion	$90.0 billion[5]	70.7% increase
Total out of pocket payments for nursing home care[4]	$19.7 billion	$23.9 billion[5]	21.3% increase
Average cost of one month of nursing home care	$2,500	$4,600[6]	84% increase

[1]US Census Bureau, Census 2000 Summary File 1: 1990 Census Population, *General Population Characteristics,* United States, (1990, CP-1-1)

[2] US Census Bureau, Current Population Reports, Series P20-537, "American Families and Living Arrangements" March 2000 and earlier reports.

[3]Bureau of Labor Statistics, "Employment Status of the Civilian Noninstitutionalized Population 16 Years and Older by Sex, 1970 to Date." Annual Averages- Household Data.

[4] National Center for Health Statistics, Health, United States, 2001 with Urban and Rural Health Chartbook. GPO 017-022-01509-9. September 2001.

[5]1999 Estimate

[6]American Association of Retired Persons, *The Costs of Long-Term Care: Public Perceptions Versus Reality*, 2001.

The CHAIRMAN. I think if we have a question or two for Jay, we can go ahead and do it now, if the other panel members do not mind.

One of the things you put in your testimony that I find very interesting and I think a lot of Americans do not really understand is the chart that you put on the last page about how things have changed just since the Pepper Commission, in terms of the demographics of how this nation looks in the year 2000 as opposed to what it looked like in 1990. We have a 12 percent increase in the number of people 65 years of age and older over 1990. We have a 38 percent increase in the number of people 85 years of age and older, which is the fastest-growing segment of our population and therein lies part of the problem. There is a 17 percent increase, Senator Rockefeller points out, in people living alone and a 70 percent increase in the total U.S. expenditures on nursing home care just in that 10-year period. I mean, those are astronomical numbers that are only going to continue to get worse.

Jay, let me just ask one question, and that is you mentioned the question of providing in the home health care areas. You also recommend, I think, as the Pepper Commission did, apparently, the coverage of short stays in nursing homes by Medicare, and you point out, regardless of income. It seems to me that we have to face a problem that we are looking at prescription drugs for seniors which I support, but it is going to come out of Social Security surplus. If we increase other Medicare benefits like covering nursing home stays, it is going to come out of Social Security surplus. We are rapidly spending the surplus for retirement on these programs that are very, very worthwhile.

It seems to me at some point we have to consider, with the limited amount of money we have, are we, in fact, going to use tax dollars to take care of the nursing home for Warren Buffett? I am just using him as an example. I could probably use the Senator.

Senator ROCKEFELLER. Somebody else. [Laughter.]

The CHAIRMAN. I could probably use someone else as an example, but it seems to me that as a nation, when we have limited resources, we have to say, all right, we are going to take care of those who need the help, but we are not going to use tax dollars to subsidize someone who is financially well off. Can you comment on that? I'm talking about means testing.

Senator ROCKEFELLER. Yes, I would be happy to. I think your point is well taken and adjustments like that could be made. I remember I started something called the Golden Mountaineer Discount Card program when I could not think of anything else to sort of help West Virginia during the depths of the recent recession and the legislature was all over my case because they said, what do you mean? We have got all these rich people who are going to be taken care of. So we did a little survey of that and discovered about 2 percent of West Virginians qualified as being wealthy and everybody else did not.

But that still does not answer your point, and your point has merit and I can live with that. I think the important part, however, is that when people need to go for a short period of time, we talk about 3 months to a nursing home, that they should not have to go through all of what you would otherwise have to go through if

you were going to qualify under Medicaid for long-term care and have to strip down everything, you know, get rid of your car, get rid of your house, all the rest of it. So you sort of create this window for people who are short-termers wherein you say, OK, you have got your 3 months based upon your acts of daily living analysis and for that we are going to go ahead and pick up the cost, not 6 months, not 5 months, not 10 months, but for 3 months.

Yes, that is social cost, and yes, we have budget problems, and yes, we have terrorism, homeland security, and I cannot help you in that, Mr. Chairman, except to say that if we are talking about long-term care, these are the kinds of things you have to do.

The CHAIRMAN. Thank you.

Are there any questions of Senator Rockefeller?

Senator WYDEN. Just one. I think Senator Rockefeller has done an excellent job in terms of outlining the history and I think particularly your last point was important. This is an area that absolutely must have a useful government role. There are steps that can be taken in the private sector. I mentioned one I am interested in, and that is the idea that you could have penalty-free withdrawals from private retirement accounts in order to pay for long-term care, so it moves toward what Senator Ensign was talking about, which is trying to use the private sector to the greatest extent possible. But there must be a role for government here and the question is really whether government is going to be smarter or whether the government is going to continue to just sort of dawdle along.

My question for you, Senator, is given the history here, why do you think that there has been commission after commission and yet nothing seems to happen after the latest report——

Senator ROCKEFELLER. I think the answer to that, Senator Wyden, is that Americans have a virtually unlimited capacity for denial on certain very tough issues that have to do with health care. We are also risk averse when it comes to health care. We were made risk averse by two events. One was catastrophic health care, which was a fantastic program which the House shot down after all those people chased Danny Rostenkowski down the street. We denied that from happening in the Senate three times and finally had to give up, so that was one. Then along comes the Clinton plan. Everybody goes ballistic, and now we have become totally incrementalist.

In the process of that, we do CHIPs, but we cannot take it on to the parents, so that we are sort of frozen, one, by risk aversion, second, by always the excuse that this is going to cost money, it is going to come out of Social Security, going to come out of Medicare, et cetera. We have all these other new things going on post-September 11.

But I think the most important thing that needs to be said is I do not think there is a bigger health care problem in this country that we have absolutely failed to deal with, face up to, even discuss, because it does not make for a particularly interesting discussion. You know, prescription drugs, you can get into some really good battles. The verbal part is colorful and all the rest of it.

Long-term care affects everybody at some point. It is the most overwhelming health care problem, in my judgment, in the country and is entirely unaddressed because it is considered too expensive,

it is considered too oriented toward the government for whatever number of reasons, and so we choose simply to deal with lesser problems, a little bit like mental health, except mental health is now changing. People are getting more friendly toward mental health. Nothing has happened in long-term care except, as I say, what we have done in the Veterans Administration, nothing.

Senator WYDEN. I think your answer is a thoughtful one. There is no question that part of this has just been being risk averse and being unwilling to take on tough issues. I think the one thing that I hope will be different now is that the country does have a history of moving when there is a crisis on the porch. In other words, you put it off if it looks like the crisis is even three doors down the block. I think you and others have laid out that the crisis is on the porch and I commend you for all of your good work and look forward to working with you.

Senator ROCKEFELLER. Thank you, Senator.

The CHAIRMAN. The system is hanging on a string. I just hope we do not have to wait for the string to break before we do something.

Senator Ensign, do you have a question for Jay?

Senator ENSIGN. Yes. I actually want to explore with you maybe just a little different angle because I think it is something that we need to think about. The cases are so individualized, and we have talked about the continuum of care, as well, some type of short-term solution, and in my opening remarks, I talked about the need for physical therapy and the need for preventative medicine.

But what I want to explore with you is the family responsibility. My grandmother, just turned 82 years of age. My parents are in their mid–60's, and between myself and my brothers and sisters, We are looking at the potentials for her care. She is still living on her own and she still wants to live on her own. However, if she did not want to live on her own, we are in a position to be able to afford to do those things. I agree with Senator Breaux as far as my grandmother goes she should not be one of these people that are helped by a government program. It should be some type of a means testing for this. But I still want to use her as the example. Let us just say we could not afford what we can afford. Maybe we are questionable.

We know that older people, and you mentioned this, want to stay in their own homes. My grandmother does not want to move even into some of the wonderful private assisted living facilities. She does not even want to go to that first step. I have been to many of those places and they are absolutely wonderful and I think she would actually like it there, but she does not want to, so we are working with that right now.

But there is this mentality with younger people, in how they are looking at this type of situation. It is a long way to say this, but it is easy to just kind of ship grandma off, and that is what I want to kind of explore. If we get more and more into, "Well, the government can take care of them, that relieves me of my responsibility," that will we, in fact, be setting up a situation where families will be taking less and less responsibility for grandma or grandpa just because it is easier.

It is hard work to take care of our elderly relatives. At a certain point, you cannot do it with Alzheimer's patients. I mean, you know that the family cannot do it. But there are a lot of times where it is hard work, but that is what part of life is. When you are a parent, you have children. Then when you are a parent and you get older, you have got your parents or your grandparents, and part of that is just the responsibility as a human being to help in those situations. But if there is a government program, you know what? We are such a selfish society that we will just let the government do it.

Senator ROCKEFELLER. I am anxious to reply to that. I do not think we are. I think we can be a society which ignores problems and which denies problems, but I do not think we are a selfish society. In fact, I think the families that you referred to have, in fact, been the government because it is—and I do not think that West Virginia is particularly unique, but those who know Appalachia know that it is extremely family oriented, but everybody can say that.

Kids come back. First of all, kids are dispersed all over. I have three sisters. When my mother had Alzheimer's, they were in four different States, all of them long ways away from where she was. So they are dispersed. They did not used to be.

Families come back. I mean, the history of long-term care, say where I live, is families coming back from Oregon, from Ohio, from Kentucky, and they bring their kids for whom they have been saving for college tuition money desperately, they move into the house, they take the responsibility. They become the government. They relieve the government. They do this almost without exception, and then they get destroyed psychologically, financially, emotionally by this process of caregiving, which they cannot measure up to because of the lack of respite care, because of the lack of experience, because of the lack of people, because they are meant to be working, and they get caught up in it.

My response would be somewhat the opposite, that the American people have been bailing out the government through their caregiving for all of these years. I am not saying that the government has to do all of this. That is why we put in that the people should pay something. Everybody should pay something.

But, no, I do not buy that at all, Senator, that the American people would choose the easy way out. I think people do try. It is not Ozzie and Harriet anymore, and I recognize that, but people are pretty serious about their parents when they get in trouble and they are pretty willing to come back and do everything that is required. As long as that happens, there is less pressure on the government, and the explanation of that is who talks about long-term care? You have got a group of people here who are going to talk about long-term care, but how often do you hear it discussed at your town meetings and other things? People are talking about prescription drugs, they are talking about other things, but they are not talking about long-term care.

Senator ENSIGN. Just to conclude, I guess we will have to agree to disagree. I think that there is some potential for that, for what I laid out to happen. I agree with you, though, it is very difficult on a lot of families depending on the level of need. That is why I

believe that there is a need out there—a severe need—for more long-term care assistance.

I guess all I am trying to raise is cautionary flags that we do not make it so easy, to not take responsibility. My grandmother was incredible when my parents were divorced when I was very young, letting us live with her for summer after summer after summer while my mom was trying to save a little money as a single mom, carrying change at Harrah's in Reno. I will never forget what my grandparents did for us, and so because of that, I feel a very, very strong commitment to her to making sure that she is taken care of.

But in a situation where if the help can be like respite care, when you see people with disabled kids or with parents or grandparents or whatever it is, I think that is the way to go. All I am saying is that when we are going forward, I think that we need to be very careful that we do not just say, OK, here is the benefit, you are relieved of all of your responsibility at this time, instead of trying to set it up to where we can give the help that is needed, but still the family has the responsibility. That is all I am trying to raise as a point.

Senator ROCKEFELLER. All I would say back, and I do not want to abuse my time, is that that is, Senator, with all due respect, kind of the classic way that legislation thereby never takes place, because it is the cautionary flag. If we do this, is there a chance that the government becomes a substitute for the family? If people are disposed to worry about that sufficiently, I guarantee you there will not be anything happening in terms of a long-term care policy that works.

So that is what I would fire back at you. I mean, it is the same thing, and the Chairman can remember this on Medicare reform. I remember we had a vote in the Finance Committee and I was one of two who voted against means testing. Now, should my mother—obviously, she should have been means tested. But what I did not want—the reason I voted against it, Senator, was because I did not want Medicare reform, and the means testing back at the time of this vote would have saved $3 or $4 billion, but it became sort of the way you defined, were you serious about doing something about Medicare. Were you a serious player in this intellectual and cerebral and emotional argument. So if you were for means testing, that meant you were, and it was $3 or $4 billion.

So it became an excuse, and what I do not want is the so-called cautionary red flag that you raise, I do not deny that possibility episodically, but I do not want it to become something which then prevents us from dealing with what I consider to be the largest most intractable health care problem in this country.

Senator ENSIGN. Thank you.

The CHAIRMAN. Jay, thank you very much for your testimony and for responding to a very interesting series of questions and dialog. We thank you very much, and if you have to go back to work, we will be happy to excuse you.

We will next hear from Governor Howard Dean. Howard, thank you and all the witnesses for being patient.

STATEMENT OF HON. HOWARD DEAN, GOVERNOR, STATE OF VERMONT

Governor DEAN. Thank you, Mr. Chairman. I want to thank the Senator from West Virginia, who is very good on these issues and has been for a long time.

I have written testimony which I will submit and I am just going to go through some of the talking points.

In our State, we have 120,000 people on Medicaid out of a population of 600,000. I did that on purpose. We insured 96 percent of all our children under 18, and of the 4 percent that are not insured, 3 percent are eligible for the program. So we essentially have universal health insurance in our State for those under 18.

More than 50 percent of all Medicaid recipients, because we have universal health insurance, are under 18. They use 14 percent of all the money. Out of the 120,000 people we have on Medicaid, we have 2,500 receiving long-term care assistance. They use nearly 50 percent of the money. This is an enormous financial problem for the States, and since you match our money in every State—different rates, obviously, for different States—it is an enormous problem for the Federal Government.

We have actually done some of the things that you are talking about doing. Let me make some suggestions. First of all, I think the notion that you have to be very careful that was raised by Senator Ensign is a very good notion. I agree with Senator Rockefeller that we ought not to let cautionary red flags prevent us from doing anything about this, but I think if you create the wrong program, you are going to create a need that is going to eclipse any ability to finance any of this, so we have to do this right.

I am going to recommend two things, one of which we have done. Institutions use up a huge amount of money. We do not think we need any more nursing home beds in this country for the foreseeable future, because if you do what we did, you will not need it. We passed a bill about 5 or 6 years ago that reduces the number of nursing home beds by 10 percent and we think we can take another 10 percent of our nursing home beds out. How can we do this with an aging population? Because of a waiver.

Now, we do not want more waivers. What we want is a law that allows us to do what we are doing without any waivers and allows every State to do it. We have basically said, we will take the Medicaid money that is going to skilled nursing facilities and we will use it in assisted living facilities. I think we are the only State in the country that uses Medicaid in assisted living facilities, and more importantly, in home health care. I think we have now 1,000 slots where we can take care of people in their own homes and they can get Medicaid assistance. The qualification is that you have to be eligible for nursing home entry.

The CHAIRMAN. Do you have a waiver for both of those?

Governor DEAN. Yes.

The CHAIRMAN. For home health care and for assisted living?

Governor DEAN. Yes. So we are basically able now to use the financing that we have to take care of more people. For every Medicaid dollar that we get, we can take care of twice as many people as we can if we did not have this waiver. So with the money that we get, we can simply take care of a whole lot more people.

Now, something like 30 percent of all the people in nursing home-type care are, in fact, taken care of in their own homes by using Medicaid dollars for skilled nursing care that needs to come into the house, respite care, which I think everybody agrees is necessary because families really do struggle when they are taking care of their folks, and it really is not easy on these people.

I think we all have our stories. I certainly have seen people, particularly with Alzheimer's, who are otherwise healthy but who are very difficult to take care of. If you try to do that on your own without any kind of support, you are basically asking for a situation where you and your family and your kids get burned out as you are trying to take care of your elderly parent whose Alzheimer's is deteriorating.

So these services are necessary, but even if you have respite services and even if you have long-term care in the home and skilled nursing care in the home and all these things, you can still take care of twice as many patients as you can inside a skilled nursing facility because the money is reallocated.

Now, this is not to say we do not need skilled nursing facilities. Of course, we do. This is a gradual aging process. People who have serious conditions like Alzheimer's or many conditions when you get to be in your 70's, 80's, and 90's, these conditions are not usually reversible. So as folks continue to transition, they do need more care and they do need to go from home into assisted living or oftentimes into a skilled nursing facility.

But right now, we put folks in this country into skilled nursing facilities who do not need to be there and we do it because everybody lives in Ohio and the mom is in Nevada and they cannot come back and they cannot leave their lives and they cannot, for most people, cannot decide they are going to move to Nevada or move her to Ohio or whatever, and so they end up in the nursing home.

The most common way people get in the nursing home is they go into the hospital. They get sick. They do not need to be in the hospital anymore, and then everybody wants to get them out of the hospital. They cannot go home because we do not have the back-up, so they end up in a nursing home. Once you are in a nursing home, it is almost impossible to get out, because basically what happens is that the level of care that a patient needs will rise to the level of the institution that they are in.

This is why I started off by saying, be careful what you create, because if you simply create a long-term program that stresses nursing homes, guess what? You are going to have a whole lot more nursing home beds and you are going to be able to take care of half the number of patients.

So the first thing I would ask for, Mr. Chairman, is a program which actually eliminates the necessity for us to get waivers and allow people and encourage States to put people in their own homes with the kind of back-up care that is necessary, augmenting the kind of family care that Senator Rockefeller and Senator Ensign were talking about, because if you augment the family care, most families do want to do the right thing, but they cannot because it is just an overwhelming task in many cases. You can eliminate the need for a skilled nursing facility in many, many cases by

simply supporting the desire of families and the patients themselves to stay in their own homes.

The next piece is more controversial. I am going to start out speaking for the NGA, but let me just be really clear that I really do not, because I am going to go beyond what the testimony is. I believe we ought to have health insurance for every American. That is something I have been very up-front about for a long time as a physician. It is something that I got into politics because of.

One of the pieces of that is this so-called swap which has been talked about for many years, which is the notion that States ought to be responsible for making sure all children, I think up to the age of 22, get health care, and we ought to have some flexibility as to how to do that and we ought to have some financial responsibility, and then the Federal Government ought to take over responsibility for all those over 65, including dual-eligibles.

The numbers work very well. If you tell States they have to insure everybody up to 22, they will yell and scream and say it is an unfunded mandate, but it turns out that you are within $1 billion in the States' favor if the Federal Government, in turn, takes over responsibility for dual-eligibles and nursing home/long-term care.

So I would urge the committee to look at that, although look at it carefully, because the biggest single problem here is that States generally, I think, do a better job than the Federal Government will be able to do in terms of inspecting and regulation of nursing homes. If you have one enormous entity regulating all the nursing homes in the country, I think you are going to have some problems.

Now, you have problems in States. From time to time, there is a big issue in one State where there is an investigation and the people are being treated badly in nursing homes and so forth and so on, but while that is going on in that State, presumably 40 out of the other 50 are doing a very good job.

We do a pretty good job. We make mistakes and so forth. Everybody makes mistakes. But I think having that flexibility of somehow keeping the regulation at the local level and having some partnership aspects, or at the State level, will serve you and serve the Federal Government and, most important of all, of course, serve the patients best.

But the biggest reason for the Medicaid costs being out of control in this population is the institutional bias of the program. The program is biased, heavily biased toward institutional care and it makes it very, very difficult without going through the hoops that are required in the waiver program to get the OK to spend the same amount of money taking care of more people in the area that they want to be taken care of, which is their own home.

Let me just close by thanking you very much for doing this, by saying this is a very difficult area, because when you are talking about long-term care insurance, what you are talking about is not making sure people get adequate health care, you are talking about asset preservation.

We have long-term care insurance in this country. It is called Medicaid. If you go to a nursing home in this country, you do not get kicked out if you suddenly cannot pay the bills. Most States—all States, as far as I know—prevent that from happening. Medic-

aid simply takes over. The issue is, for middle-class people, do you want to force them to impoverish themselves and impoverish their spouse in order to survive in a nursing home?

I am not trying to say we do not need long-term care insurance. We do need long-term care insurance. But I think we have to recognize that this is not an issue like universal health care, where there are 40 million people who do not have it and, therefore, they get bad care because they end up in the emergency room after ignoring a problem for 3 months and it ends up costing the system more money. This is an issue where it is not access, where it is asset preservation. It is an important issue. There is a role for the private sector here. There is a role for the government here and I wish you good luck in sorting it out.

The final word is that I think Senator Rockefeller is absolutely right. This is an issue that somehow has been pushed to the back burner for a long time. It is a major issue confronting this country. It is certainly a major issue confronting the budgets of all of our States, every single one of which is in one form of deficit or another these days. Medicaid is the biggest driver in the State budgets, all 50 of our budgets, and in Medicaid, the biggest drivers are long-term care and pharmaceutical prices.

So I think these hearings have been very timely. I know you have put an enormous amount of effort and time into this and I sincerely hope that you will get a bill that will give the States more flexibility to spend both your money and our money more wisely, cover more people in the circumstances that they want to be covered, and also to be careful when you create a long-term care program that it not have a bias that is contrary to the wishes both of the patients and of those of us who end up budgeting for the care. Thank you.

The CHAIRMAN. Thank you, Governor. As a medical doctor, you certainly bring a unique perspective to this issue.

[The prepared statement of Governor Dean follows:]

Governor Dean's Testimony

Senate Special Committee on Aging

June 20, 2002

Thank you for inviting me today to speak on behalf of the National Governors Association.

As this Committee well knows, the state Medicaid programs bear most costs of long term care for our seniors and adults with disabilities, through nursing home care, Medicaid Waiver programs and various state plan Medicaid services. These costs are increasing dramatically. Our current model of long term care is unsustainable for the future. We must make very significant changes if we are to meet the challenges of the future.

I suggest a new paradigm with two major elements:

First, shift our public policy away from providing institutional care and more towards home based services.

Second, dramatically change the state and federal partnership for long term care and the Medicaid program.

Let me talk about the institutional bias in long term care first. Nursing home care is an entitlement under the Medicaid Program while people who would prefer to be on the Home and Community Based Waiver program must wait, often for a long period of time, on waiting lists. This means that elderly and disabled Americans are entitled to receive the highest cost and least desirable service, yet they must wait in line for the cheaper and more desirable service. There is something very wrong with this picture. Imagine a person with early signs of heart disease. His doctor's first interventions likely will be to recommend changes in diet, exercise, monitoring and perhaps some medication to manage the condition. The doctor is not likely to recommend a quadruple bypass as the first option. Yet, when it comes to long term care, we put the most expensive and least desirable service first.

This calls for a complete paradigm shift. We need to treat nursing homes and other institutional care as the last option, after all other options have been tried and failed. In our current system, expensive nursing home care is often the first option. Experience has shown that we can serve many more people with the same funding, and serve them in the setting they prefer, when we are able to keep them at home and avoid institutional costs.

Perhaps more importantly, we can provide a higher quality of life by avoiding institutional services whenever possible. People who need long term care want it to be provided at home. No one wants to spend their last days or even years surrounded by

strangers, separated from their families and friends, enduring constant changes in staff and regular changes even of the people who share their nursing home room.

The states are showing today that this can be achieved. It is no longer just a dream. Over the past twenty years many new and innovative services have developed around the country. Nationally, nursing home occupancy rates are dropping as consumers are given other options. Consumers are demanding more alternatives and rejecting institutional care. All we have to do is listen to them and follow their lead. If we do, we will have a better system of care and one which provides for more people for the same dollars.

Consumers want more control over their long term care services. They want to be able to direct their own care and hire their own caregivers whenever possible. They want to remain in their communities and participate in community life. Even if they can't remain in their own homes, they want care that resembles the care they would receive at home: caring, individualized and flexible care. The flexibility that consumers want doesn't cost more; in most cases, it actually costs less.

If states are freed from the yoke of paying so much for institutional care, they can dedicate some of the saved dollars to other non-traditional forms of care, and to preventive care. We believe that many people do not receive the care they need until their conditions have worsened to the point that they need institutional care. We believe that if states were given the flexibility to manage long term care differently the states could identify elders and adults with disabilities sooner who, with some support, could prevent more expensive care in the future. We believe we could prevent not only nursing home care but many expensive hospital stays.

All this is doable if we shift the paradigm away from institutional care. Even with the initiatives coming from the administration today which foster choices and alternatives, there will be too little progress until Congress acts to limit the institutional bias and create a level playing field between nursing home care and home based care. We will still need quality nursing home care for the foreseeable future. But we can maintain the necessary level of needed nursing home care while growing home and community based services if Congress will give the states the tools. We do not need more Waivers; we need the authority to cap nursing home expenditures at a reasonable level and re-direct funds to the alternatives that consumers tell us they want.

Some people insist we will need more nursing homes. They are wrong. Baby boomers today are looking for alternatives for their parents. By the time the baby boomers need long term care, and that is 20 to 25 years away, they will expect, even demand other options. We can't afford to protect the status quo. We need to listen to our people and act boldly to develop those services they want and which are more affordable.

That doesn't mean we will not need some quality nursing home care for the foreseeable future. We will and we need to do everything we can to ensure that it is of the

highest quality. However, we need to find the right balance - a balance that does not exist yet.

This will not be an easy transition. There are still significant problems finding enough caregivers and accessible housing. However, many states are developing new approaches to these problems as well. Which brings me to my second major point.

It is time to rethink the federal and state partnership for long term care financing. I propose that the federal government take over the financing of all long term care services. This would work for several reasons.

First, today the federal government funds various long term care and related services through Medicaid, Medicare, the Older Americans Act, the Social Services Block Grant and other funding streams. There are many possibilities for reorganizing the funding for these services into a more comprehensive and flexible program.

Second, the federal government could establish a basic outline, or set or services so that all Americans had similar opportunities to receive the long term care option of their choice. This could be done without sacrificing the flexibility states need to be innovative.

Thirdly, it could create the opportunity to meld Medicare and Medicaid funding for long term care into one program. The current system confuses everyone, from consumers to providers. Given the opportunity, states could manage the funds and services to the so called "dually eligible" population and, in all likelihood, save the federal government money. Or, as I have said, serve more people for the same dollars.

We believe this change could help the states, in partnership with the federal government, manage the costs of long term care while, through flexibility and innovation, shift the paradigm to home and community based services.

In return, the states would accept responsibility for the Medicaid and health insurance costs for other constituents, especially children.

This new partnership would help all parties. Responsibilities would be clear, and not murky and contradictory as they often are today. Savings in a given arena would devolve to the governmental entity responsible for them. Programs and services would be unified and better coordinated.

This new partnership could begin with a new paradigm on long term care. Until and unless we make that change, the costs for long term care will continue to grow and states will be hindered from reigning in costs or improving services by federal law and the inherent institutional bias.

The CHAIRMAN. Next, we will hear from our former colleague, Senator David Durenberger. David.

STATEMENT OF HON. DAVID DURENBERGER, CHAIRMAN, CITIZENS FOR LONG-TERM CARE COALITION, WASHINGTON, DC

Senator DURENBERGER. Good morning. Thank you, Chairman Breaux and members of the committee. Thank you for holding this hearing today, but more importantly, thank you for your continued leadership on long-term care issues. You will eventually be honored for all 13 of those hearings. I greatly enjoyed my years of service on this committee and I am honored to be testifying.

As Chairman of Citizens for Long-Term Care, I have been privileged to represent more than 60 national organizations representing seniors, people with disabilities, long-term care providers, labor unions, insurers, and other professionals. Last year, this diverse group of organizations coalesced behind the development of a national framework for reforming long-term care financing. Among its recommendations was the strong assertion that long-term care is an insurable event, and so it requires an insurance-based solution as opposed to the current welfare-oriented approach.

Today, we are releasing an analysis that provides a new perspective on how policymakers should view long-term care within the context of national entitlement program reform. In short, it concludes that as the nation's population ages, it has become increasingly clear the Nation needs an expanded national financial security policy for access to both health and long-term care just as much as it needs a national energy policy or a national defense policy.

The major findings are: long-term care spending is growing rapidly and the costs threaten Medicaid and family budgets. In 2002, 40 States anticipate budget shortfalls because of growing Medicaid budgets.

Second, Social Security and Medicare reform will be threatened unless long-term care financing is included.

Third, we must develop a national commitment to long-term care financing that includes a limited social insurance cash benefit, generous incentives for private insurance, increased personal savings and some of the tax policy changes that Senator Wyden mentioned, and a Medicare program better designed to treat chronic illness.

Finally, the inclusion of long-term care in Social Security and Medicare reform will increase efficiency, promote family caregiving, increase private resources, lower the cost of care per beneficiary, and better treat chronic illness, among other benefits.

The fiscal challenges Federal and State legislators face with the growing pressures on financing, on workforce issues, and on the care quality have been articulated both by Governor Dean and by the NGA's request for a Commission on Medicaid. Our report makes the case for including long-term care financing reform in the Social Security and Medicare reform dialog over our nation's financial security goal.

In our judgment, the time to begin is now. The chairman referred earlier to how do we deal with spending the surplus. The reality, Mr. Chairman, is it is time to bring 1935 and 1965 programs into the realities of the 21st century. It is that simple.

In the past, when health and income security of our seniors and people with disabilities were threatened, society responded with the development of Social Security in the mid-1930's, and Medicare and Medicaid in the mid-1960's. These programs were designed and built on what we knew in the early and mid-20th century. But by the end of the 1970's, policymakers were well aware of new realities and the need for change in the programs' responsibilities.

In 1982, President Ronald Reagan proposed a new federalism as his effort to clarify inter-governmental responsibility for financial security. The heart of this proposal, endorsed by the National Governors' Association and led by Dick Snelling, would have made the Federal Government responsible for financing supportive services for the elderly and for people with long-term disabilities. State government would have taken responsibility for the financial commitment to non-disabled low-income individuals, those eligible for short-term public assistance, or as we know it, welfare.

In 1990, under the direction of Senator Rockefeller, the Pepper Commission made a recommendation that was much like the CLTC recommendation, that there be an insurance premise under long-term care financing. The need for long-term care would exceed the ability of Medicaid State-Federal financing system to keep pace with demand, and we said in 1990, you have to move to an insurance system.

As a member of the Senate's Committee on Finance, I participated in both of these efforts and I am well aware of the politics of health and financial security. I am convinced that President Reagan and the NGA were right in 1982, that the Democrat and Republican House and Senate leadership on the Pepper Commission were right in 1990. I am convinced the many national long-term care associations who make up CLTC are right today.

The combination of demographics and cost increases that are driving calls for Medicare, Medicaid, and Social Security modernization require we look for new solutions to address the future needs of people with disabilities and our aging population. We cannot expect our elected officials to undertake the bruising political battles associated with Medicare and Social Security reform only to have the same issues again several years later in the form of long-term care financing reform.

If Congress reforms Social Security and Medicare without addressing long-term care financing, they will have missed a unique opportunity to fully address the health and financial security of society's most vulnerable members.

The important analysis that CLTC releases today represents the consensus of nearly every association with a stake in improving access to and the quality of long-term care services and supports in this country. Despite the usual differences between the many associations, they all share the belief that long-term care financing must be reformed before the current situation becomes more critical, and to that end, they recognize they inherent reasonableness and the rationality of integrating this issue with any entitlement reform discussion. We hope the work that CLTC has produced helps generate much-needed interest and understanding in this regard.

I thank you for the opportunity to testify and will be happy to answer any questions.

The CHAIRMAN. Senator Durenberger, thank you very much for your work as well as your testimony. It is very, very critical to finding a solution.

[The prepared statement of Senator Durenberger follows:]

Written Testimony of Hon. David Durenberger,
Chairman of Citizens For Long Term Care

Submitted to the Special Committee on Aging
June 20, 2002

Good morning and thank you Chairman Breaux and Members of the Committee. I greatly enjoyed my years of service on this Committee and I am honored to be asked to testify.

Thank you for holding this hearing today, but more importantly, thank you for your continued leadership on long term care issues. Your attention and that of your colleagues and the staff of the Aging Committee have shown a great dedication to long term care issues. Advocates for those in need throughout the country owe you a great debt.

As Chairman of Citizens for Long Term Care, I have been privileged to represent more than 60 national organizations representing seniors, people with disabilities, long term care providers, labor unions, insurers and other professionals and paraprofessionals. Last year, this diverse group of organizations coalesced behind the development of a national framework for reforming long term care financing. Among its recommendations was the strong assertion that long term care is an insurable event that requires an insurance financing solution as opposed to the current welfare-oriented approach.

New CLTC Analysis on Long Term Care and Medicare and Social Security Reform

Today, we are releasing an analysis that provides a new perspective on how policymakers should view long term care within the context of national entitlement program reform. In short, it concludes that, as this nation's population ages, it has become increasingly clear that the nation needs an expanded national financial security policy for health and income that integrates long term care financing as well.

The fiscal challenges federal and state legislators now face with the growing financial demands, delivery system and personnel challenges inherent in long term care are simply overwhelming. The inevitable aging of the 77 million Baby Boomers makes it critical

that we include long term care financing reform within any national financial security policy debate. Today's report makes the case for including long term care financing reform in the upcoming Social Security and Medicare reform debates, and doing so without delay.

The major findings of the new report include:

- **Long term care spending for Americans is growing rapidly.** In 2000, expenditures on chronically ill Americans of all ages from both public and private sources totaled $137 billion, and represented 11 percent of total U.S. health care expenditures. By 2050, long term care costs for the elderly alone could reach as high as $379 billion.

- **Long term care costs are threatening Medicaid and family budgets.** At an national average cost of over $50,000 per year, and exceeding $100,000 in some communities, for nursing home care, long term care expenditures are literally threatening the fiscal well-being of states. This is caused by afflicted families who are all-too-frequently forced to impoverish themselves in order to get the care they need. In FY 2002, 40 states faced budget shortfalls as a result of rising Medicaid costs, particularly those related to long term care, prescription drugs, and slow economic growth.

- **Long term care financing reform must be integrated into the emerging Social Security and Medicare reform debates.** Without such reform, the expense of long term care can be expected to continue to bankrupt families, drain state budgets, and undermine the success of Medicare and Social Security reform. While addressing long term care may seem to be a daunting task in a time of limited resources, failing to do so will threaten any effort to rationally address the health and financial security of society's most vulnerable members

- **A two-pronged policy approach to addressing the long term care challenge is necessary.** In order to help individuals access the services and care they need, a combination of additional cash benefits provided through social insurance and a refocusing of the Medicare program on chronic illness is necessary. A limited cash benefit would help prevent the permanent impoverishment of people with disabilities that is associated with the current Medicaid system, promote family caregivers while helping to ease the caregiver crisis, and help people to stay in their homes longer. It would also provide a more seamless integration with private insurance while creating efficiencies in the system. A Medicare program that better addresses chronic illness could prevent or delay the onset of conditions that require a more intensive and expensive level of care.

- **Integrating long term care financing into Medicare and Social Security reform can make better use of existing funds.** Coordinating income and health security programs will assure a more efficient use of funds to support families and individuals, encourage family members to serve as caregivers, improve quality and outcomes, and create better utilization of personal resources to ensure that people with disabilities or chronic conditions receive the health and social services that they need. While the growing demand for long term care services will assure that even these financing reforms will not reduce the total dollars spent on long term care, these reforms will ensure a more rational, efficient, and outcomes-oriented system that best serves the needs of people with disabilities of all ages.

History of Retirement Security Teaches Valuable Lessons

In the past when the health and income security of seniors and people with disabilities were threatened society responded with the development of Social Security in the mid-1930s and Medicare and Medicaid in the mid-1960s. However, these programs were designed and built on what we knew in the early and mid-20th century. By the end of the 1970s, policymakers were well aware of the need for change to the programs' responsibilities. As we embark on the early stages of the 21st century, we must acknowledge the growing need to reexamine the responsibilities of our national financial security system.

In 1982, President Ronald Reagan proposed a "New Federalism" as his effort to clarify inter-governmental responsibility for financial security. The heart of his proposal, endorsed by the National Governors Association, would have made the federal government responsible for financing supportive services for the elderly and for people with long term disabilities. State government would take responsibility for the financial commitment for non-disabled, low-income individuals–those eligible for short-term public assistance or welfare.

In 1990, under the direction of Senator Rockefeller the Pepper Commission made a similar recommendation for long term care financing on the premise that Americans' need for long term care was growing to the point where the Medicaid state/federal financing system could not survive very far into the 21st century. It would need to be replaced by an insurance system backed by national policy changes.

As a member of the U.S. Senate's Committee on Finance, I participated in both of these efforts. I am well aware of the politics of health and financial security policy and I am convinced that President Reagan and the National Governors Association were right in 1982, that the Democratic and Republican House and Senate leadership on the Pepper Commission were right in 1990, and that the many national long term care associations who make up CLTC are also right today. America needs to integrate long term care financing into its national financial security policy now and the best way to achieve this is through Social Security and Medicare reform.

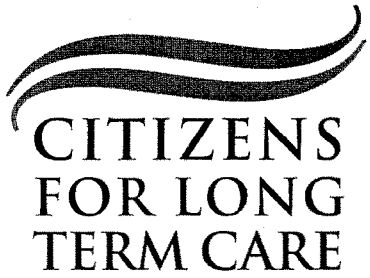
Conclusion

While the usual skeptics will say that politics will not permit the long overdue discussion about long term care within the context of broader entitlement reform, it is important to note that there is a growing consensus amongst a broad array of interests about the need to act. Certainly defining the need for long term care financing reform, the pending crisis, or the common ground on moving from welfare to an insurance system need not involve partisan politics.

As the cornerstone programs for financial security for people with disabilities, the Medicare and Social Security reform debates will address the key issues in long term care financing: health and income security. Considerable resources in Social Security and Medicare are already helping to finance long term care. But 40 percent of the $137 billion spent on long term care annually is still flowing through a broken down federal-state Medicaid financing program, which is faltering miserably. It will sink even further or perhaps entirely under the weight of demographic demands within the next decade if changes are not made.

The combination of demographics and cost increases that are driving calls for Medicare, Medicaid, and Social Security modernization require we look for new solutions to address the future needs of people with disabilities and our aging population. We cannot expect our elected officials to undertake the bruising political battles associated with Medicare and Social Security reform only to have to address the same issues again several years later in the form of long term care financing reform. If Congress reforms Social Security and Medicare without addressing long term care financing, they will have missed a unique opportunity to fully address the health and financial security of society's most vulnerable members.

The important analysis we are releasing today represents the consensus of nearly every association with a stake in improving access to and quality of long term care services and supports in America. Despite the differences between the many associations, they share the belief that long term care financing must be reformed before the current situation becomes even more critical. To that end, they recognize the inherent reasonableness and rationality of integrating this issue within any entitlement reform discussion. We hope the work that CLTC has produced helps generate much needed interest and understanding in this regard. I thank you for the opportunity to testify, and will be happy to answer any questions you may have.



Long Term Care Financing Reform:

An Integral Part of Social Security and Medicare Reform

Citizens For Long Term Care

June 2002

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Citizens For Long Term Care
Washington, D.C.

Citizens For Long Term Care is a nonprofit coalition of long term care providers, consumer and patient advocates, insurers, workers and advocates for people with disabilities who seek to inform and educate policymakers about the need for long term care financing reform.

Chairman's Letter

In February 2001 Citizens For Long Term Care (CLTC) released a document entitled *Defining Common Ground: Long Term Care Financing Reform in 2001*. The paper represented a collaborative effort by the most influential stakeholders in the long term care financing and delivery debate. National representatives of consumers (seniors and people of all ages with disabilities), for and nonprofit providers, labor unions, insurers, professionals and others coalesced around the development of a national framework for long term care financing reform. Among its many recommendations was the strong assertion that the need for long term care is an insurable event that requires and insurance based financing system as opposed to the current welfare based solution.

In this current paper, CLTC undertook a similar collaborative process with its leading members to develop a perspective that suggests a new way to think about national entitlement program reform. Our nation needs a national financial security policy that addresses current realities as much as it needs a national energy policy or national defense and security policy that respond to current challenges. The fiscal challenges legislators currently face at the national and state level demonstrate why we must develop a new national financial security policy. More importantly, the inevitable aging of the 77 million Baby Boomers makes it critical that we include long term care financing reform in our national financial security policy now. This paper makes the case for long term care financing reform's inclusion in the Social Security and Medicare reform debates.

Our history demonstrates how we have approached similar national financial security crises in times past. The development of Social Security in the mid-1930's and Medicare and Medicaid in the mid-1960's are the results. But these programs were designed and built on what we knew in the early and mid-20th century. By the end of the 1970's policy-makers were well aware of the need for change to the programs' responsibilities. As we embark on the early stages of the 21st century we must acknowledge the growing need to reexamine the responsibilities of our national financial security system.

In 1982, President Ronald Reagan proposed a "New Federalism" as his effort to clarify inter-governmental responsibility for financial security. The heart of his proposal, endorsed by the National Governors Association, would have made the federal government responsible for financing supportive services for the elderly and for people with long term disabilities. State government would take responsibility for financial commitment for non-disabled, low-income individuals–those eligible for short term public assistance or welfare.

In 1990, the Pepper Commission made a similar recommendation for long term care financing on the premise that Americans' need for long term care was growing to the point where a state/federal (Medicaid) financing system could not survive very far into

the 21st century. It would need to be replaced by an insurance system supported by national policy changes.

As a member of the U.S. Senate's Committee on Finance, I participated in both of these efforts. I am well aware of the politics of health and financial security policy and I am convinced that President Reagan and the National Governors Association were right in 1982, and that the Democratic and Republican House and Senate leadership on the Pepper Commission were right in 1990, and that the many national long term care associations who make up CLTC are also right today. America needs to integrate long term care into a national financial security policy now and the only way to achieve this is through Social Security and Medicare reform.

Skeptics say politics won't permit it. But, there are no partisan politics to long term care financing reform. There are no politics to defining the need, the pending crisis, or the common ground on moving from welfare to an insurance system. This paper demonstrates that considerable resources in Social Security and Medicare are already helping to finance long term care and support Medicaid. But 40 percent of the $137 billion spent on long term care annually is still flowing through a broken down federal-state Medicaid financing program, which is faltering miserably today. It will sink even further or perhaps entirely under the weight of demographic demand within the next decade if changes are not made. If Congress reforms Social Security and Medicare without addressing long term care financing, they will have missed a unique opportunity to fully address the health and financial security of society's most vulnerable members.

This paper represents the consensus of nearly every association with a stake in improving access to and the quality of long term care services and supports in America. Despite the differences between the many associations, they share the belief that long term care financing must be reformed before the current situation grows even more critical. To that end, they recognize the inherent reasonableness and rationality of integrating this issue within any entitlement reform discussion. We hope this important paper generates much need interest and understanding in this regard.

Sincerely,

David F. Durenberger (R-MN 1978-1995)
Chairman

Executive Summary

The states' Medicaid crises demand we begin to change the way America finances long term care. Long term care advocates have cited the aging of the nation's 77 million Baby Boomers and their projected need for care and services as impetus for beginning financing reform prior to the Boomers' retirement. However, the recent explosion of long term care costs combined with a slow economic growth are fueling budget shortfalls in 40 states suggests that long term care financing reform is needed now. As a potentially bankrupting expense for individuals and families and a key cost driver in state Medicaid budgets, long term care has shown itself to be a legitimate threat to financial and economic security that must be addressed sooner rather than later.

To begin the process of long term care financing reform, policy makers must integrate finance reform into the emerging Social Security and Medicare reform debates. While addressing long term care may seem to be a daunting task in a debate over limited resources, failing to do so will threaten the success of any effort to address the health and financial security of society's most vulnerable members. In the 1930's and again in the 1960's the federal government faced similar crises and enacted social insurance programs to help people maintain health and economic security after retirement or disability.

In addition, the federal government has developed a complementary publicly supported private national financial security system designed to help people develop and maintain financial security in their working years. Among its many components are programs such as tax deferred IRAs, 401(k)s, home mortgage interest deductions, and tax incentives for employers to offer health insurance. Together these incentives for private mechanisms, combined with Social Security and Medicare, form a national financial security system designed to help people avoid impoverishment. **Unfortunately, long term care has never been integrated into this system.**

What has developed to help families deal with the burdens of long term care is a patchwork of services and programs derived from a variety of sources which helps people until they impoverish themselves and qualify for Medicaid. A joint federal-state program, **Medicaid is the single largest payer of long term care services, financing nearly 40% of all long term care and over 60% of all institutional long term care.** State financing of long term care not only creates a fiscal challenge for the states, because each one has a different tax capacity, but it also makes it more difficult for people and families in need of care to find, coordinate, and pay for services because of the differences between state programs. Moving away from Medicaid-based financing and instead addressing long term care financing in the context of entitlement reform could ease some of the consequences of the demographic bulge on state spending and provide consistency in the financing of long term care services.

Rethinking long term care financing and services in the context of Social Security and Medicare reform would enhance individual and family choice, provide the opportunity to better coordinate existing programs, increase treatment of chronic illnesses, support family caregivers, and enhance the use of personal resources and private long term care insurance. Financing reform would substantially improve the ability of persons with disabilities –whether caused by age, accident, illness or developmental disability – to access care that can fit their evolving needs over the course of a lifetime. In order to help people with different kinds of disabilities access the services and care they need, a combination of additional cash benefits provided through social insurance and a refocusing of the Medicare program on chronic illness is necessary. A limited cash benefit provided through social insurance will help people in need support family caregivers, coordinate increased personal resources and private insurance, and access appropriate housing. A Medicare program that better addresses chronic illness could prevent or delay complications which require a more intensive and expensive level of care.

Since the demand for long-term care services is expected to increase significantly in coming decades, these financing reforms will not reduce the total dollars spent on long-term care in the future. However, the current patchwork system of long-term care financing creates confusion, does not support family caregivers, generates overlaps and inconsistencies in service delivery, and it does not work well with private resources. All of which waste funds already appropriated for care. By coordinating these programs and integrating long-term care financing into Medicare and Social Security reform, we can make better use of existing funds to support families and individuals, encourage family caregivers, increase choices, quality and outcomes, improve utilization of personal resources to ensure that people with disabilities or chronic conditions receive the health and social services that they need in order to life with dignity.

Long Term Care Financing: An Integral Part of Social Security and Medicare Reform

The approaching retirement of the "Baby Boom" generation will cause rapid growth of the population entitled to Social Security and Medicare benefits without providing a corresponding increase in dedicated revenues. This projected fiscal imbalance has compelled the United States Congress and other policy makers to review and propose modifications to the Social Security and Medicare programs. Entitlement reforms of this magnitude cannot succeed without alleviating one of the most significant threats to the financial security of seniors, persons with disabilities, and their families – the high cost of long term care.

In 2000, long term care spending for people of all ages totaled $137 billion from all public and private sources and represented 11 percent of total U.S. health expenditures for that year.[1] Studies show that the risk of needing long term care is real. At age 65 the risk of needing any nursing home care is 39%.[2] For people age 25 and older, studies (based on people who died in 1985 and 1986) have shown that 27% resided in a nursing home at some point in their lives with 16% of those who entered a nursing home having spent five or more years in a facility.[3] At an average cost of $50,000 per year for nursing home care, $22,000 per year for assisted living services,[4] and $84,000 per year for care in an intermediate care facility for persons with mental retardation and related conditions,[5] families are already struggling to pay for care. State budgets are currently stretched to their limits, in fiscal year 2002 40 states faced budget shortfalls as a result of rising Medicaid costs and slow economic growth.[6] These problems will only be exacerbated in the future when long term care costs for the elderly alone could reach as high as $379 billion by 2050.[7] If long term care is not addressed as part of the expected entitlement reforms, the cost of caring for the elderly and people with disabilities through the current

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[1] Centers for Medicare and Medicaid Services, *2000 National Health Expenditures*. Washington, D.C.: 2002

[2] Mutaugh, Kemper, Spillman, and Carson, "The Amount, Distribution, and Timing of Lifetime Nursing Home Use," *Medical Care*, 35(3): 204 (1997)

[3] L. Alecxih, "What is it, who needs it, and who provides it?" *Long Term Care: Know the Risk*, Boyd (ed.), Health Insurance Association of America, Washington, DC, 1997, p.1-17

[4] LifeCare, Inc., *"Who Buys Long-Term Care Insurance in 2000? A Decade Study of Buyers and Nonbuyers,"* Health Insurance Association of America (HIAA), October 2000; citing AARP and ALFA reports.

[5] R. Prouty, G.Smith, and K. Lakin. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Research and Training Center on Community Living Institute on Community Integration; University of Michigan, June 2001

[6] National Association of State Budget Officers and National Governors Association. *The Fiscal Survey of States*. Washington, DC, May 2002, p.IX

[7] David Walker, Comptroller General of the United States. *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*. Testimony before the U.S. Senate Committee on Aging, March 21, 2002.

system will continue to bankrupt families, drain state budgets and undercut the success of Medicare and Social Security.

Despite these daunting statistics, policymakers should not avoid addressing long term care financing for fear that the needs are too great to be addressed in the context of a debate over limited resources. Historical precedent shows that timely government intervention may avert large-scale fiscal crises and create lasting social benefits. For example, in the 1930's President Roosevelt proposed Social Security in the face of projections that within a few decades more than half and as many as three-quarters of older Americans would rely upon state public assistance programs for their income.[8] A generalized work-based contribution program was designed to provide income support before citizens spent down their resources into poverty, thereby alleviating the burden on the working children of seniors and preventing an explosion in state welfare costs. Similarly, in the 1960's Medicare was designed to offer older people health care coverage in the face of rapidly increasing medical costs. Today, we face yet another challenge to the needs of elderly and people with disabilities. By 2040, the number of older Americans, not including people with disabilities, needing long term care is expected to double, further straining an already overburdened system. If we address the long term care crisis now, as part of entitlement reform, we may be able to mitigate the threat to the financial security of our most vulnerable populations.

Rethinking long term care financing and services in the context of Social Security and Medicare reform would provide the opportunity to make better use of existing resources and restructure core programs. Any solution to the long term crisis will have to coordinate and reform the way long term care services are delivered. The best way to begin this process is to examine how long term care can be better integrated into the debate about Medicare and Social Security reform. These federal programs are intimately connected to long term care because while Medicare addresses medical needs and Social Security addresses financial needs, long term care services include both the medical and financial aspects of caring for the elderly and people with disabilities. In particular, long term care often involves the need for medical care for chronic illnesses, and the need for sufficient income to obtain supportive services.

In considering how to address the long term care crisis, policymakers must also bear in mind that the population of persons requiring long term care services is incredibly diverse – ranging from small children and adults born with disabilities to young adults with mental or physical impairments to frail elders. Social insurance programs that provide income and health security only for people in retirement will fail to meet the needs of older Americans with severe disabilities and functional limitations. Because no one set of long term care solutions can be appropriate for every American with a disability, efforts to reform Social Security and Medicare must be as flexible as possible to support individuals of all ages and their families and communities.

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[8]U.S. Senate, Committee on Finance, Report to Accompany H.R. 7260, 74th Congress, 1st Session, Report No. 628, May 13, 1935

Persons with disabilities, caused by developmental disability, age, chronic illness or accident need the flexibility of care that can fit their evolving needs, and the predictability of access to a range of services and supports over a lifetime. Disability income programs (primarily Social Security Disability Insurance) that are tied to labor force participation and prior work history fail to address the needs of people whose disabilities have kept them out of the workforce. As a result, individuals with lifelong disability and others whose disabilities do not fit work-based criteria must often rely on public assistance, Medicaid and other means-tested programs. Income security programs for people with disabilities should base benefits on the degree of their functional incapacity rather than their work history.

Compared to previous generations, families today benefit from a well-developed financial security system that has been designed to help people develop and maintain economic security. If these existing resources can be better coordinated, an expansion of either Medicare or Social Security to cover long term care can be more limited. Because disability is a truly insurable event (meaning that the risks of having a disability needing extended long term care are relatively low, but the financial consequences are not), we must explore ways to better combine publicly supported programs which help develop and maintain personal financial security (such as tax-advantaged retirement accounts, savings, and home equity created through home mortgage deductions) with the continued development and maturation of long term care insurance as a viable long term care financing mechanism. The best approaches to accomplishing this goal and solving the long term care financing crisis will find a way to integrate these private funds with Social Security and Medicare, the two programs, which provide the bedrock of financial security for seniors and people with disabilities. To begin this process, policy makers must integrate long term care financing reform into the Medicare and Social Security reform debates.

The Financial Burden of Long Term Care on Families and Individuals

Long-term care financing has never been integrated into our national retirement and disability security system. Instead, states have financed long term care as a public assistance program that provides support for seniors and people with disabilities only after they have impoverished themselves by spending down their income and assets. Long-term care recipients and their families must work with separately administered – and rarely coordinated – federal, state, and local programs in order to piece together the services they need.[9] The programs that provide the bulk of assistance for long term care are:

> Medicaid: provides funding for nursing homes services, home health care, personal care services, and adult day care to qualifying low income individuals. It

[9] J. Tilly, S. Goldenson, and J. Kasten, *Long Term Care: Consumers, Providers, and Financing. A Chart Book*, Urban Institute: Washington, DC, March 2001, p.33.

is the single largest payer of long term care. Medicaid waivers permit Medicaid funds to be used for a wide variety of non-medical and home and community-based services.

Medicare: provides funding for short stays in a skilled nursing facility (such as a nursing home) after a hospitalization, as well as for a limited amount of home care, to eligible adults 65 and older. Younger individuals who have been disabled (under a restrictive definition) for at least two years may also receive Medicare funds.

Supplemental Security Income (SSI): provides cash assistance to low-income elderly individuals and couples, and children and adults with disabilities.

Social Services Block Grant (SSBG): provides funding for a variety of long term care and community-based services including homemaker services, assessment and case management, transportation and nutritional assistance. While these funds do not have to be used solely for low-income or elderly persons, most are directed toward these individuals. SSBG funds are also distributed to children's programs, as well as to persons with disabilities and older and low income persons.

Older Americans Act of 1965: finances a variety of services for the elderly. States can use these funds to provide supportive services, senior centers, in-home services and nutrition services. The Older Americans Act also funds long term care ombudsman services.

Rehabilitation Act of 1973: provides vocational rehabilitation, employment, training, education and independent living services for adults with physical or mental impairments that prevent them from becoming employed.

The Department of Housing and Urban Development (HUD): HUD and the Rural Housing Service at the Department of Agriculture have funded over 1.6 million units of housing for older persons with low incomes and younger persons with disabilities through various programs including Section 8, 202, and 811. The Low Income Housing Tax Credit program continues to finance the construction of housing for older persons and persons with disabilities. The small Congregate Housing Services Program (CHSP), established in 1978, has been an important model for federal and state efforts to provide supportive services in housing settings. New HUD efforts include funding for the conversion of units in elderly housing projects to assisted living and service coordinators to address the need for services and the role of housing in long term care.

Department of Veterans Affairs: provides low-income veterans and those with service-connected disabilities a variety of medical, institutional, residential, and support services.

Despite the number, cost, and variety of these programs – all of which are intended to provide assistance with long term care costs – individuals and their families still pay out-of-pocket for nearly one-third of long term care expenses.[10] The costs are substantial and constitute the single largest health related expense for seniors and their families as a group. The average annual cost of a stay in a nursing home is roughly $50,000 per year, assisted living services averages $22,000 per year, home care costs approximately $15,000 per year, and an intermediate care facility for a persons with mental retardation and related conditions costs approximately $84,000 per year. In addition to these direct costs, families often bear the indirect costs associated with serving as family caregivers. Unpaid caregiving, which is typically provided by friends and families, is valued by the Department of Health and Human Services at $45 billion to $94 billion per year.[11]

The average senior cannot afford these costs over an extended period of time. In a study prepared for the U.S. Department of Health and Human Services (HHS) in 1994,[12] Lewin/ICF estimated that more than half of elderly couples, and 60 percent of elderly singles, did not have assets to pay out of pocket for a one-year stay in a nursing home. Only three percent of elderly couples could pay for this stay out of their combined income without using any financial assets. Only 16 percent could afford to pay for a one-year stay without depleting more than 50 percent of their assets. For one half of couples, a one-year stay would reduce their financial assets by 50 percent and leave a reduced level of income protection for the spouse. For 60 percent of elderly singles (83 percent of disabled elderly singles), a one-year stay would leave them with no remaining financial assets. These statistics support the finding that, while spend down rates vary by state, on average, 47 percent of residents on Medicaid began their stay as a private pay patients.[13]

A recent Milbank Fund-EBRI study found that a large portion of the baby boom cohort is not adequately prepared to pay for long term care costs in retirement.[14] The study projected future retirement income based on current asset accumulation of various age cohorts and matched this figure to predicted costs of living, with variations in the use of long term care services. Families were found to be better prepared generally than single men and women. If current Social Security benefits remain intact, 100 percent of families and 100 percent of single men in the three baby boom birth cohorts (1946 to 1950, 1951 to 1955, and 1956 to 1960) would have sufficient retirement income to cover basic expenses in retirement. Only about 75 percent of single women would have sufficient income to meet basic expenses. Preparedness deteriorated substantially, however, when

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[10] J. Tilly, et al,. p. 35.

[11] Department of Health and Human Services, "*Informal Caregiving: Compassion in Action*," Washington, D.C., June 1998.

[12] L. Alecxih and D. Kennell, *"The Economic Impact of Long-Term Care on Individuals,"* Report Prepared for the U.S. Department of Health and Human Services, October 1994.

[13] Weiner, Sullivan and Skaggs, "Spending Down to Medicaid: New Data on the Role of Medicaid in Paying for Nursing Home Care." AARP, 1996

[14] J.L. VanDerhei and C. Copeland, *"Oregon Future Retirement Income Assessment Project: Final Report,"* Unpublished paper for a project of the EBRI Education and Research Fund and the Milbank Memorial Fund, September 7, 2001.

long term care costs were added. Only about half of single women and 90 percent of single men were predicted to have sufficient resources to meet basic expenses and pay the average cost of any home health care. Only about one-third of single women, 85 percent of single men, and 95 percent of families were expected to have sufficient resources to cover basic expenses and more than 121 days of home health care. Although the authors of the study did not calculate the impact of needing facility based care, at an average national cost of greater than twice that of home care, facility based care would significantly increase the financial impact of long term care.

An even greater threat to retirement security is realized when various options for modifying Social Security to restore solvency are considered, combined with a reduction in the preparedness of the baby boom cohort for retirement, and looming long term care costs are acknowledged as a distinct possibility. Adding 121 days of home health care in the context of reduced Social Security benefits lowers the percentage of singles and married couples with sufficient retirement income to meet their needs. Only about one-quarter of single women, about half of single men, and a little over 90 percent of families would have sufficient resources to meet their needs. Under this scenario for Oregon alone, single males in the 1961 to 1965 birth cohort would need an additional $782 million and single females an additional $1.7 billion to meet their basic and long term care needs.

The Financial Burden of Long Term Care on States

Under the current system, states bear the principal burden for paying long term care costs through Medicaid and related public assistance programs as a result of people "spending down" their assets until they qualify for Medicaid. A joint federal-state program, Medicaid is the single largest purchaser of nursing home and other long term care services.[15] Two out of every five dollars spent for long term care services comes from Medicaid – almost half of national nursing home expenditures and a sixth of home health spending.[16] As the population ages, increased demand for long term care services will further elevate Medicaid costs. Currently, nearly two-fifths of Medicaid costs are for long term care, and Medicaid accounts for 20 percent of state budgets. In the future, Medicaid will consume ever-larger portions of state budgets as Medicaid spending increases at nearly double the rate of spending on other state responsibilities,[17] outstripping relatively weak state revenue growth.[18] While Medicaid spending grew at the relatively modest average annual rate of 5.5 percent between fiscal years 1996 and 1999, it grew by 9 percent in fiscal year 2000 and by an estimated 11 percent in fiscal year 2001. Over the next several years Medicaid is anticipated to grow between 8-9% annually.[19]

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[15] "*The Role of Medicaid in State Budgets*," The Henry J. Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured, October 2001, p. 1.

[16] J. Tilly, S. Goldenson and J. Kasten, *Long-Term Care: Consumers, Providers, and Financing. A Chart Book,* Urban Institute, March 2001, p. 35-37.

[17] National Association of State Budget Officers. *The Fiscal Survey of the States, June 2001*. pp. 12-21.

[18] Kaiser Family Foundation, p. 4.

[19] Kaiser Family Foundation, p. 1.

A recent analysis of the federal portion of Medicaid spending projections by the Congressional Budget Office concluded that the increased cost of caring for elderly and people with disabilities was the single largest factor behind the $12.4 billion increase in federal Medicaid spending between 2000 and 2001.[20] Abt Associates projects that the share of the economy dedicated to Medicaid spending will expand by 60 percent by 2050 (from less than 2 percent to three percent of gross domestic product (GDP)). At the same time, Abt projects that the share of the economy dedicated to overall government spending on long term care will double (from 0.9 percent to 1.7 percent of GDP).[21]

Attempts to reduce the cost of long term care at the state level have had mixed results. In an effort to give states greater flexibility in spending their Medicaid dollars, a federal waiver program was created to allow use of Medicaid funds for supports and services in home and community settings. Since Medicaid funds for long term care are usually restricted to payment of facilities, the waivers are expected to reduce costs by allowing individuals to be receive supports and services in less costly settings. States are currently operating about 261 different home and community-based waivers that serve more than one million individuals at a federal cost of approximately $7 billion – accounting for one quarter of total state Medicaid long term care expenditures. While the waivers provide much needed flexibility in the use of Medicaid funds, each state has designed their waivers differently causing further disjunction between each state's programs. In addition, the waivers are time limited, requiring states to periodically re-apply for waivers in order to continue the programs and creating further complexity in the patchwork system of services and financing.

State financing of long term care creates not only a fiscal challenge for the states, but also needless complexity for Americans with disabilities and their families. There is tremendous variation in the eligibility, benefits, and requirements of long term care services between different states. This patchwork system for financing complicates decisions by vulnerable individuals and their families and discourages personal planning for private financing or insurance. It also results in inconsistencies and redundancies in coverage that waste public resources and leave individuals without adequate protection

De-emphasizing Medicaid-based financing and instead addressing long term care financing in the context of entitlement reform could mitigate some of the consequences of the demographic bulge for state public assistance spending. Such an approach could also provide much needed consistency in national financing for long term care services. Appropriate financing for long term care is not likely to reduce total government long term care spending because larger numbers of people are expected to need coverage in the future. However, creative solutions to long term care financing and delivery in the context of entitlement reform could alleviate the burden on families and states while

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[20] Kaiser Family Foundation, p. 7.

[21] S.D. Pizer, A.R. Frakt, and F.H. Decker, *"Financing Long-Term Care for the Baby Boom Generation,"* Unpublished paper prepared for the American Health Care Association, May 17, 2001.

preserving the value of Social Security and Medicare benefits for individuals who are 65 or older or for people with disabilities.

Program Costs Are Driving Social Security and Medicare Reform

Entitlement programs provide income, insurance, or in-kind assistance to individuals based on certain eligibility criteria. The costs of these programs are driven by the number of people who are eligible. Federal spending on these programs is automatic – meaning that it does not require a congressional appropriation. Modifying benefit levels or eligibility criteria are the only way to control costs. Entitlements include both direct spending programs – social insurance that has universal eligibility and public assistance that is means-tested – and "tax expenditures" that provide subsidies for specific social policy purposes through tax exclusions or tax credits. Since both Medicare and Social Security are entitlement programs that address the health and income security of the elderly and people with disabilities, the debate over modifying benefit levels or benefit criteria further complicates the question of how to best deliver and finance long term care services, which are Medicaid entitlement only after impoverishment.

The Social Security Trustees predict that, with no changes in taxes or benefits, the program will need to rely on earned interest as the program begins running cash deficits in 2017, growing to more than $120 billion a year (in today's dollars) by 2022, and nearly $300 billion a year by 2031, and increasing the public debt by nearly $367 billion by 2040.[22] Medicare imbalances are expected to be as significant. The Trustees estimate that by 2027 Medicare will have an annual shortfall between benefits paid and tax and premium revenues of nearly $150 billion in today's dollars.[23]

OPPORTUNITIES IN REFORM

There are a wide variety of options for restoring fiscal balance in the Social Security and Medicare. For example, more effective management of chronic disease (which now accounts for 80 percent of Medicare costs) could help reduce expenditures. Greater efficiencies in health care treatment, service delivery, insurance administration, elimination of fraud and abuse, and adoption of models which integrate social insurance with private long term care insurance may have the potential of reducing costs. In addition to potentially reducing expenses, entitlement reform could also provide opportunities for better integrating long term care services for seniors and individuals with disabilities. Integration of care could eliminate duplication, gaps and other inefficiencies in services for frail or disabled individuals and families. It also has the

[22] The 2002 Annual Report of the Board of Trustees of the Old Age and Survivors Insurance and Disability Insurance Trust Funds. March 26, 2002. Supplemental Tables, TableVI.E.8.

[23] The 2002 Annual Report of the Board of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds. March 26, 2002. Table II.A.5. The shortfall is estimated to be 0.8 percent of GDP, which is equal to $141 billion in constant dollars, based on Social Security Administration projections.

ability to reduce costly institutionalization while potentially reducing the cost of care per beneficiary.

Dual Eligibles

A good example of our current patchwork system is the situation faced by "dual eligibles," the estimated five million elderly and people with disabilities who receive health coverage from both Medicare and Medicaid.

A high proportion of dual eligibles have both chronic illnesses and functional disabilities, which are treated by both the Medicare and Medicaid programs. The federally administered and financed Medicare program provides acute care for "spells of illness," while the primarily state-administered and partly state-financed Medicaid program provides long term care for the functional disability. Neither Medicare nor Medicaid takes responsibility for the entire system of care for dually eligible recipients. In addition, both programs are built around short-term interventions, with Medicare limiting the duration of services and Medicaid limiting eligibility.[24] The design of these programs has made it particularly difficult to create a comprehensive and continuous package of services for dually-eligible beneficiaries. Many factors, including inconsistencies, overlapping requirements, administrative complexities, and cost shifting from Medicaid to Medicare have been estimated in one study to raise the costs of Medicare care services for dually eligible beneficiaries by 45 percent.[25]

Integration of Medicare and Medicaid financing could enable dually eligible individuals and their care providers to manage chronic conditions more effectively, thereby avoiding delay or duplication of services. In an ideal system, eligibility would be based on functional needs and resources would follow the beneficiary through a variety of therapies and settings. Such a system would allow individuals, their advocates, or care professionals more choice and flexibility in selecting the most appropriate services and settings.

Several groups have already developed successful models for the integration of financing and services for dual eligible populations. Within these pilot programs, services are organized around specific patient needs rather than around settings. Providers have the flexibility to develop a mix of benefits rarely available under traditional insurance and to organize teams of caregivers which can address the full array of patient needs. Some of these initiatives include the Program of All-Inclusive Care for the Elderly (PACE), Evercare, and the Community Medical Alliance (CMA). These models, though not yet widely replicated, could provide the outlines for broader Medicare and Medicaid reforms. So far, these initiatives have been successful in reducing hospital use and expenditures

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[24] B.C. Vladeck, "You Can't Get There from Here: Obstacles to Improving Care of the Chronically Ill," *Health Affairs*, November-December 2001.

[25] K. Liu, S.K. Long, C. Aragon, "Does Health Status Explain Higher Medicare Costs of Medicaid Enrollees?" *Health Care Financing Review*, v. 20, no. 2, 1998.

and in redirecting Medicare and Medicaid spending from hospitals and nursing facilities to primary care and community-based long term care and medical services.[26]

Successful integration of Medicare and Medicaid financing and services could eliminate gaps or duplication in services and provide more tailored services for vulnerable individuals and their families. However, greater efficiency in these programs does not necessarily mean reduced healthcare expenditures. Short-term program savings from these efficiencies may be offset in the long run by a greater demand for services that better meet patient needs and by the provision of a higher level of appropriate care. Integration can greatly enhance quality and improve outcomes for individuals who need services, but whether it can yield financial savings for Medicare and Medicaid is unknown.

Home and Community-Based Care

Home and community-based care is an important and growing segment of long term care. Eighty percent of the elderly who are believed to need assistance with daily living are at home or in community-based settings; an estimated 60 percent of this population relies exclusively on unpaid caregivers.[27] Most individuals with disabilities living in the community also rely on their families and other unpaid sources for their care. Even with increased public and private financing for long term care, families will continue to play a major role in meeting and supporting the long term care needs of people who are elderly or have disabilities. While these individuals generally prefer home or community care to the restrictions of nursing home care, coordinating financing and delivery of services in these settings can be difficult.

In order to facilitate the increased use of home and community-based care, a federal-state waiver program was launched in 1981 to allow states to use Medicaid funds to pay for these services. Medicaid Home and Community-Based Services (HCBS) waivers (under Section 1915(c)) were initially intended to slow the growth of Medicaid spending by providing services to individuals in less expensive home or community settings who would otherwise be placed in institutions.[28]

The HCBS waiver program has grown substantially over the last twenty years. Total waiver expenditures rose from $290 million in 1985 to nearly $18.2 billion in 2000,[29] accounting for nearly 27 percent of Medicaid long term care expenditures for that year.[30]

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[26] R.J. Master and C. Eng, "Integrating Acute and Long-Term Care for High-Cost Populations," *Health Affairs*, November-December 2001.
[27] K.G. Allen. *Long-Term Care: Implications of Supreme Court's Olmstead Decision Are Still Unfolding.* Testimony before the Special Committee on Aging, United States Senate. September 24, 2001.
[28] S. Lutzky, L. Alexcih, J. Duffy and C. Neill, *"Review of the Medicaid 1915(c) Home and Community Based Services Waiver Program Literature and Program Data: Final Report,"* Prepared for Department of Health and Human Services, Health Care Financing Administration, The Lewin Group, June 15, 2000.
[29] S. Lutzky, et al; p. 8 and K.G. Allen; p. 12, Figure 3.
[30] K.G. Allen; p. 12, Figure 3.

The greatest increase in the HCBS waiver population has been among recipients of mental retardation/developmental disabilities (MR/DD) services. The MR/DD population receiving waivers nearly quadrupled (from 58,000 to 216,000) between 1992 and 1997.[31] It is significant that 222% more people with mental retardation and developmental disabilities (based on 1999 numbers) receive HCBS than the numbers who live in intermediate care facilities for mental retardation (ICF-MRs)[32]. As of 1998, nearly three-quarters of all public spending on MR/DD services was for home and community-based services.[33] Currently, 261 HCBS waivers are in effect around the nation, and every State (except Arizona) had at least one waiver for the mental retardation/developmental disabilities (MR/DD) population and one waiver for seniors or the non-aged disabled population.[34]

The success of the HCBS waiver program is difficult to assess. On the positive side, states appreciate the flexibility in allocating their Medicaid funds and where available consumers value having more control over their own lives. A growing body of research suggests that younger individuals, and individuals with fewer cognitive impairments, strongly prefer to make their own decisions about the care they receive.[35] However, the HCBS waiver program also faces a number of challenges, such as coordinating services effectively and monitoring service quality. In addition, the program has not been shown to reduce Medicaid costs. Home and community-based services can reduce the cost per beneficiary, but the increased utilization by substantially more people can result in greater overall program costs.

The movement toward home and community-based services is likely to accelerate as states begin to implement their responses to the 1999 Supreme Court decision in *Olmstead v. L.C.* 19 S. Ct. 2188 (1999). The *Olmstead* decision prohibits states from placing persons with disabilities in inappropriate institutional placements, asserting that, under the Americans with Disabilities Act (ADA), continued unjustified institutionalization is a violation of an individual's right to live in the most integrated setting appropriate to his other needs. The decision provides a legal framework for efforts to enable individuals with disabilities to receive services in the community. However, certain conditions must be met before states are required to provide community-based treatment for persons with disabilities. According to the ruling, the transfer must be determined as appropriate by the state's treatment professionals, accepted by the affected individual, and be able to be "reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

Since the *Olmstead* decision, 40 states have created task forces, commissions, or agency workgroups to assess their long term care systems, and 18 of these groups have issued

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[31] S. Lutzky, et. al.,

[32] R. Prouty, G.Smith, and K. Lakin: p.xii

[33] J. Tilly, et al, p. 44.

[34] Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services. "Home and Community-Based Services 1915(c) Waivers." www.hcfa.gov/medicaid/hpg4.htm.

[35] S. Lutzky, et al, p. 24.

plans or papers. State efforts are still in progress, but experts anticipate that states will shift a significantly larger portion of their resources into home and community-based services, including housing, transportation, and expansion of Section 1915(c) waivers, education, outreach, and transition assistance.[36]

On the federal level, the Bush Administration launched in February 2001 its "New Freedom Initiative" aimed at removing barriers to community living for persons with disabilities. As part of this initiative, the President issued an executive order directing the federal agencies to assist states and localities in quickly implementing the *Olmstead* decision and reviewing the barriers to community integration for Americans with disabilities Americans. The Initiative includes a task force to improve Medicaid's support for community services, a new HHS office on Disability and Community Integration to coordinate programs within HHS, and a program of grants to support community integration for people with disabilities.[37] The combination of the "New Freedom Initiative" and the *Olmstead* decision should have a significant effect in shifting resources from institutional settings to home and community-based care, and in improving the flexibility of services and resources in meeting the needs of people with disabilities and their families.

Developing the Resources to Implement Reform

To achieve the goals of the New Freedom Initiative, the *Olmstead* decision, and other reform efforts, existing state and federal health and social service programs should be expanded and redesigned to better coordinate acute and chronic care and to ensure financing for a range of services and supports, ranging from low levels of personal services to intensive medical and skilled nursing care. Funding for the social services and varying levels of personal care necessary to support these new initiatives is already largely available through a patchwork of specialty aging and disability programs. However, it could be more effectively distributed through more flexible funding mechanisms, including additional income support designed specifically for persons with disabilities and functional limitations. A combination of additional cash benefits provided through social insurance, increased resources to support informal caregivers, higher personal savings rates, private long term care insurance and the availability of affordable and accessible housing combined with a Medicare program that better manages chronic illness are the keys to helping families and persons with disabilities and chronic conditions finance long term care services.

A. Medicare Focused on Chronic Illness

[36] W. Fox-Grage, D. Folkemer, T. Straw, and A. Hansen. *The State's Response to the Olmstead Decision: A Work In Progress*. National Conference of State Legislatures (NCSL), Forum for State Health Policy Leadership. December 2001.

[37] The Executive Office of the President. *Fulfilling America's Promise to Americans with Disabilities*. www.whitehouse.gov/news/freedominitiative/freedominitiative.html.

When Medicare was designed in the early to mid 1960's, it was supposed to help the elderly obtain access to the same level of medical care that was available to younger workers with health insurance. At the time, medical care focused on medicine's growing ability to cure acute illnesses, not chronic or long term care. Chronic and long term care were mostly custodial and undertaken by family and friends or in extreme cases by institutions funded by state and local funds. The language used in the statute governing Medicare forbids payment for care services that "are not reasonable and necessary for the diagnosis or treatment of illness of injury to improve the functioning of a malformed body". The statute also forbids payment for, "personal comfort items. ...[and] custodial care."[38] When enacted Medicare was expressly designed to cover "treatment of illness" only when it was expected that such treatment would improve the well being of a person.[39]

Since the enactment of Medicare, the further development of medical technologies and treatments have greatly enhanced the potential to delay and prevent the onset of chronic illnesses, but the medical systems and reimbursement systems do not provide appropriate incentive to treat chronic illness. The most obvious and glaring example of Medicare's insufficient support for treating chronic illness has been its lack of a prescription drug benefit. While rectifying this hole in the Medicare program is the subject of most Medicare "reform" efforts, it is only one part of a much-needed increase in attention to chronic illness. To better address chronic illness, the care of people in need could be better coordinated by appropriate teams of experts who are encouraged through the payment system to confer with other experts, the beneficiaries and family members as to the best and most appropriate course of care.

Other reforms to Medicare that must be considered are a critical examination of the home care provision of Medicare. Under Medicare, beneficiaries are eligible for covered care when they are "homebound" and need "skilled services" on an "intermittent" basis. This definition clearly reflects an acute model because chronic illnesses do not always require skilled care and frequently the care needed is not intermittent but rather custodial. Moreover, the definition of "homebound" does not recognize the ability of family caregivers and extended family members to work together to provide care in a variety of settings at different times. While there are legitimate concerns about the potential for increased costs and loss of quality in making the program more responsive to chronic illnesses, Medicare reform must at the very least take into greater account the ability to work with and support family and unpaid caregivers.

B. Support for Unpaid Caregivers

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[38] 42 U.S.C. 1395y Section 1862 (1)(I)(6)

[39] B.C. Vladeck, "Round Pegs and Square Holes: Medicare and Chronic Care," prepared for the Study Panel on Medicare and Chronic Care in the 21st Century, National Academy of Social Insurance, April 2002, p.3

Unpaid caregivers working alone currently provide nearly three-quarters of the care for adults age 18 through 64 receiving long term care assistance, and more than half of the care for seniors.[40] The family members who provide unpaid caregiving services to a parent, spouse, or child often experience serious emotional, physical, and financial stresses. Unpaid caregivers may also be forced to quit their jobs or otherwise reduce their work hours in order to provide care, creating even greater financial strain. Through entitlement reform, financing and services can be structured to support and empower – rather than supplant – these important individuals.

One way to help people in need support unpaid caregivers would be to establish a social insurance cash payment benefit with eligibility and benefit levels based on the level of an individual's functional need. Such an approach would give the individual in need or their families the flexibility to tailor services to individual needs and preferences. It would also enable persons with disabilities to pay for services provided by previously unpaid caregivers, such as friends, neighbors, or relatives. Paying family members or friends for caregiving would also relieve the shortage of paid caregivers.[41] While a cash payment benefit program would offer greater flexibility, it may not be the best solution for all individuals. Safeguards would have to be built into any cash payment benefit program to prevent fraud and abuse.

In recent years, a few states have experimented with disability-based cash benefits, most prominently in the Cash and Counseling Demonstration and Evaluation-- jointly funded by HHS and the Robert Wood Johnson Foundation. Under this program, three states (Arkansas, Florida, and New Jersey) have obtained Medicaid waivers to "cash out" Medicaid-funded home and community-based services. Preliminary results from Arkansas indicate that 90 percent of participants used the cash to hire family members, neighbors or friends to provide personal care services.[42]

A more extensive test of this strategy has been conducted in Germany. In 1994, Germany enacted a new system of financing long term care that includes a home care benefit that varies based on the severity of the case, and can be provided as services or cash.[43] The program imposes no limits on the use of the cash and encourages participants to hire friends or relatives. In 1998, three-quarters of the beneficiaries chose cash rather than services.[44] The program's initial success suggests that it may be a model that can be utilized to develop a similar national program in the United States.

C. Personal Resources

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[40] J. Tilly, et al, p. 24-25.

[41] R. Stone, "Providing Long-Term Care Benefits in Cash: Moving to a Disability Model," *Health Affairs*, 20:6, p. 96-108.

[42] R. Stone, p. 101-102.

[43] R.J. Vollmer,. *"Long-Term Care Insurance in Germany,"* Paper presented at the European Seminar on Dependency: A New Challenge for Social Protection, May 12, 2000; and J. Wilbers, *"Long-Term Care Insurance in Germany."* Institutional Longevity Center. www.ilcusa.org.

[44] R. Stone, p. 103.

Expanded incentives and opportunities to accumulate private retirement savings will be a critical factor in ensuring the retirement security of today's workers. Declining savings rates and rising debt are leaving today's average worker with insufficient assets to meet future retirement needs. Public programs will not be able to respond to growing income needs of baby boom retirees without increased supplementation from private investment and savings.

Americans have historically had low personal savings rates compared to residents of other industrialized nations. Even during the economic growth of the mid-1990s, personal savings rates in the U.S. declined to the lowest levels ever – to practically zero. In 2000 and 2001, Americans saved less than 1.6 percent of their disposable income (only 1 percent in 2000).[45] Even with a rapid increase in personal wealth during this period caused by rising stock prices, savings rates at the beginning of the new millennium were lower than at anytime in the last decade.

Another factor contributing to low financial resources among retirees is the disappearance of traditional pension plans. In the past, employees were guaranteed a steady stream of income in retirement by their employers. Each company hired financial advisors to manage their pension funds and ensure regular payments to retirees. In recent years, however, pensions have increasingly been replaced by defined contribution plans, such as 401(k)s and IRAs, which place the financial planning burden on individuals. While these plans allow greater control of one's assets, the average person may have difficulty calculating and accumulating the funds needed for retirement.

While the growing long term care burden will place an exceptional demand on our nation's limited personal retirement assets, it may be possible to ensure additional private savings through innovative programs. For example, the federal government could encourage people to save for long term care expenses by creating a specialized Roth Individual Retirement Account. Just as an Education IRA allows tax-free withdrawals for college tuition, a Long-Term Care IRA could permit tax-free spending on long term care expenses prior to the age at which funds can currently be withdrawn without incurring penalties (59.5 years old). Creating this new kind of IRA would encourage people to begin saving at a younger age and allow them to take advantage of compound interest. If a person died without spending the funds saved in their Long-Term Care IRA, the account could be turned over to the person's heirs. Similar incentives for long term care saving could be attached to 401(k) plans and life insurance annuities. If spending on long term care were considered an approved and non-taxable use of these funds, people might be motivated to increase their personal savings.

In addition to exploring new options to increase personal savings we must also consider new ways to help people utilize the significant resources available to people through their

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[45] Bureau of Economic Analysis, U.S. Department of Commerce. Personal Income, January 2002. News Release. http://www.bea.gov/bea/newsrel/pi0102.htm.

investments in home ownership. The home mortgage interest deduction, which is a publicly supported benefit open to all home-owing taxpayers has helped a record 68% of Americans purchase their own homes. In 2001 the combined value of this homeownership reached an estimated value of $14 trillion,[46] a significant amount of resources, which if correctly utilized has the potential to help finance long term care costs. Moreover, within long term care the cost of housing is a significant portion of care costs and the ability to find ways to help people to stay in their own homes and receive the necessary care could reduce the cost of care.

While personal savings alone may not be enough to finance the total cost of long term care services, these funds can be used to purchase private long term care insurance or bridge the gap between insurance payments and the cost of care. While no one solution will be right for all families, greater personal resources and greater flexibility in the use of those resources will increase the options available for providing the most appropriate level of long term care.

D. Private Insurance for Long-Term Care

While private long term care insurance has become more popular in recent years, only a small proportion of seniors have long term care policies and they tend to purchase them later in life. Today, the growing market for private long term care insurance finances four percent of total long term care expenses for the elderly.[47] The total number of Americans who have purchased long term care insurance policies has increased from 1.9 million in 1990 (the year they became more widely available) to 6.8 million in 1999.[48] The number of long term care policies sold annually has grown by an average of 18 percent a year, with more than three-quarters of a million policies sold in 1999. As of 1997, about 3.2 to 3.8 million policies were in force, providing coverage for fewer than 10 percent of seniors.[49]

Long-term care insurance is primarily acquired by older people. In 2000, 40 percent of all purchasers were age 70 or older, illustrating that people delay the purchase of long term care insurance for as long as possible. Although the average age of a long term care insurance purchaser declined slightly from 68 to 67 years old between 1990 and 2000, more important was that the percentage of buyers age 55 to 64 increased from 25 to 33 percent during that same period, a trend that is expected to continue as younger people

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[46] "*Attack on America: Economic Consequences for the U.S. Real Estate Markets*," National Association of Realtors White Paper, (October 2001) p. 8

[47] Congressional Budget Office, *Projections of Expenditures for Long-Term Care Services for the Elderly*, CBO Memorandum, March 1999.

[48] Health Insurance Association of America (HIAA), *"Number of Americans with Long-Term Care Insurance Triples over 10 Years, New HIAA Survey Shows,"* Press Release, February 22, 2002.

[49] J.M. Wiener, J. Tilley, and S.M. Goldenson, "Federal and State Initiatives to Jump Start the Market for Private Long-Term Care Insurance," *Elder Law Journal*, 8:1 (2000).

plan for long term care as part of their financial future[50]. Since premiums rise, as an individual grows older, and long term care insurance can be only purchased when a person is in relatively good health, there are financial and medical incentives to buy insurance at younger ages. For example, the average cost for a long term care insurance policy is $649 at 40, $881 at 50, and $1,802 at 60.[51]

The 1996 Health Insurance Portability and Accountability Act (HIPAA) has helped make private long term care insurance more affordable for some people by creating a tax deduction for health plan premiums. However, since an individual must itemize deductions on his or her tax return to receive the benefit of the legislation, HIPPA primarily assists higher income individuals. Current pending legislation to make the deduction available "above the line" should help to put private coverage within the reach of more individuals of moderate income who may not itemize deductions on their tax return.

In another attempt to reduce the cost of private long term care insurance several states have formed creative "partnerships for long term care" which blend public and private resources. Under these partnership initiatives, four states (California, Connecticut, Indiana and New York) provide a higher level of asset protection in the Medicaid program for individuals who purchase private long term care insurance policies that meet state requirements. The intent of these programs is to enable individuals of moderate income who purchase their coverage through the programs to have the guarantee of lifetime benefits through a combination of private insurance and a Medicaid safety net. The private partnership policies cover the initial period of care purchased by the individual, and if the policyholder needs further care after the private insurance benefits are exhausted, he or she can become eligible for Medicaid without facing the standard "spend-down" rules. An individual can protect one dollar in assets for every one-dollar paid out under the private policy and still be eligible for Medicaid if needed. A 1993 federal law that requires states to recover protected assets when Medicaid enrollees die has stalled creation of partnership programs in other states. (The four original state partnerships pre-dated this law.) Pending legislation to remove this provision will allow state long term care partnership programs to spread more broadly and should expand availability of private insurance coverage to many more people of moderate income.

Additionally, in an effort to encourage people to purchase private long term care insurance earlier in life, some employers have begun offering long term care insurance plans as an employee benefit. Ideally, employee benefit managers are able to improve the cost and quality of the available plans through group purchasing negotiations. However, few employers currently offer long term care insurance as a benefit. As of 1998, 2,185 employers sponsored long term care plans and more than two-thirds of them were

[50] LifePlans, Inc. "Who Buys Long-Term Care Insurance in 2000?: A Decade Study of Buyers and Nonbuyers." Health Insurance Association of America (HIAA), October 2000, table 3.
[51] Coronel, Susan A. *"Long-Term Care Insurance in 1998-1999"*, Health Insurance Association of America, February 2002. (A comprehensive policy assuming preferred underwriting, $150 daily benefit with 5% compound inflation).

employee-pay-all policies. An average of 6 percent of employees offered plans elect to participate. One way to increase employee purchase of long term care insurance would be to include it in Section 125 plans, also known as "cafeteria style" benefit plans. If long term care insurance were allowed under Section 125 plans, the cost of coverage would be lowered substantially for employees and the opportunities for purchasing affordable coverage at younger ages would be dramatically increased. Legislation to allow long term care insurance in Section 125 plans is pending and ultimately, employer sponsorship may raise awareness of the need for private long term care coverage.

The Combination of Elements Necessary for Reform

In order to meet the wide variety of needs presented by the elderly and persons with disabilities, we must find flexible and creative solutions that can bridge the gaps in the current patchwork system of benefits. Private insurance alone cannot serve this purpose in part because it has been designed to supplant, not supplement, government programs that already finance a significant amount of care. The four elements addressed in the previous discussion each play a key role in reforming long term care. First, Medicare must be reformed to better address chronic illnesses. Second, to provide the flexibility that will allow people in need of care to arrange necessary services or to expand informal caregiving options, we must empower people through a national cash assistance program with appropriate safeguards. Third, individuals must plan for their own long term care by increasing their own resources. Fourth, private long term care insurance must be utilized more frequently and greater opportunities must be explored for increasing its affordability and availability. Only when all of these elements are brought together will we be able to provide the elderly and people with disabilities the affordable, flexible, and high-quality health care they deserve.

Successful Long Term Care Financing Is Inextricably Linked to Entitlement Reform

Entitlement reform will give policymakers the opportunity to restructure income support and health care programs to meet more effectively the multifaceted needs of the diverse array of persons with disabilities and chronic conditions. In so doing, the Congress can enable individuals and families to make better use of resources that have already been committed to long term care needs. The key to using these funds more efficiently is to provide flexibility – to enable individuals and families to tailor income and health care support to meet their unique needs. Programs need to supplement, but not supplant, the personal resources individuals and families can provide, while simultaneously encouraging them to prepare and provide for themselves.

At the same time, any attempt to reform national retirement and disability income and health insurance without addressing the threat that long term care costs pose to economic security runs a great risk of failure. While adequately financing long term care may seem to be a daunting task, failing to do so may impair the success of other income security and health solutions. In addition, entitlement reform that does not address long term care

needs is likely to further exacerbate the bureaucratic confusion that hampers delivery of care to elderly and people with disabilities. The disjointed collection of programs that currently provide income support, health care, housing, and other services to those in need is already difficult to navigate. If Congress attempts to reform Social Security and Medicare without addressing their connections to long term care services, lawmakers will have missed a unique opportunity to fully address the health and financial security of society's most vulnerable members.

Because long term care financing was never integrated into our national retirement and disability security system, an unstable and convoluted patchwork system of financing has emerged. Federal programs do not co-ordinate with or even complement private long term care insurance. States provide long term care as a public assistance program that helps seniors only after they have reached the poverty level while it condemns people with disabilities to a life of permanent impoverishment. Unless they have purchased long term care insurance or have significant savings, the average family must try to patch together limited Medicare coverage, public services, and personal resources, until they spend down to Medicaid eligibility. Clearly, the complexity of the health care financing system requires a multi-faceted solution. Public and private resources must be mobilized and –most importantly– coordinated into a flexible array of programs that can be adapted to provide appropriate levels of care at a reasonable cost.

Further exacerbating the instability of the current patchwork long term care system is the impending retirement of 77 million Baby Boomers. While long term care spending for people of all ages totaled $137 billion from all public and private sources in 2000, [52] that figure could reach $379 billion by 2050.[53] The sheer number of new enrollees in entitlement programs, combined with rising health care costs, will precipitate a major financial crisis early in the 21st century. In the past, Congress averted similar crises by enacting Social Security in the 1930s and Medicare in the 1960s -- programs that have since become the base of economic security for seniors and persons with disabilities. Today, policymakers once again have the opportunity to prevent a fiscal crisis by taking action while it can still be averted.

As the population ages and health care costs increase, more resources will be directed to long term care in the future no matter how legislators choose to reform Social Security, Medicare, and Medicaid. The best solution is for legislators to provide these resources in ways that will increase the self-reliance and dignity of the young and old with disabilities and chronic conditions requiring long term care. Entitlement reform is the most effective and efficient way to meet the diverse needs of these populations. If Congress successfully integrates long term care into entitlement reform, the result will be greater economic security for each family, each state, and our nation as a whole.

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[52] Walker, Senate Aging Committee testimony, March 21, 2002.
[53] Walker, Senate Aging Committee testimony, March 21, 2002.

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The CHAIRMAN. Next, we will hear from Ms. O'Shaughnessy.

STATEMENT OF CAROL O'SHAUGHNESSY, SPECIALIST IN SOCIAL LEGISLATION, CONGRESSIONAL RESEARCH SERVICE, WASHINGTON, DC

Ms. O'SHAUGHNESSY. Thank you, Senator Breaux. Good morning, Senator Breaux and Senator Ensign. Thank you for the opportunity to testify. Today, I am going to take a little different tack and talk about international trends for long-term care financing, which I know you are interested in.

The first point is that population aging is a worldwide phenomenon. The aging of societies over coming decades has commanded the attention of policymakers worldwide and will have dramatic implications on pension plans, income programs, and health and long-term care systems. While growth of the elderly population in industrialized countries of North America and Europe is well recognized, developing countries are also experiencing rapid growth in their older populations, predicted to increase by two- to fourfold by 2030.

By 2015, in 9 of 11 Western European countries, older persons will represent 18 percent or more of the total population, and by 2015, an astonishing one-quarter of Japan's population will be 65 and older. While the United States, Canada, and Australia are relatively young by world standards, a large growth rate will come in coming years, as members of the panel have discussed.

These demographic factors will have immense impact on public and private spending for pensions, social welfare, and health and long-term care systems. Policy makers worldwide are planning, or have already taken steps to change their long-term care financing and service delivery systems. Although countries differ in approach, many have recognized that the provision of long-term care is one of three pillars of social support for the elderly, along with retirement income and medical care.

Comparison among countries is challenging because of the different economic and political circumstances of each country and the nature of the social contract that each country shares with its citizens. For example, two countries that have instituted long-term care reform, Germany and Japan, have certain characteristics that differ from other countries. Germany has more than a century-old tradition of public responsibility for health care of its citizens. Japan unlike many other countries, has a long tradition of filial responsibility for older family members. Older family members usually go to live with their oldest son, with the daughter-in-law providing most of the care.

A landmark study prepared for the Organization for Economic Cooperation and Development, OECD, for its 29 member nations, indicated that comprehensive reform to address the economic and social implications of aging populations will be necessary, and OECD noted that there is a limited window of opportunity for many nations to take action.

Regarding long-term care, OECD recommended a number of things that have been talked about in the hearings over the course of the last year. First, OECD recommended that financing schemes

should be developed to share the financial burden jointly by the working age and older populations.

Second OECD recommended coverage of catastrophic costs, which Senator Rockefeller just spoke about; third, there should be wide support for home care programs and family care rather than institutional care, and, fourth, there should be a harmonizing of long-term care services with health care policy.

A key challenge according to the OECD for its 29 member nations is to develop systems that can provide chronic care and improve the balance between health care and chronic care, between family and formal care systems, and between medical and social services. As in the United States, many nations have found this very difficult to accomplish.

During the 1990's, a number of nations enacted major legislation to change long-term care systems. Some details of some of those systems are in my written testimony, but I would like to highlight certain aspects of programs in Germany and Japan that have drawn attention in the U.S.

In 1994, Germany created an employer-mandated social insurance program where employer and employee share in a 1.7 percent tax on wages to pay for long-term care on a pay-as-you-go basis. The program is a capped entitlement with maximum per person benefits; it provides nearly universal coverage. Over 90 percent of persons in Germany are covered by the plan, and eligibility for assistance is not related to income and assets.

However, the program was not intended to be fully comprehensive. Cost sharing by recipients is a key element. When costs of care exceed the benefit maximums, the difference must be paid by the individual or his or her family, and if the individual cannot pay, a means-tested welfare system kicks into place.

The German plan provides both cash and services up to maximum amounts for various multi-levels of care; home care services are specifically designed to supplement family care. Cash has been a predominant choice of long-term care clients, but recent trends show that people prefer a combination of cash as well as formal services.

Japan, which has a very large elderly population implemented a social insurance program in 2000. The program provides both home care and institutional care according to five levels of need. As in the German program, benefits for care are fixed, depending on the level of need that is required, and public subsidies pay for one-half of the care. The other half of the cost is funded through income-related premiums and a flat 10 percent copayment by individuals. So there is a mix of public-private funding in this program.

In summary, Mr. Chairman, reviews of various countries have found some similarities in the goals of reform. These include the following. Policymakers are attempting to find the right balance between public and private responsibilities, as in the U.S. Countries are striving to create a more balanced approach to home and community-based care. In some cases, the desire to control institutional care, as Governor Dean had mentioned, has been a propelling reason for seeking out home and community-based care.

Countries recognize the important role of unpaid care provided by family and friends and a key feature of these designs in various

countries is to avoid creating, as Senator Ensign was talking about, disincentives to family support and to supplement the informal care that is provided. A number of countries are developing systems that allow consumers greater choice between services and cash payments, as we are experimenting with in this country.

Responsibilities for administration are generally decentralized. Also, in terms of financing, in some countries, eligibility is based on need, not ability to pay. But on the other hand, as in Germany and Japan, those reform programs require individuals to pay for a portion of their costs, either through fixed or variable rate schedules, either through premiums or cost sharing.

Just to conclude, Mr. Chairman, Senator Rockefeller talked a lot about adult day care programs; adult day care is a blossoming industry in this country. We actually got the idea for adult day care from Britain and from Russia in terms of the experimentation that they had done, in the early part of this century. This is an example of a model that we have transferred from other countries.

So that concludes my statement. I will be glad to answer questions.

The CHAIRMAN. Thank you very much, Ms. O'Shaughnessy.

[The prepared statement of Ms. O'Shaughnessy follows:]

Trends in Long-Term Care Financing In Selected Countries

Testimony before the Senate Special Committee on Aging

Carol V. O'Shaughnessy
Specialist in Social Legislation
Congressional Research Service

June 20, 2002

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Good morning, Senator Breaux and Members of the Committee. My name is Carol O'Shaughnessy, Specialist in Social Legislation at the Congressional Research Service. Thank you for the opportunity to testify. This morning I will present an overview of trends in long-term care financing in selected countries.

Population Aging Is a Worldwide Phenomenon

The world's elderly population is increasing dramatically. In many Western European countries and in Japan, the elderly population already represents over 15% of the total population. While the United States, Canada, and Australia are relatively young by world standards, with the elderly population hovering around 13% of total population, a large growth rate will occur later. From 2000 to 2030, the U.S. elderly population is estimated to increase by just over 100%. Many European nations and Japan will experience a growth rate of more than 50% over that period.

The aging of societies over coming decades has commanded the attention of policymakers worldwide and will have dramatic implications for pension plans, labor markets, and health and long-term care systems. Lowered fertility rates and increased longevity will continue to affect the share of population that the elderly represent in many industrialized countries for some time to come. While growth in elderly populations is well recognized in the industrial nations of Europe and North America, developing countries are also experiencing rapid growth in their older populations – predicted to increase by two- to four-fold by 2030.

The industrial nations of Europe have the highest proportions of elderly populations, and growth of that population will continue well into this century. In 2000, of 11 Western European countries, in only one – Italy – did older persons constitute 18% or more of the total population. However, by 2015, in nine of these 11 countries, older persons are estimated to be 18% or more of the total population.[1] Moreover, Japan is experiencing extremely rapid growth in its elderly population that exceeds that of many European nations and North America. By 2015, one-quarter of Japan's total population will be age 65 or older.

Table 1. Estimate of Persons Aged 65 and Older, and 80 and Older, as a Percent of Total Population, 2000, 2015, and 2030, Selected Countries

	2000		2015		2030	
Country	**Percent 65 and older**	**Percent 80 and older**	**Percent 65 and older**	**Percent 80 and older**	**Percent 65 and older**	**Percent 80 and older**
Australia	12.4	3.0	15.8	4.1	21.1	6.0
Austria	15.4	3.4	18.8	4.9	25.2	7.0
Canada	12.7	3.1	16.1	4.3	22.9	6.2
France	16.0	3.7	18.8	5.8	24.0	7.5
Germany	16.2	3.5	20.2	5.4	25.8	7.2
Japan	17.0	3.7	24.9	7.0	28.3	11.1
Russia	12.6	2.0	13.8	3.1	20.5	4.1
Sweden	17.3	5.0	21.4	5.7	25.1	8.6
United Kingdom	15.7	4.0	18.4	4.9	23.5	7.0
United States	**12.6**	**3.3**	**14.7**	**3.8**	**20.0**	**5.3**

Source: U.S. Bureau of the Census and U.S. Department of Health and Human Services. *An Aging World*, November 2001.

[1] Austria, Belgium, Denmark, France, Germany, Greece, Italy, Sweden, and the United Kingdom.

Many Nations Are Focusing on the Economic and Social Challenges Presented by Population Aging. Reform of Long-Term Care Financing and Service Delivery Is a Key Component of Review

These demographic factors will have immense impact on public and private spending for pension, social welfare, health and long-term care systems in many nations in the future. As the United States and other countries prepare for an aging society, policymakers worldwide are planning or have already taken steps to change their long-term care financing and service delivery systems. Although countries differ in their approach, many have recognized that provision of long-term care is one of three pillars of social support for the elderly, along with retirement income and medical care.

Comparisons among countries is challenging because of the different economic and political circumstances of each country and the nature of the social contract that each country shares with its citizens. For example, two countries that have instituted long-term care reforms, Germany and Japan, have certain characteristics that differ from other nations. Germany has more than a century-long tradition of public responsibility for the health care of its citizens. Unlike many other countries today, Japan has a long tradition of filial responsibility for older family members.

A landmark study prepared by the Organisation for Economic Co-operation and Development (OECD) for its 29 member nations,[2] *Maintaining Prosperity in an Ageing Society,* focused attention on a number of complex and interrelated challenges posed by aging populations. The study indicated that comprehensive reform to address the economic and social implications

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[2] The OECD consists of 29 countries, including the 15 European Union (EU) countries of Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, the Netherlands, Portugal, Spain, Sweden, and the United Kingdom. It also includes six non-EU European countries (the Czech Republic, Hungary, Norway, Poland, Switzerland, and Turkey); two Asian countries (Japan and South Korea); three Oceanic countries (Australia, Iceland, and New Zealand) and three North American countries (Canada, Mexico, and the United States).

of these demographic factors on care systems will be necessary.[3] OECD noted that for many societies there is a limited window of opportunity to put reforms in place before experiencing the full impact of rapidly aging populations.

Along with the impact that population aging has on pensions, labor markets, and health care, OECD focused attention on the need to reform long-term care systems. OECD pointed to the need to develop medical technology to reduce physical dependency and chronic disease in old age as well as the need to improve integration of health and social services for older persons. OECD recommended that frailty in very old age should be treated as a normal part of the aging process and that reforms should result in:

- treating long-term care as a normal risk of life, with the burden of financing shared by the working-age and older populations;
- providing coverage against catastrophic costs, while insuring a balanced access to home help and institutions;
- encouraging a multiple-pillar system of delivery, with more emphasis on supporting people in their own home or in similar home-like settings and less in publicly subsidized nursing homes .... [and]
- harmonizing long-term care policy with health reforms in order to support the best mix of health and caregiving elements.[4]

A key challenge, according to OECD, is to develop a system that can provide chronic care and improve the balance between care in community settings and institutional care, between family and formal care systems, and between medical and social services. As in the United States, many countries have found this balance difficult to accomplish.

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[3] Organisation for Economic Co-operation and Development (OECD), *Maintaining Prosperity in an Ageing Society*, Paris, 1998.

[4] OECD, *Reforms for an Ageing Society*, Paris, 2000. p. 66.

Although there are scarce comparable multi-national data regarding total long-term care spending, OECD estimated that public spending for long-term care is a small, but growing, proportion of the Gross Domestic Product (GDP) of many nations. Estimates indicate that public spending for long-term care services in selected countries in 2000 was less than 1% of GDP, and ranged from .6% of GDP in the United States, to almost 3% in Sweden. (See Table 2.) Projections of future spending is affected by many variables, including assumptions about economic growth, fiscal constraints, and disability rates of elderly populations; however, the data are illustrative of the growing financial implications of long-term care in many countries.

Table 2. OECD Projections of Publicly Financed Long-Term Care as a Percent of GDP, Selected Countries
(Data assume that past trends in disability rates and institutionalization rates continue)

Country	1996	2000	2010	2020
Australia	0.81	0.82	0.88	0.99
Canada	0.71	0.74	0.81	0.93
Germany	0.71	0.72	0.78	0.90
Japan	0.75	0.83	1.10	1.40
Sweden	2.86	2.71	2.59	2.88
United Kingdom	1.05	1.06	1.08	1.22
United States	0.66	0.64	0.59	0.61

Source: OECD Economic Studies No. 30, *Is the Health of Older Persons in OECD Countries Improving Fast Enough to Compensate for Population Ageing?* By S. Jacobzone, E. Cambois, and J.M. Robine. OECD, 2000. Estimates were based, in part, on projections of the number of disabled elderly persons and of working age population, the cost of long-term care in each country (institutional and home care) in a baseline year, and institutionalization rates. Some countries, including the United States, have experienced decreased rates of disability among the elderly. The authors attribute the decline in the percent long-term care is of GDP in the United States to steeper declines in the disability rates in the United States as compared to other countries, among other things. The United States percent of GDP for long-term care would rise over the period if no change in disability and institutionalization rates is assumed.

Some Nations Have Enacted Major Reforms in Long-Term Care Financing

During the 1990s, a number of nations enacted major legislation to redesign their systems of long-term care for the frail elderly.

- In 1994, Germany created an employer-mandated insurance program where employer and employee share equally in a 1.7% levy on wages to pay for long-term care services.
- Japan enacted major legislation to establish a public long-term care insurance system, which was implemented in April 2000.
- In 1990, the United Kingdom enacted major legislation to transfer funds from the central government to local governmental authorities to be used for home and community-based services and to correct a financial bias that favors institutional care. More recently, in 1999, the Royal Commission on Long-Term Care made far-reaching recommendations to the British Parliament regarding changes in the current system, including elimination of means-tested programs for personal care assistance that lead to impoverishment of frail older persons. It also recommended establishment of a national family caregiver assistance program.
- In the 1990s, Australia enacted measures to support family caregiving, including providing financial support and respite care for caregivers.
- In 1993, Austria enacted legislation to assist families using a combination of cash benefits and social services, with eligibility based on multi-level need categories.

Reviews of various countries have found some similarities in the goals of reform. These include the following:

- Policymakers of all industrialized countries are attempting to find the right balance between public and private responsibility for long-term care.
- Many countries are striving to create greater incentives for home and community-based care, and in some cases, to correct incentives that favor institutional care. In some cases,

the desire to control costs of institutional care has propelled policymakers to expand home and community-based care.

- Countries are striving to integrate the delivery systems for acute and long-term care.
- Countries recognize the important role of unpaid care provided by families and friends to assist older persons with functional and/or cognitive disabilities. The role of women in providing unpaid care is especially salient.
- A key feature of reform designs is to avoid creating disincentives to family support. Increasing assistance to family caregivers is an important part of redesign efforts in many countries.
- A number of countries are developing systems that allow consumers greater choice among the types of services and service providers.
- In many countries, responsibilities for administration are generally decentralized, divided among federal and local (or provincial) authorities. Local governmental agencies or insurance plans (in the case of Germany) are responsible for assessment of an individual's need for service and development of a care plan according to services available.
- In some countries, eligibility for services is based on need, not ability to pay. On the other hand, some reform programs require individuals to pay for a portion of the cost of their care through fixed or variable cost-sharing schedules, based on income.

The following presents a summary of recent reforms of long-term care systems in Germany, Japan, and the United Kingdom.

GERMANY[5]

Demographic Trends. Changing demographics were an influential factor in establishing a long-term care insurance system for Germany's aging population. In 1980, 9.4 million people in the Federal Republic of Germany were 65 years of age or older. By 2000, the number 65+ in Germany had grown by 44% to over 13 million. This rapid growth is partially attributed to the reunification of the German Democratic Republic (East Germany) and the Federal Republic of Germany (West Germany).

The younger generation in Germany is decreasing, both in absolute terms and as a proportion of the total population. In 1997, the number of people under 15 years of age totaled 13.1 million (16% of the total population), a slight decrease compared to prior years. The Federal Statistical Office of Germany calculates that in a few years there will be more people aged 65 years and over than those 15 years and under.

Projections about the growing older population and a desire to expand home and community-based care led to a major redesign of the German long-term care system. The redesign was enacted into law in 1994. The law established a mandatory universal social insurance program for long-term care financed through equal employer and employee contributions.[6] The program is separate from the general health insurance program.

Before the enactment of a social insurance approach, long-term care services for the chronically ill were covered under the federal welfare law,

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[5] This section of testimony is taken from CRS Report RL30549, *Long-Term Care for the Elderly: The Experience of Four Nations*, by Mayra M. De La Garza and Carol O'Shaughnessy, April 27, 2000.

[6] The German Bundestag (Lower House) approved a draft bill addressing social provisions for long-term care on April 22, 1994. One week later, the Bundesrat (Upper House) consented to the bill. On January 1, 1995, long-term care insurance was established as an independent branch of the social insurance system and gradually phased in. The long-term care insurance program has provided benefits for home care since April 1, 1995, and for long-term institutional care since July 1, 1996.

and financed at the local level. Under the welfare program, eligibility for services was means-tested and determined by assessing a person's income and assets. Services included cash support and/or in-kind benefits.

The new long-term care social insurance program is considered a capped entitlement program with maximum per-person benefits. It provides nearly universal coverage and, unlike the prior welfare program, eligibility is not related to a person's income and assets. For persons covered by the statutory health insurance program administered through the sickness funds (insurers), long-term care insurance is compulsory and is also administered by the sickness funds. Privately insured persons, i.e., self-employed persons, are required to purchase private long-term care insurance. While the long-term care insurance program covers institutional care, the insurance system favors home care over institutional care. Non-professional caregivers receive training and compensation for their caregiving efforts, and providers of institutional care are compensated on a per-resident, per-month basis.

The most recent data we have (November 2000) indicates that the number of persons with long-term care insurance totaled 80 million or 97% of the total population. At the end of 2000, 1.9 million, or 2.4% of the total insured population, had been beneficiaries of the insurance, with 70% requiring home care and 30% requiring institutional care.

Eligibility. The long-term care insurance program provides benefits and services to anyone requiring assistance with the "regular tasks" of daily life on a long-term basis (estimated at 6 months or longer).[7] Under the public long-term care insurance program, the medical service department of each health insurance fund is responsible for assessment of individuals in their

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[7] Section 14(4) of Volume 11 of the Code of Social Law defines regular tasks as *personal hygiene* – washing, bathing, cleaning teeth, combing hair, shaving, emptying bowels and bladder; *food* – preparing or administering food; *mobility* – getting in and our of bed, dressing and undressing, walking, standing, climbing stairs, leaving and returning to one's home; and *household tasks* – shopping, cooking, cleaning the home or apartment, washing-up, changing and washing bed linen and clothing, or heating of the home.

own homes to determine eligibility and the extent of need for long-term care services.[8] Each person in need of assistance is assigned to one of three levels of care based on need for care. Each level of care is associated with a maximum insurance allowance, i.e., level of cash and services a person may receive. The entitlements provide for both home care services and nursing home costs. National guidelines and pre-determined benefits are intended to ensure uniformity of assessment and equality of treatment.

While the long-term care insurance program is focused on the elderly, it also provides for the younger disabled population in need of nursing care. These persons receive a flat-rate allowance to help cover treatment costs. The goal is to help disabled people live in the community rather than be compelled to live in nursing homes. German law emphasizes integration of persons with disabilities into the community and the workplace by promoting their employment. German law requires that at least 6% of the workforce of government and private employers (with more than 16 employees) be persons with disabilities. If the employment quota for the disabled is not met, the employers must pay a fee which ultimately subsidizes costs for those who do employ disabled persons.

Services. Germany began phasing in its long-term care insurance program in 1995. Home care benefits were provided beginning April 1, 1995. In July 1996, the second phase began, providing for institutional care. Anyone paying into the long-term care insurance fund can receive full benefits immediately. Home care services are designed to supplement family care. The plan pays for care in institutions, but not for room and board expenses.

The insurance plan in Germany provides both cash and services so that beneficiaries may receive a nursing allowance, a home care allowance, and/or payment of full institutional care. There are no restrictions as to the combination of cash and services received, so that recipients may choose

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[8] Section 18 of the Code of Social Law XI.

from an array of services, ranging from comprehensive services and minimal amounts of cash, to receiving all benefits in the form of cash and buying privately delivered services. Although cash has been the predominant choice of long-term care clients, recent trends show the number of people choosing only cash is declining. More people seem to prefer tailored individual home care services or combination packages that provide both in kind and cash benefits. The majority of people in need of long-term care desire to live at home or in familiar surroundings for as long as possible.

Benefits for caregivers are also covered. The plan provides free nursing care courses for relatives and other caregivers. In addition, the plan gives statutory pension and accident insurance benefits to primary informal caregivers.

Financing. The public long-term care insurance plan is financed entirely through equal employer and employee contributions. Assistance received, however, is not related to amount paid in to the insurance fund or to a person's financial situation. What began as a 1% contribution rate in 1995 rose to a rate of 1.7% of wage income with the implementation of the second phase of the program in 1996. The increase was planned and the tax rate has remained stable. Contributions are split evenly between the employer and employee. They are directly deducted from wages and transferred to the health insurance fund. Cost sharing by recipients is a key element. When costs of care exceed benefit levels, the difference must be paid by the person requiring care or his/her family. If the individual or family cannot afford additional costs, the welfare system finances the additional costs.

Japan

Demographic Trends. The Japanese tradition of filial duty has characterized the country's system of care for many years. While most elderly remain in their own homes, many reside with their eldest sons. In 1998, approximately half of elderly persons lived with their children. Once

a Japanese older person begins to live with his/her child, the daughter-in-law becomes the main provider of care, often spending years tending to the nursing and daily needs of her "patient."

While children of aging parents carry the responsibility of providing care for the senior population, this Japanese tradition is being affected by a number of social and demographic factors. These include: a rapidly growing elderly population, lower fertility rates, decreasing youth population, and greater life expectancy. In addition, Japanese women are now entering the labor force in larger numbers and are increasingly leaving behind the roles of housewife and caregiver.

Japan's public long-term care insurance system was implemented beginning in April 2000. It provides comprehensive in-home and institutional benefits for persons aged 40 and over who need long-term care services. Its purpose is to provide comprehensive and high-quality long-term care services, including in-home care and institutional services. The goals of this new system are to:

- allow users to choose freely from diversified services;
- offer integrated welfare and medical services;
- provide more efficient medical services for long-term care; and
- separate traditional medical insurance from provision of long-term care services.

Services offered through the insurance system were expected to rectify the overuse of expensive long-term stays in hospitals, a practice referred to as "social hospitalization." "Social hospitalization" (or "social admissions") refers to the practice of hospitalizing those in need of long-term care due to the shortage of community care and nursing homes. In Japan, almost 6% of the elderly population are institutionalized (compared to about 5% in the United States).

Eligibility. A "certification"or assessment process administered by the Long-Term Care Certification Committee in each municipality assesses a person's eligibility based on his/her mental and physical condition. Standards for certification for care are objectively determined nationwide.

Under this system, people age 65 and older are the "primary insured." This group was estimated to be 22 million in FY2000. The "secondary insured" are those between the ages of 40 and 64, estimated to be 43 million people in FY2000. These two age groups are categorized as "primary" and "secondary" because of differences in methods of assessment and collection of premiums for each.

People between the ages of 40 and 64 may receive in-home and institutional care based on age-related factors leading to early onset of senility, cerebrovascular disorders, and other illnesses associated with aging. Those 65 and over who require long-term care or support because they are bedridden, physically weak, or have dementia may receive care under this system. Those who require support due to physical conditions are provided in-home services to prevent institutional care. The degree of family support available is not a factor in eligibility determinations.

Services. After determining an individual's needs, a care planning organization allows the insured person to select his/her preferred services from a variety of home care services, and creates a service plan. The goal is to allow users to choose the services they want.

With the new insurance system, frail persons in need of physical support may receive approximately ¥62,000 (US $500 in 2002) per month in home benefits while those requiring more intensive care (for example, those who are bedridden or have dementia) may receive an amount up to almost six times that amount per month, depending on the level of care needed. Benefits for institutional care are fixed for each type of institution, and depend on the level of care required.

In-home services include:

- Home-visit/day care (home help),
- Home-visit nursing services,
- Home-visit rehabilitation,
- Commuting assistance for rehabilitation,
- In-home medical care management guidance,
- Commuting assistance for care (day service),
- Short stays in facilities,
- Communal living facilities with care-takers (group homes),
- Long-term care at fee-charging homes for the elderly,
- Rental service for welfare equipment, and
- Funds for home improvement and adaptation.

Institutional care services include:

- Special nursing homes for the elderly,
- Health services facilities for the elderly, and
- Sanatorium-type wards.

Financing. Financial support for the long-term care insurance program is provided by the national government, prefectures,[9] medical care insurers, premiums paid by the insured, and copayments paid by service recipients. Public subsidies pay-one half of the total benefit expenditures, with the national, prefectural and municipal governments contributing 25%, 12.5%, and 12.5%, respectively. To keep a balance between service users and non-users, and to raise awareness of service costs, beneficiaries pay a 10% coinsurance amount for long-term care services. Moreover, recipients are responsible for their own meal costs at long-term care facilities.

"Primary" insured users (age 65 and older) pay fixed insurance premiums based on income, as determined by each municipality. Premiums

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[9] Japan is divided into 47 prefectures, which are administered by governors and assemblies. A prefecture is further subdivided into minor civil divisions, including the city, town, and village, which have their own mayors, or chiefs, and assemblies.

are deducted from pensions. The medical insurance systems of the "secondary" insured users (aged 40 to 64) determine premiums for long-term care, based on a national standard. A portion of these premiums for this group are paid by employers. These premiums are collected together with the medical insurance premium by the medical insurer.

United Kingdom

Demographic Trends. The number of people aged 65 years or over increased from 7.3 million people (13.2% of the total UK population) in 1971, to 9.3 million (15.7% of the total) in 2000, a growth of 27%.

Recognition of the demographic trends and dissatisfaction voiced by many U.K. policymakers with the current long-term care system led to a major policy review in 1997. The Royal Commission on Long-Term Care was appointed by the Secretary of State for Health to analyze the current system and to make recommendations for improvement. The Commission was to examine options "for a sustainable system of funding of Long-Term Care for the elderly, both in their own homes and in other settings." The Royal Commission presented its findings and recommendations in a report to Parliament in March 1999 (*With Respect to Old Age, A Report by the Royal Commission on Long Term Care).*

While a major reform enacted in 1990 was designed to improve the system of care, the Royal Commission concluded that the "current system is failing." Reasons included insufficient home care and assistance to caregivers, lack of progress in correcting the institutional care bias, poor quality of institutional care, and lack of a client-based focus. Among the Commission's conclusions were the following:

- "Long-term care is a risk that is best covered by some kind of risk pooling – to rely on income or savings, as most people effectively have to do now, is not efficient or fair due to the nature of the risk and the size of the sums required;

- Private insurance will not deliver what is required at an acceptable cost, nor does the industry want to provide that degree of coverage;
- The most efficient way of pooling risk ... across all generations, is through services underwritten by general taxation, based on need rather than wealth [with some cost sharing];
- ... more care (should be given) to people in their own homes. Therefore the role of housing will be increasingly important in the provision of long-term care;
- More services should be offered to people who have an informal carer [caregiver]."[10]

The Royal Commission found that, despite attempts to lessen the bias toward institutional care in favor of home care envisioned by the 1990 Health and Community Care Act, more effort is needed. The Commission indicated that its proposals to provide personal care services, free of charge, would lead to expansion of home care services. It also recommended that more support be given to families and others who provide unpaid, informal care, and proposed that a national caregiver support program be established.

The Royal Commission recommended the continuation of the current pay-as-you-go model to finance long-term care. While the Commission considered other methods, it recommended no major changes in taxation. As discussed above, the Commission recommended changes so that individuals would be required to contribute toward the cost of their care. Policymakers have debated legislation that would enact a number of the Commission's recommendations.

Table 3 compares major components of three countries' systems.

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[10] A Report by the Royal Commission on Long Term Care. *With Respect to Old Age: Long Term Care–Rights and Responsibilities.* Presented to Parliament by Command of Her Majesty. March 1999. p. xviii-xix. See also, Roll, Jo. Social Policy Section. House of Commons. *Royal Commission on Long-Term Care,* February 17, 2000.

Table 3. Comparison of Selected Country Characteristics and Long-Term Care Systems

population % 65+	Germany	Japan	U.K.
United States 12.6% (2000) 14.7% (2015) 20.0% (2030)	16.2% (2000) 20.2% (2015) 25.8% (2030)	17.0% (2000) 24.9% (2015) 28.3% (2030)	15.7% (2000) 18.4% (2015) 23.5% (2030)
Financing	employer mandated insurance; 1.7% of wages, shared equally by employer and employees; cost-sharing based on income.	public long-term care insurance plan; public subsidies; insurance premiums and copayments paid by beneficiaries	pay-as-you-go taxation; individual contributions toward cost of care; tax credits for caregivers
Eligibility	assessment of need for care by medical service department of health insurance fund; benefits granted on basis of care requirement and not financial resources	assessment of need for care by municipalities	assessment of need by local authorities; requires individuals to contribute toward the cost of care based on a fee schedule (called a "means test")
Services and benefits	pre-determined benefits according to three levels of care/need; beneficiaries able to choose a mix of cash or services	12 at-home care programs to choose from, three institutional care services; maximum benefits at fixed yen amounts based on care needs	wide range of institutional and home care services in varying amounts
Problems	low fertility rate and growing elderly population	rapid growth in elderly population and decrease in number of potential caregivers; decline in family care	bias toward institutional care; lack of uniform application of eligibility criteria; uneven quality and access

Source: CRS Report RL30549, *Long-Term Care for the Elderly: The Experience of Four Nations*, by Mayra M. De La Garza and Carol O'Shaughnessy. April 27, 2000.

Summary

Projections of growing elderly populations and the institutional bias in long-term care systems have served as an impetus for policymakers in many industrialized nations to review their systems of long-term care financing and delivery. Areas of reform have included programs to assist family caregivers, expansion of home care programs, and financing methods to spread the costs of long-term care between public sources and private financing (through insurance plans, as in Germany, and/or fixed or sliding fee cost-sharing on the part of those persons needing care), among other things. Policymakers are attempting to find the right balance between public and private responsibility for long-term care while at the same time striving to create greater incentives for home and community-based services that most older people want.

The CHAIRMAN. Our final witness will be Mr. Steve Chies.

STATEMENT OF STEVEN CHIES, VICE CHAIR, AMERICAN HEALTH CARE ASSOCIATION, WASHINGTON, DC

Mr. CHIES. Thank you, Senator. Let me also extend my thanks to the committee for the substantial amount of time that you have invested in examining the many aspects and future implications of our nation's long-term care financing crisis.

As baby boomers approach retirement age, millions of Americans will be confronted by the need for long-term care and confounded by the inability to pay for the care that they will demand. Consider this fact. The average cost of a year's stay in a nursing home is in the range of $50,000, far too much for many Americans to pay, and it is fair to say that in America, the greatest long-term care risk that you face for financial and societal is to stay in a long-term care facility, as Senator Rockefeller mentioned.

It is also fair to say that the heart of the nation's long-term care financing structure, Medicaid, is quickly becoming one of the most underfunded government programs we have in relationship to its mission and mandate. A recent report by BDO Seidman showed that the Medicaid program is underfunding skilled nursing care by approximately $3.7 billion in the year 2000.

AHCA and NCAL have spent a great deal of time and resources examining the nation's long-term care financing structure. To assist us, we engaged the health policy experts of Abt and Associates, a well known, highly regarded public policy research firm based in Boston. Working with Abt, we developed a sophisticated micro simulation model that we have been using to test and analyze various approaches toward long-term care financing reform, and here are some of our observations.

Because of demographic changes, Medicaid spending for long-term care as a percentage of gross domestic product will double during the first half of the 21st century. The continuum of long-term care services will need to be greatly expanded to meet the needs of aging baby boomers, and access to this continuum is essential. Reliance on family caregiving will be strained simply because there are too few family members available to provide the care.

To address these challenges, we concluded the following. Congress must not only continue to endorse and support the growth of a long-term care insurance market through changes in the tax code, but it must do so in a specific way to target assistance to low- and moderate-income Americans to help them purchase and maintain insurance. We believe a public-private program should be created to help all Americans prepare for their long-term care needs. Not only will this entail changes in the tax code to promote long-term care insurance, but should also include restructuring of our current patchwork system of financing long-term care into an effective, efficient public policy program at the Federal level.

Mr. Chairman, our research shows that a national voluntary public-private program for financing long-term care is possible and can provide better access to the range of long-term care needs for Americans elderly and disabled. We believe it is possible to ease the growing dependence on Medicaid with policies to make it pos-

sible for a majority of individuals to pay privately for care they receive in the future. This could be accomplished by shifting the role of government from government paying for care services to government helping individuals and families plan for their long-term care needs.

Tax incentives can be an important component in shifting the role of government. One incentive is the above-the-line deduction now being considered by this Congress and supported by you, Mr. Chairman, and other members of the committee. But more importantly, we see a critical need for a refundable tax credit, one that is targeted toward low- and moderate-income Americans, those who have the greatest need for government-paid long-term care services by Medicaid. If a major goal is to reduce dependency on the Medicaid program, then we see this as the best way to reach it.

Once tax incentives allow for greater reliance on long-term care insurance, it becomes much more feasible to shift the government's role of the coverage of long-term care to the Federal level, thereby relieving the States of the increasingly onerous budgetary burden. This restructuring will allow for the coordination of both acute and long-term care services of the elderly and long-term care for the disabled. Coordinating the long-term care at the Federal level will eliminate today's failed patchwork financing system, thus creating a more efficient and seamless system for covering the care.

Finally, Mr. Chairman, the key element necessary to establish the legitimacy and awareness of this program must be public education. The comments from Senator Rockefeller really hit home for me. A national effort designed to help individuals understand the risk they face and what options they have. Once they do, we believe they will choose to act responsibly and plan for their long-term care needs.

That being said, we neither support nor advocate any system in which individuals do not take some financial responsibility for their care. This is the American way, and if you want to control your destiny, you must take some responsibility. This approach provides all Americans with the means to do just that. AHCA and NCAL believe the components of this financing model are viable and maximize the best the public and the private sectors have to offer for the good of all.

This obviously cannot be implemented overnight but is likely to take several years. This is why it is important for all elected officials to recognize the severity of this problem, just as you do, Mr. Chairman and the members of the committee, and begin addressing this situation today, regardless of what the final approach we ultimately decide on.

Again, thank you for this opportunity and for your dedication to try to help the elderly and disabled in this country.

The CHAIRMAN. Thank you very much, Mr. Chies, and all the members of the panel for excellent testimony.

[The prepared statement of Mr. Chies follows:]

My name is Steve Chies. I am the First Vice-Chair of the American Health Care Association (AHCA) and serve on the Board of Directors and Executive Committee of the National Center for Assisted Living (NCAL). I have been involved in the long term care profession for more than 25 years. I also serve as Vice-President for facility operations for Benedictine Health System, based in Cambridge, Minnesota. In this capacity, I am responsible for operations at 44 long term care facilities.

Thank you, Senator Breaux, for the substantial amount of time this Committee has invested in examining the many aspects and future implications of the nation's long-term care financing crisis.

As you, your staff, and every member of this Committee are well aware from the many hearings you have held over the past two years, the current system is inflexible and unsustainable for the long term. As you know, this is not an opinion – it is a fact.

Unfortunately, with all of the immediate, pressing health care priorities facing our nation – such as prescription drugs and Medicare reform – the long term care financing challenge facing our nation are too often perceived as an issue that does not require urgent attention. This is the most common misperception plaguing the debate about this complex and important matter. This is not an issue that can be dealt with after the baby boomers enter the long term care continuum. It is an issue that must be tackled now – not five years from now or ten years from now, but now – starting today.

If you ask most Americans what crises they expect to face during the next few decades, chances are that few will mention the cost of nursing home care, home health care, assisted living care, or other long-term care expenses. These are not matters at the forefront of public consciousness. Most everyone believes they are somehow covered one way or another, or they mistakenly believe they will never need long term care of any kind at any time. Well, let's take a look around the room, because two out of five of us here today will need some form of long term care at some point in our lives. And it is not just the frail elderly who need care. Many persons who develop disabilities benefit from long term care in a variety of settings.

The number of Americans who need long-term care is growing rapidly. Understandably, according to the U.S. Bureau of the Census, people age 85 and older are more likely to need nursing home care than any other age group. In the year 2010, the number of individuals 85 and older – approximately 3.5 million – will double to seven million by 2020, and double again to 14 million by 2040. During this same period the number of workers per retiree, whose tax dollars support government programs for retirees, will decline from about 4.75 workers per retiree in 2010 to about 2.75 workers per retiree in 2040. Without reform, this will constitute an increasingly heavy tax burden on workers when compared to 1950 when the worker to retiree ratio was 16 to 1.

As baby boomers approach retirement age, millions of Americans will be confronted by the need for long-term care, and confounded by the need to pay for it. For

most of these individuals, they will face the cruel reality of poverty and dependence at a time in their lives when a person should be in control of their golden years.

Consider this fact: the average cost for a year's stay in a nursing home is as much as $50,000 – and far more in larger cities and metropolitan areas. For too many American families, these costs are simply out of reach. For others, a stay in a nursing home can wipe out the savings from a lifetime of work. That's why it's entirely accurate to say the cost of long-term care is the greatest un-funded liability facing most Americans.

It's also fair to say, Mr. Chairman, that a key pillar of the nation's long term care financing structure – Medicaid – is quickly becoming one of the most under funded government programs we have in relation to its mission and mandate. A recent report by BDO Seidman showed that Medicaid was under funding skilled nursing care by approximately $3.3 billion in 1999, and a follow up analysis, soon to be released, will show under funding reaching close to $4 billion in 2000.

Complicating the Medicaid under funding crisis is the fact that, increasingly, the nation's Medicare program is being forced to cross-subsidize Medicaid, and the trend lines in this regard are not encouraging. While we are, and will continue to be, vocal advocates for strengthening Medicaid and Medicare, we are under no illusion these programs – regardless of their funding levels – can ever replace the need for families and individuals to take charge of their retirement futures.

We recognized early on that the gravity and the severity of the challenges ahead required being addressed head on. As a result, AHCA and NCAL have spent a great deal of time and resources examining this issue – and thinking about ways to avoid watching families and individuals spend their way into poverty by relying solely on the existing long term care structure.

Nearly five years ago, a consortium of concerned providers across the nation came together, and convinced our association that we had a responsibility to invest time and resources toward a possible solution, or set of solutions, to help address critical care issues.

We decided to roll up our sleeves and assemble a task force to study the long term care financing issue. To assist us, we engaged the health policy experts at Abt Associates – a well known and highly regarded public policy research firm home-based in Boston.

Working with Abt, we developed a sophisticated micro simulation model that we have used to evaluate and work our way through various approaches toward long term care financing reform. A preliminary finding from our modeling is that an insurance-based approach, if it includes refundable tax credits for insurance for the most needy with tax deductions for others, is an approach that merits further consideration and investigation. Such a public-private insurance model could provide affordable coverage for everyone, regardless of income, and allow individuals a choice in long term care

settings. And when I say choice, I mean the most appropriate health care setting for those Americans who need long term care services.

I want to be clear to this Committee, Mr. Chairman – I am not here today as an advocate only for skilled nursing care. But I am here to advocate the most appropriate health care setting for all Americans – whether it is nursing care, home health, community-based, or assisted living.

A public-private insurance model is one that Americans appear ready to embrace. Aside from evaluating financing models with Abt, we also conducted research asking Americans about their concerns in long term care. Our preliminary research clearly found that individuals had major concerns about cost and choice, as is logical. The research also demonstrated that Americans had significant concerns over a program that was either totally controlled by the private sector, or totally controlled by the public sector. There was an element of distrust and concern for one side taking full ownership of this issue. But there was more confidence when both sectors were involved – taking the best of what each had to offer.

The private sector would promote market competition and efficiency, while public involvement would provide a safety net and a watchful eye to protect consumer interests.

In evaluating the best long term care scenarios for Americans in, it was clear that our key parameters must be affordable care to the individual and choice.

We believe any reform in financing long term care must gradually transform our current system from one requiring individuals to impoverish themselves to one that empowers and encourages individuals to plan for their own long term care needs, providing options, providing choice, and providing flexibility so that everyone can participate.

Such a reform mirrors the true fabric of who we are as a people, and what we want in our retirement years. We treasure our freedom, we cherish our ability to choose, and we value maintaining control over where we live, and how we spend our lives. Our current long term care system does not allow that. It robs Americans of their financial independence and their freedom to choose how and where they will live. The status quo essentially forces one to become a ward of the state in one's elder years. This is unacceptable.

In our work with Abt, testing financing approaches with our simulation model, we arrived at some initial observations, which I will summarize:

- Because of demographic changes, Medicaid spending for long term care will continue to consume increasingly greater proportions of the gross domestic product and of state budgets while the revenue base in states shrinks during the first half of this century.

- The number of workers per retiree is declining; the tax base is simply not there to financially sustain programs for the elderly including long term care. The demographic information is very clear about this.

- The capacity of the continuum of long term care services will need to be greatly expanded to meet the needs of aging baby boomers and access to this continuum is essential.

- Reliance on family care giving will be strained simply because there will be fewe family members available to provide this care.

To address these challenges, we agreed on the following:

- Congress must not only continue to endorse and support the growth of the long-term care insurance market – but it must begin doing so in a way that specifically targets assistance to low- and moderate-income Americans to help them purchase and maintain insurance.

- We believe changes in the tax code can accomplish this important objective. Our research has found that refundable tax credits promote stability in the long-term care insurance marketplace. Help in maintaining coverage and premium payments is one of the central roles of a refundable tax credit provision. Our preliminary analysis indicates that without such a provision, real stability in the long term care insurance marketplace – to provide individuals true access to the long term care they need – is unlikely.

- We believe a public-private program should be created at the federal level to help all Americans prepare for their long-term care needs. This, we believe, should entail combining changes in the tax code with an eventual restructuring of public long term care financing that moves away from a dual system of Medicaid and Medicare to finance the long term care needs of citizens to one uniform public-private program. Considering the scope of this undertaking, an incremental approach to this restructuring may indeed be required – an incremental approach that first focuses on increasing the availability of insurance and individual savings for long term care through appropriately targeted tax incentives.

Mr. Chairman, we believe through our research that a national, voluntary public-private program for financing long term care is possible and can provide growing access to the range of long term care needs aging Americans. It acknowledges that most Americans would prefer to be cared for at home, in a community-based setting in assisted living, but also provides for nursing home care when it is appropriate.

Today, two out of three individuals we care for are Medicaid eligible – their long term care is paid for with public dollars after they have spent down and impoverished themselves. This is a sad but true fact.

Because the Medicaid program is struggling today, as I discussed earlier, and because our research shows us that Medicaid cannot meet the needs that will be placed upon it by the baby boom generation, we have sought to devise a new financing system that will lessen the dependence on government-paid services while offering more choice and access.

With diligent program development and implementation, a public-private program could make it possible for a majority of today's Medicaid-eligible retirees in the future to pay privately for the care they receive. This can be accomplished by shifting the role of government – from government paying for services to government helping individuals save for their long term care needs.

Tax incentives can be an important component in shifting the role of government to one of helping individuals prepare for their long term care needs. One incentive is the "above-the-line" deduction now being considered by this Congress and supported by you, Mr. Chairman, and others on this Committee. The deduction could help to dramatically increase the number of people who purchase long term care insurance by reducing the costs of this insurance.

However, we also envision the critically important need for a "refundable tax credit" – one that is targeted toward low to moderate income Americans. Such a tax credit makes insurance coverage more affordable to this segment of our population than a pure "above-the-line" tax deduction. A refundable tax credit also enables persons who may have purchased insurance earlier with the benefit of a tax deduction to maintain their coverage when their income drops.

In the future, it is the low to moderate income Americans who will have the greatest need for government paid long term care services provided by Medicaid. Therefore, we must target this group for support to help lessen dependence on Medicaid.

Ultimately, we have concluded that "lifetime" long term care coverage is the most sensible insurance policy to fully increase individual access to the full long term care continuum – to home care, community-based services, assisted living and nursing home care – and to allow individuals access to the setting that is best for them in terms of the highest level of quality possible. Lifetime coverage also means the government will not have a back end cost for providing care to individuals with such long term care insurance coverage.

For low- to moderate-income individuals, the refundable tax credit would fully or partially pay the premium cost of a long term care insurance policy – a private policy or a public policy offered by the government. The level of premium subsidy would be based upon a sliding scale of the individual's income and assets.

An individual, for example, with income of $10,000 or less might receive a 100% subsidy; with income between $10,000 and $20,000, one might receive a 50% premium subsidy; those with incomes between $20,000 and $30,000 might receive a 25% subsidy.

Of course when there is a targeted refundable tax credit coupled with a tax deduction for those at higher income levels, there can be some instances when a low to moderate-income individual's potential tax deduction may exceed the value of a tax credit. In such cases, the individual could choose the most beneficial tax benefit.

I want to note, Mr. Chairman, these are hypothetical figures, but want the Committee to understand the basic income parameters associated with this approach.

This approach envisions creation of a new safety net – one that not only helps individuals purchase coverage, but also works to help them maintain that coverage. As an individual's income changes because of job loss, retirement or disability, the provision of premium subsidies through a refundable tax credit ensures flexibility so that coverage purchased at a younger age can be maintained.

Once tax incentives enable greater numbers of Americans to provide for their future long term care needs through insurance, there is a second logical step. With an established insurance market it becomes more feasible to move the government's role in the coverage of long term care to the federal level – thereby relieving states of an increasingly onerous budgetary burden. This restructuring at the federal level will allow for the coordination of both acute and long-term care for the elderly and long-term care for the disabled. This coordination of care at the federal level – not the state level – will eliminate today's failed patchwork financing system, thus creating an efficient and seamless system of care.

A key component in this public-private program – one that in the end moves the public sector role to the federal level – calls for intensive national education – a national program designed to help individuals understand what risks they face, and what options they have. We believe that when individuals understand the risks they face, the costs of care and the options they have, they will choose to act responsibly and plan for their needs.

As we envision in this effort, the federal government will maintain a safety net to provide care for those who, through no fault of their own, could not insure against the risk of needing long term care. In such cases, government has the role of providing care. But in any voluntary system there will be those with means who choose not to participate. If care is needed, we believe these individuals must fully contribute to the costs without benefit of any asset protection.

We neither support nor advocate any system in which an individual does not take some financial responsibility for their care. This fundamental premise reflects American values: Americans want to control their destiny, but a central element of this effort is that every individual, in varying degrees, must take some responsibility for their future.

AHCA and NCAL believe the components of a public-private based financing model that I have just outlined are viable, and we believe it's a very strong start. It offers a common sense approach to meeting future long-term care needs. It is a system that best utilizes the public and private sector for the good of all.

This can't be implemented overnight. This is necessarily a transitional effort from a very large, cumbersome, restrictive Medicaid system into a new federal system involving the private and public sectors. This transition would take approximately ten years.

All of our elected officials must recognize the severity of this problem – just as you do Mr. Chairman. Regardless of what final approach is ultimately decided upon, we need to start today.

With the proper public education and planning, we can lay the groundwork for a financing system that will encourage, support and protect future generations, and our loved ones. It is sensibly based on the principle that, "If armed with the facts and the means, people will do the right thing to protect their interests."

Mr. Chairman, thank you for this opportunity to outline our perspective on this important matter, and I thank you for your continued dedication and perseverance on this vitally important issue that, inevitably, will indeed impact every American. I would be happy to entertain the Committee's questions.

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The CHAIRMAN. Governor Dean, I think that the story in Vermont has been unique and I think it has been highly successful. I was really impressed with the fact that you said that because of the waivers you have received, that you have been able to essentially spend the same amount of money and I think you had talked about actually covering almost twice as many people with the same amount of money through the use of alternatives other than just skilled nursing facilities. Do I understand that correctly?

Governor DEAN. That is true, although you have to throw in cost-of-living, so it is not the same dollar amount, but it is the same adjusted dollar amount. We can take care of twice as many people outside a skilled nursing facility as we can inside and they are just as sick.

The CHAIRMAN. You have had to come to the Federal Government——

Governor DEAN. Excuse me. They are just as sick as the ones who would have been in. We are not talking about really ill people who clearly need to be in skilled nursing facilities.

The CHAIRMAN. Now, you have come to the Federal Government to request the authority to have those waivers, right?

Governor DEAN. Right. I think the first waiver is not uncommon—I am pretty sure there are other States that have it—which allow us to spend Medicaid money on home health care. We happen to have a fair number of slots. It is about a third of all our slots.

The CHAIRMAN. You can also spend it for assisted living facilities?

Governor DEAN. Yes. That, I think, is relatively unique, and certainly some of the members of the panel have more expertise than I do, but I am not aware of another State that has that, although there may be——

The CHAIRMAN. Your recommendation is that you should not have to come to Washington to get the waivers, that the State ought to have the flexibility to use the money as they see fit within the options that are out there?

Governor DEAN. Not only that, although I am never in favor of Federal mandates. Certainly, anything that you can do to push States to take care of the maximum number of people outside the skilled nursing facilities and even assisted living. Somebody mentioned the least restrictive environment. That is what people want. People want to be in their own homes if they can be.

Obviously, at some point, it does not make sense to spend $250,000 keeping somebody in their own home when they could do it for a good deal less in a skilled nursing facility. But for most people, we can keep them in their own homes for about half of what it costs to put them in a skilled nursing facility, and they can be pretty sick, particularly if family is willing to participate in their care, or able or they are present in town, which is the case for most people.

The CHAIRMAN. Mr. Chies, you have heard Governor Dean's recommendations. On behalf of your association, what do you think about them?

Mr. CHIES. We have supported waivers in the past and will continue to support the waiver process. I think, Governor, I am aware of at least 38 States that have similar waiver programs for assisted

living and home-based services, so it is being done extensively out there and I think the Governor's recommendations probably to allow States to do that on a much more broader basis is probably indicative of what the States are demanding out there.

The CHAIRMAN. So I take it what Governor Dean is suggesting is that the current waiver process, whereby they have to come to Washington and officially request a waiver to use Medicaid funds for things other than skilled nursing facilities, that that be made a sort of permanent waiver? I take it you are not trying to get away from some kind of Federal guidelines——

Mr. CHIES. No.

The CHAIRMAN [continuing.] Because that is not going to happen. I mean, if we are going to have my State get 70 percent of the Medicaid money, from the Federal Government, then we want to make sure that we have a responsibility to see that the money is being spent responsibly. I mean, this is a partnership here. We do not just toss it up in the air and hope it comes down and does good, but we have a responsibility to make sure that we are doing what we intend to do. Do you support that concept, Mr. Chies?

Mr. CHIES. Yes. Mr. Chairman, I think you will find that most long-term care providers would agree substantially with what the Governor has presented here. I think the Medicaid waivers is a short-stop effect here. It is not really where we need to be as a society. We need to look at a much broader program of getting people the resources and letting them control it. The discussions from Carol about Germany and Japan, about the ability for people to have cash payments to go out and buy the service that they want makes a lot of sense from our perspective and allow the marketplace to drive the quality and the quantity of services that people receive.

The CHAIRMAN. Are your nursing home owners moving into other types of long-term care facilities? If I was in the nursing home business, I would be broadening my base of operations as fast as I possibly could into assisted living facilities and home health care, as well as the traditional 24-hour-a-day, 7-day-a-week skilled nursing facilities. In some States, there is a group of operators of nursing home facilities operators that are very much against the being able to use waivers for other types of facilities, because they feel it takes business away from them. Can you comment on that?

Mr. CHIES. I think that is a fair rendition of what is going on in the field out there. I think the reason you will see a lot of operators oppose assisted living is because of the pinched State budgets we have had in the Medicaid program and a concern that there will not be sufficient funding to adequately care for the people that do require nursing home care. But many long-term care providers who are in various segments of the business—the organization I work for right now has a number of assisted living and housing units and we believe they are very compatible in terms of how you move people through a continuum of providing care and services.

The CHAIRMAN. I thank you for that answer. I would just suggest that all of them look to the future and that is where some of the answer is going to be, not only from a service standpoint, but also from an economic and business standpoint. People are going to be demanding that type of care. They are already demanding that

type of care. So it is good to hear that they are moving in that direction and that the association essentially supports the waiver process that Governor Dean, I think, has so well outlined for us.

Governor DEAN. Mr. Chairman, if I might just add one thing, just to make sure this does not get glossed over, because this was a real point of contention between ourselves and the industry when we did this, we did pass a bill mandating that over a period of years we reduce the total number of nursing home beds by 10 percent and we are now in the process of taking it down another 10 percent and nursing homes, smaller, weaker ones, have started to close.

The CHAIRMAN. That does not mean 20 percent less care.

Governor DEAN. No.

The CHAIRMAN. It means——

Governor DEAN. It actually means 20 percent more care because you take down 20 percent of the beds and you can add 40 percent more care capacity outside the system by using the money. But this is not painless for nursing home operators. The smaller ones cannot get into the health care business because they are mom-and-pop organizations with maybe 30 beds. The larger chains could, if they wanted to, and some of them have done that and some of them have not.

The CHAIRMAN. David, you know the problem we struggle with up here. We are trying to add a prescription drug benefit to Medicare and we have got ranges from $1 trillion to $190 billion on how much we are going to spend in that area. We still have 44 million Americans who have no health insurance at all. At least if you are on Medicare, you have got about 53 percent of your health care being paid for through Medicare. If you are one of the 44 million Americans who have no health insurance, you are subject to emergency rooms as your principal provider for health care in the country. Now we are talking about long-term care.

The money is coming out of the Social Security trust fund, and that is where it is coming from. You can say, well, I want a $1 trillion drug program. I can write you a great drug program for $1 trillion, free drugs for everybody, and some would endorse that. But you have got to realize where it is coming from. It is coming from your children and our grandchildren's Social Security retirement.

All of this is a money problem as much as anything. Long-term health care insurance, which Steve has endorsed and I think I have introduced, is a refundable tax credit approach. That is going to cost money. That money is going to come out of Social Security retirement funds right now.

Do you have any suggestions? You have outlined some really good suggestions. The question is, how do we pay for it? If you had the answer, we would make you king for a day or maybe for the rest of your life.

Senator DURENBERGER. First, if you take a look at this Abt-produced study called Life Plan, I think it gives you an example of how you might do this, if you want something other than my opinion. There is an example of how, over time, we might do it.

Second, and I am speaking only for myself, part of the reason that we are all recommending dealing with long-term care financing reform at the same time we deal with the others is there are

a lot of resources available. They may not all be in the Federal Treasury, but the Federal Treasury decisions are being run by our predecessors in 1935 and 1965, basically. So you have to tackle the realities of that in the context of the 21st century. What do we know now compared to what we knew then?

We have in retirement today, including myself, I guess, although I am not retired, a huge amount of wealth that is about to be transferred to another generation. We have something like $14 trillion in home equity in America today. I do not know what we have in savings and 401(k)s and (b)s and all that sort of thing, and I think Ron Wyden already spoke to that. Some changes in the tax code enable people to make different decisions.

So the point of changing this from a "wait until you have got a problem and then make a decision" to a system in which we make the financial security decisions when we are young or when we go to work, and then when the occurrence of need comes—maybe within a year, you have a developmentally disabled child, or 7 years from now, when like my mom, you have a dementia called Alzheimer's, but you have prepared financially for that eventuality and you have not waited until the need arises to make these decisions.

That is why, when I listen to this conversation, with all due respect to all my colleagues who are in government, much better decisions are made by people in families than are made by Governors, or Congressmen, or Tommy Thompson at HHS, or Tom Scully at CMS, and the idea of an insurance system which is partially social insurance, partially private insurance, the idea of the Germany system, which, at Carol's suggestion, I went over and looked at last week, is that families make these decisions, and if they make them in advance, there are lots of resources in this country, privately held as well as the retirement plan surpluses, that can, over time, be committed to meeting these needs.

The CHAIRMAN. Senator Ensign, any questions?

Senator ENSIGN. First of all, I just want to say thank you to all of you. It has really been a terrific hearing and I think some great suggestions here. Obviously, there are some incredible challenges for us as policymakers up here.

Governor Dean, I think that your suggestion is probably the easiest one of everything that has been talked about up here as far as being able to do, and if the only thing we can do is incremental, that is at least an incremental step we ought to be taking. I want to try to work with you on that and the Chairman trying to be able to do that in a bipartisan way. It is short term but it has shown real progress. You have shown leadership on this, and that it could be done across the country.

Ms. O'Shaughnessy, I thought it was really fascinating, some of the things that you were talking about. I am glad that you studied them and I want to follow up with a question on the experience. I was talking to Senator Rockefeller about the family incentive. What have those other countries found, because, for instance, Japan is famous for how they take care of their parents, their grandparents. They are known all over the world for how they revere the elderly. We sometimes are a throw-away society for our elderly and that is the cautionary flag I was trying to raise is that

we do not encourage more of that, but that we actually get more to the incentive of keeping family to-family decisions and types of care as much as we possibly can.

What has been the experience of Japan and Germany as far as that? Has anybody looked at that aspect of it?

Ms. O'SHAUGHNESSY. Well, in terms of Japan, with the demographic factors and the lower fertility and increasing number, I mean, 25 percent in just a few years of the total population will be elderly, and what has happened is that women in Japan going into the workforce more dramatically than before—all these factors have put a huge amount of pressure on the family structure there. So they recognized after some years of thought, that they needed to incrementally assist individuals through a formal care system.

I looked at it a little bit in terms of evaluation, which the Japanese government puts out, and basically, they are saying that people seem to be very satisfied with the care that they are getting through the formal system, but, you know, you still have this strong family network that has got to be there just to serve the number of people.

Also in Germany, realizing that the German plan is not comprehensive—it is universal but it does not provide comprehensive coverage—the levels of care, I think the highest they can pay, except for one exception, is something like $1,400 a month for care. Most people are either at level one or level two, so you are still relying upon the informal support system a great deal even though you have a minimum benefit that helps take off the pressure, and perhaps is for nursing care at home that the families do not know how to do.

In terms of looking at countries, Austria and Australia also enacted national family caregiver programs in terms of a limited benefit. I think that is the way at least OECD sees the issue going—enact programs that will assist families, not supplant them.

Senator ENSIGN. Mr. Chairman, I will just conclude with an observation. My son has a wonderful piano teacher and they have a severely disabled son who is now about 16 years of age. A couple of comments on them.

First of all, it is unbelievable to see the difficulties that they go through with this child. He is the typical child that most families would probably not be able to handle and would institutionalize. A lot of families would, anyway. Maybe not most, but certainly a lot of families would. But to see the relationship with him and his siblings, who are younger, and the way that they interact with him is awesome to see, and I know that these kids are going to be better people because of learning to serve him.

But also, watching mom and dad and financial hardships that it has been on their family, there is no question about that. They are making it through it. They are doing OK. But part of the help that is really needed is a lot of what has been talked about, here such as respite care.

I do not want to get away from encouraging people, and that is the point I was trying to make, by setting up a system where it is just easy. You know, just put them in an institution where it is more expensive, the care and all that kind of thing. Rather let us get people the help that they need so they can stay together as a

family with much home care as is needed. If they need to go into a facility or whatever, get them out as quickly as possible. But keep as much of the incentive there as possible to keep families together.

I think, overall, if we set that out as one of our main goals, I think that we can form the right policies up here to take care of the problem that people are concerned about. The problem of impoverishing themselves by going in and then once they go into a facility they are stuck there, and they know they are going to be there for the rest of their lives. We need to go toward where they know that there is some hope, where they are not afraid to get the help because maybe they can end up worse than before; where they were actually a little more independent and those kinds of things.

I think that if we put our heads together and not let ideology get in the way we can get there. It is just a question of how we get there, and I think that if we are willing to work together, I think we can really come up with some policies that will be good for the country and that will be more affordable. I do not think any of it is affordable, especially with our aging population. But it is a question of what is going to be more affordable, and I think that doing the right thing and trying to keep family as much together as possible and doing the things like Governor Dean is doing, is a more affordable way to do those things. You help more people and you keep them in situations where the quality of life is better as well.

So I think, overall, all of those goals can work together and I really want to applaud your leadership, Mr. Chairman. You have really done a great job.

The CHAIRMAN. Thank you very much, Senator Ensign, and thank you for being with us for the entire hearing.

I think today's hearing really represents a wake-up call to America about the enormous challenge and the enormous problems, but also at the same time the enormous opportunities that those challenges present us in addressing something that is not going to go away. The Congress can talk about it, but until we start acting, the problem will only increase in its severity and the challenge of helping to solve it.

Again, the Aging Committee has done a summary of all 13 hearings we have had with ideas and concepts, and hopefully, we can build on that report that we have presented and move forward aggressively with legislation to try to address this problem. It is one of the top priorities, I think, that this Congress should face.

I want to also recognize the son of Frances Stevenson, a woman from Napoleonville in Louisiana. Her son, Major Stevenson, is here and we thank him for attending our hearing, and also, again, my wife and our teacher interns from Louisiana who have sat through this long hearing and hopefully have an idea of how their government works.

The panel has just been terrific. We thank each and every one of you very much for your presentations, and with that, the committee will stand adjourned.

[Whereupon, at 11:06 a.m., the committee was adjourned.]

APPENDIX

Statement for the Record Submitted by the
American Association for Geriatric Psychiatry to the
Special Committee on Aging
United States Senate
Hearing on
Long-Term Care Financing: Blueprints for Reform
June 20, 2002

The American Association for Geriatric Psychiatry (AAGP) is pleased to have the opportunity to submit a statement for the record on long-term care financing and the reforms needed in the current patchwork of systems under which care is provided. AAGP is a professional membership organization dedicated to promoting the mental health and well-being of older people and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists, as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP recognizes the exceptional work that has been done by the Special Committee on Aging in recent months in holding hearings and developing a report on the full spectrum of long-term care issues facing our nation. In our statement today, we will address a number of financial barriers to care that are of particular concern to older Americans with psychiatric and mental health impairments.

It is important to note that numerous studies show that at least half of all nursing home residents have a dementing illness and the prevalence of depression in nursing homes is about 20 percent. As our society rightly focuses on finding ways to allow elderly Americans to remain at home or in community settings and to remove the current system's bias towards institutional care, it is crucial that we acknowledge the nature of the illnesses that, more and more, are the impetus for institutionalization. Early diagnosis and interventions in mental disorders, as well as help and training for caregivers, are necessary if we are serious about changing the *status quo*. For those elderly persons who are in skilled nursing facilities, there are a number of important mental health issues that must be addressed if the frailest of our fellow citizens are to be able to live out their lives with dignity.

With respect to services provided by Medicare, there are two systemic issues that constitute major barriers to patients who require psychiatric services.

First of these is the issue of mental health parity. The lack of mental health parity in the private market has been much on the public agenda in recent years, as it should be. It is an issue for Medicare beneficiaries as well: Medicare imposes a 20 percent co-insurance rate on most outpatient services except for mental health services, which require a 50 percent co-insurance rate. That unfair bias in the system – a product of and continuing contributor to the stigma tragically associated with mental illness – is a major barrier to access to care. In addition, the distinction causes confusion and improper carrier reimbursement decisions, such as the continuing decisions by carriers to reimburse only 50 percent for medication management services in patients with Alzheimer's disease and other dementias, contrary to specific instructions issued by the Centers for Medicare and Medicaid Services (CMS).

Second, even if patients have access to mental health practitioners, they must also be able to have access to the necessary treatment. Prescription drugs are essential components of treatment for a number of mental illnesses – and an outpatient prescription drug benefit, including full coverage of psychotropic medications, must remain high on the Congressional agenda.

Other changes to the Medicare system which would benefit geriatric patients with mental health needs would include broader coverage of case management and care plan oversight, now limited to patients who are receiving home care or hospice care; full coverage of Medicare/Medicaid cost-sharing for low-income patients; and revisions in reimbursement policies for services delivered in assisted living facilities

For patients in skilled nursing facilities, there are similar disincentives to appropriate care built into the reimbursement policies and systems. Most mental health services in nursing homes are funded by state and federal Medicare and Medicaid payments and are therefore subject to changes in reimbursement policies and restrictions. Efforts to control expenditures through caps on nursing home beds, restrictions on reimbursed services, and below-going-rate reimbursements for services provided restrict the ability of most nursing homes to increase levels of mental health services. Staffing requirements under Medicare do not address needs for assessment and psychiatric treatment of residents. Regulatory requirements focus on screening for mental illness, a system that itself is inadequate, but even with screening, necessary mental health services are all too often inadequate or unavailable.

Among the barriers that make it difficult to improve mental health services in nursing homes is the confusion in funding sources. The split between institutional payment for facility-based services (Medicare Part A, Medicaid, private insurance, self-payment) and individual payment for professional providers (Medicare Part B) creates an artificial distinction between needs of individual residents and those of facilities in assessing, understanding, and designing treatment for these needs. The consequent problems ultimately lead to inadequate mental health care – or no care at all.

Another important factor in the lives of our patients is that virtually all of the frail elderly are dealing with comorbidities that may include physical as well as mental ailments, circumstances that require careful collaboration among patients, families, caregivers, and practitioners from a variety of health care disciplines. Reimbursement for services under these conditions is cumbersome at best and is often a barrier to best practices.

In conclusion, AAGP would reiterate that access to appropriate mental health services is at the heart of providing the long term care to elderly Americans in the way that is most desired by patients, their families, and health care practitioners. The financial barriers imposed by an antiquated structure, complicated by antiquated notions of mental illness and treatment, must be reformed. AAGP appreciates the leadership exhibited by this committee, and we look forward to working with Senators in finding solutions to the problems that have been identified in the delivery of long term care in our nation.

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