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LONG-TERM CARE: WHO WILL CARE FOR THE AGING BABY BOOMERS?

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

FIRST SESSION

WASHINGTON, DC

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CONTENTS

	Page
Opening statement of Senator Russell Feingold	1
Statement of Senator Thomas Carper	3
Statement of Senator John Breaux	4
Statement of Senator Larry E. Craig	17

PANEL I

Hon. Tommy G. Thompson, Secretary, Department of Health and Human Services	5
David F. Durenberger, Chairman, Citizens for Long-Term Care	24
Carol V. O'Shaughnessy, Specialist in Social Legislation, Congressional Research Service	68
Robert B. Blancato, Executive Director, The 1995 White House Conference on Aging; and President, Matz, Blancato & Associates, Inc.	87

LONG-TERM CARE: WHO WILL CARE FOR THE AGING BABY BOOMERS?

THURSDAY, JUNE 28, 2001

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

The committee met, pursuant to notice, at 11:20 a.m., in room SD–226, Dirksen Senate Office Building, Hon. John Breaux (chairman of the committee) presiding.

Present: Senators Breaux, Feingold, Carper, and Craig.

OPENING STATEMENT OF SENATOR RUSS FEINGOLD

Senator FEINGOLD. We will call the committee come to order.

The chairman, Senator Breaux, is on his way from the floor and is very involved with the patients' bill of rights. He will be here shortly, but I would like to begin the hearing.

This is the first in a series of hearings that Chairman Breaux has called on the subject of long-term care, and I am just delighted that he has done this. I can't imagine an issue that is more important for the future of our country, and I commend him for taking this step.

I am especially pleased, of course, to have the honor of starting this hearing because the first witness, Secretary Thompson, who I still prefer to call Governor Thompson, is the very first witness.

There is no more appropriate witness that we could have here today than the Secretary.

I have worked on long-term care issues for nearly 20 years now, first as a member of the Wisconsin State Senate, where I chaired the Aging Committee for 10 years, and now as a member of the U.S. Senate and this committee. And when I was elected to the State Senate in 1982, Senator Thompson was already a distinguished legislator and a part of the leadership in the State assembly.

Four years later, he was already overseeing the State's long-term care programs as our Governor. The State experience in long-term care he brings with him to his current position is extremely valuable, because it is really at the State level that most of the work on long-term care reform has been done.

As Secretary Thompson will attest, long-term care is not a partisan issue, at least it has not been in Wisconsin. The reforms we have been able to enact in Wisconsin, and especially the Community Options Program, which is the centerpiece of those reforms, was very much a bipartisan effort.

The program was actually begun under Governor Lee Dreyfus, a Republican Governor. It was greatly expanded under Governor Tony Earl, a Democrat, and then further expanded and fostered under then-Governor Thompson.

This kind of bipartisan political consensus should not be a surprise. Members of both parties in State government know all too well what we face. They know that the current system is a train wreck waiting to happen.

In Wisconsin we saw the train wreck beginning to happen earlier than other States, in large part because we had so many nursing homes. And the prospect of an exploding Medicaid budget actually motivated policymakers to initiate some structural reforms to help alleviate the problem.

And let me emphasize, however, that Wisconsin has been able to buy itself some time because of those reforms but not completely avoid the coming crisis.

States cannot rely solely on their own resources to tackle this problem. A sustainable solution can only come with fundamental Federal reforms of our long-term care system.

In previous Congresses, I introduced legislation that I believe is a sustainable solution based on Wisconsin's long-term care reforms. It allowed States to provide those needing long-term care with the kind of flexible, consumer-oriented, consumer-managed services that we have seen in Wisconsin that will actually lower long-term care costs.

It paralleled the long-term care reforms that had received bipartisan support during the larger health care reform debate of the early 1990's, reforms that were the result of a multiyear effort by long-term care reform advocates.

Long-term care reform has not been on the national agenda in a serious way, in my view, since that time. With the exception of a few improvements, such as the family caregiver provisions included in the reauthorization of the Older Americans Act, we have only really treaded water at the Federal level, and we have left States to fend for themselves in this area.

Despite this lack of support, some States have done some wonderfully creative things with the resources they have.

And in this regard, Secretary Thompson deserves a great deal of credit for the work done in Wisconsin to create the Family Care Program, which utilizes existing Federal Medicaid waivers to package together a much more flexible system of long-term care services. This is something I think other States will want to examine, and I want to touch on that with the Secretary later.

So let me again thank the chairman for calling these hearings. Long-term care reform has been a long time coming. It has been 7 years since the Senate has considered it in a serious way. I hope we will not wait another 7 years before finally taking action.

With that, I am delighted to turn to my friend and the Secretary, Tommy Thompson.

Secretary THOMPSON. I wonder if Senator Carper would like to make an opening statement?

STATEMENT OF SENATOR THOMAS CARPER

Senator CARPER. Well, I do, but I don't want to delay Governor Thompson's testimony.

But I do have—let me just do this first thing.

I just left the Senate floor. Senator Breaux was awaiting the outcome of the vote on his amendment. He said: I don't want to leave until I am sure what is going to happen.

So he should be along very, very shortly.

Let me just say welcome to my old colleague—I shouldn't say old colleague—my former colleague. [Laughter.]

And it is great to see you, great to be with you. And I wish you, as you know, all the best in your new job.

All right, if the chairman were here, I would thank him—or ranking member—for calling today's hearing. And I certainly thank our witnesses, including our lead-off witness, for testifying.

It seems like the most important issues do not always receive the most attention, either here in the halls of Congress or from the media. And I think it is great that this committee today is shining the light on a potential crisis and one that is under appreciated but is very serious nonetheless.

And as I get older—I am 54 this year—I continue to appreciate more the seriousness of this issue.

I often say that our health care system in this country resembles what I describe as a patchwork quilt and one that, for that matter, is fraying a bit at the edges for many of our people.

If our system of health insurance is a patchwork quilt, I think it is fair to say that our system of long-term care is a crazy quilt. [Laughter.]

As Senator Durenberger will testify later on, "There is no national cohesive long-term care system," in this country. And Senator Durenberger will also attest this makes what system we do have, "inefficient, inequitable, and often ineffective."

Most Americans believe that Medicare will cover their health care needs when they retire. Most Americans don't know if they end up in a nursing home, Medicare won't cover the cost. Most Americans don't know that the single largest payer of long-term care, Medicaid, requires that people effectively impoverish themselves in order to access public assistance.

I have seen firsthand the high cost of long-term care. My mom, who is almost 79 years old, today lives in a terrific nursing home in Ashland, KY, where she battles Alzheimer's disease and requires constant care to maintain her quality of life.

As the father of two young boys, I also worry that our children will someday face the same problems as our generation, my generation, ages.

The cost of long-term care will be a growing burden for our nation to bear. In the absence of reform, I question whether we can carry that burden.

The magnitude of this challenge suggests the needs for some significant Federal response.

At the same time, as a former Governor who made use of a Medicaid waiver to expand options for home and community-based long-term care, and to help people stay out of institutional care wherever possible, I know that sometimes the best thing the Fed-

eral Government can do is to give States and local communities the flexibility that they need to meet local needs.

We all know that this is a complicated issue. That is why hearings like this one are so important. I look forward to hearing from our witnesses, and I am especially pleased to welcome Governor Thompson.

STATEMENT OF SENATOR JOHN BREAUX, CHAIRMAN

The CHAIRMAN. Thank you, former Governor Carper and former Governor Thompson, and thanks to the committee for getting started.

I was on the floor with an amendment. We were just kind of waiting on the outcome of it. And——

Senator CARPER. Well, what happened?

The CHAIRMAN. It passed. [Laughter.]

If it had failed, I wouldn't have shown up. [Laughter.]

But, no, it passed, and we are happy.

I won't delay the Secretary's statement any longer. And I do want to say that this committee is particularly concerned about the questions that longevity bring to us as a society and us as a Congress in particular.

I have often said that the good news is that people are living a lot longer; the bad news is that people are living a lot longer.

And what I mean by that is that we certainly are happy that medical technology and science has allowed life expectancy of women to be almost 80 years of age and men almost 75 years of age, and that is good. But it also presents society an incredible number of problems on how we take care of those people in their golden years.

It is not enough for people just to live longer; they also must be allowed to live better. And I think that is the real challenge that we have.

And when you look at the fact that most of the Federal dollars that are spent on helping seniors, in terms of how they spend those years, so much of it is spent in institutionalized care, which I think is not necessarily the best way to be spending those dollars.

I mean, what you have done in your State, in Wisconsin, as a leader, is something that is very important to the rest of the country to hear about.

And we are spending anywhere from $40,000 to $80,000 a year in putting people in nursing homes. I seriously question if that is the best procedure for the majority of senior citizens in this country.

We have 77 million baby boomers who are rapidly approaching that period of time when they are in their golden years. So we are going to have a lot more people living a lot longer. I mean, that is the huge challenge that we face as a society.

And this hearing is really to try and hear, Mr. Secretary, what you did in your State and what your ideas are about what we might be doing as a Nation under your leadership as Secretary of Health and Human Services, and what we might do as a committee and as a Congress to try and help you to reach that goal of allowing people to live longer but also allowing them to also live better lives.

So we are happy that you are here. We apologize for the delay, and happy to hear from you.

[The prepared statement of Senator John Breaux follows:]

PREPARED STATEMENT OF SENATOR JOHN BREAUX

I have called for this hearing-the first in a multi-part series on long-term care in an effort to provide a forum for examining the potential crisis we face given the changing demographics in this nation. Advances in medical technology ensure that most of us will live into our 70s and 80s. When one pairs that fact with the statistic that there are 77 million baby boomers who are aging, it is apparent that there will be increasing demands on our long-term care system in the next couple of decades.

I am especially grateful to Secretary Thompson for taking the time out of his busy schedule to be here with us today. The Secretary was committed to finding innovative solutions to funding long-term care when he was Governor of Wisconsin and he brings that same commitment to his new capacity. I look forward to hearing about the federal initiatives that I know that the Department of Health and Human Services has commenced in an effort to support states in their long-term care efforts.

I believe today's hearing will provide an opportunity for all of us to gain an improved understanding not only of the current status of long-term care services and how they are financed but also a sense of what the future is likely to behold. We all know that the population aged 85 and older is the group most likely to need assistance with daily living. Whereas in 1998 there were 4 million Americans in that age group, the U.S. Census Bureau expects that number to jump to 7 million by the year 2020-a vivid illustration of the new demands that will be placed on the system in the near future.

I feel that the time is ripe for a call-to-action on the issue of long-term care-and that is the purpose of today's hearing. Policymakers, providers and consumers need to partner to determine the most appropriate avenues for reform. Today's hearing will provide all of us with a better sense of what this nation's long-term care population is facing and I look forward to subsequent national dialog on this issue so vitally important to America's seniors.

STATEMENT OF HON. TOMMY G. THOMPSON, SECRETARY, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Secretary THOMPSON. Thank you so much, Chairman Breaux.

And let me just start out by thanking you for your leadership and your vision. Congratulations on your amendment.

And the nice thing about being in front of you, Senator Breaux, is it gives me an opportunity to thank you for your leadership in so many issues. And this issue is probably the most important one of all the ones that you have taken such strong and passionate leadership. And I just want to take this opportunity to thank you and compliment you.

My good friend, Russ Feingold, truly was a leader back in Wisconsin on aging problems. He was the chairman of the Special Committee in the State Senate, and he led the efforts on our very good and comprehensive Community Options Program so elderly citizens could stay in their own home, and he also took a very strong and passionate leadership on Alzheimer's.

And I am sorry he is not here so that I could compliment him in person. But I am sure that somebody will tell him that I said nice things about him. And they are well-deserved, and I want to applaud him.

Senator CARPER. I will tell him. [Laughter.]

Secretary THOMPSON. And, Senator Carper, it is always a pleasure—it is difficult for me to call you Senator, because—I know it is difficult to get over the word "Governor."

Senator CARPER. I still call people on the phone, I say, "Hello, this is Governor Carper," and they say, "Oh, no, it isn't." [Laughter.]

"Wait a minute. What happened?" But I thank you so very much for your friendship and partnerships on so many efforts that we have teamed up together on in the past, and I am sure we will in the future. And I thank you so very much for being here.

This hearing is so important regarding the long-term care needs of our Nation's elderly and our disabled citizens.

In 1900, a person born in the United States could expect to live 49 years from birth. In the course of the past century, we have added nearly three decades to the life expectancy of a newborn.

Three decades is also about how long we have had Medicare and Medicaid. These programs have served millions of Americans very well. Yet as the population of older Americans has grown and as the possibilities for new kinds of long-term care have increased, Medicare and Medicaid have pretty much remained the same as when they were first begun in the mid–1960's.

And I know that, Senator Breaux, you have taken a leadership in this effort, and I absolutely compliment you on that.

For example, Medicaid will pay for your care in a nursing home. But if a State, like Delaware, Wisconsin, Louisiana, wants to pay for respite care—that may help keep families together and be a better alternative—it has to come to Washington, DC., for a waiver. That just doesn't make any sense to me, and I am sure it doesn't make any sense to you.

It is time to modernize Medicare and Medicaid, to customize them to meet the wide array of needs of our growing population of senior and disabled Americans.

And one of the key elements of this modernization is the transformation of long-term care.

Long-term care used to be limited almost exclusively to nursing homes, as you mentioned, Senator Breaux, which consumed a substantial amount of the Medicaid budget. Now long-term care can be provided in a wide range of settings and today accounts for one-quarter of total Medicaid long-term care expenditures.

There are more choices than ever for persons who are elderly or have a disability, and I think that is great. But I think we can do a much better job.

The States are providing long-term care with the aid of about 250 home and community-based waivers from the Department of Health and Human Services. These waivers provide approximately $7 billion of care, funding that enables the State governments to serve more than 1 million people. We are working with a few States to pilot waivers that allow for a much more positive, complete, coherent system.

Public service at every level of government must do a better job of preparing for the future. That is why the proposals outlined in the President's New Freedom Initiative are so promising and encouraging.

The New Freedom Initiative is designed to break down the barriers faced by the 54 million disabled Americans. His proposals will give our elderly and disabled the freedom to participate more fully in the community and, yes, in the workforce as well, a goal that

everyone shares. And it is a goal shared by all three political parties: the independent, the Republican, and Democrat.

Mr. Chairman, we have no time to lose. Today the 35 million people aged 65 or older account for about 13 percent of the total population. It is projected that this population, or one in five, will be age 65 or older in a few years.

Preparing for the future requires us to rethink the strategies of the past. Innovative approaches to delivery of long-term care services have the potential to preserve the independence and enhance the quality of life of all of our seniors, and be able to enjoy it in a cost-efficient manner.

The Federal Government now provides 60 percent, nearly 60 percent, of the funding for nursing home care. Providing quality, cost-effective care is going to become increasingly important as the baby boomers age.

Community-based care could save individuals and families and taxpayers and the government a substantial amount of money. More importantly, it promises to help seniors more fully sustain their independence and their personal freedom.

In addition, while today's hearing is focused on community-based alternatives to nursing homes, let me touch briefly on the subject of nursing homes.

Nearly 3 million Americans spend at least some portion of the year in our nursing homes.

Let me share some good news. According to the second annual CMS report—that is the old HCFA, now Centers for Medicare and Medicaid Services, CMS—their report on nursing homes quality, several quality indicators point to some very positive emerging technologies and trends.

For example, since 1998, there has been a 35 percent decrease in the proportion of deficiencies for care problems resulting in actual harm to nursing home residents.

That is going in the right direction. Am I satisfied? No. Should anybody be satisfied? No.

But nursing homes cited for immediate jeopardy represent fewer than 2 percent of all nursing homes. Improper use of physical and chemical restraints has also declined. And the problems of involuntary weight loss is on a downward trend.

This news is encouraging. Is it good enough? No, but it is encouraging, and we are going in the right direction, and we want to continue to build upon it.

But we face serious nursing home worker shortages that compel us to look for creative solutions to this problem. To help us address these issues, I have discussed with Labor Secretary Elaine Chao to ask the Labor and HHS to work collaboratively to find effective solutions. Our staffs plan to meet early next week to map out a new strategy that would join the DOL's training dollars with nursing programs supported by HHS.

I plan to investigate other cross-departmental opportunities to see if we can address this nursing shortage on a governmentwide basis.

We also are going to make a fresh examination of the Medicare and Medicaid regulations to determine if current regulations actually present barriers to training needed workers.

And we are also working to identify and publicize promising State-developed practices.

In Wisconsin, we have utilized the single-task workers for several years in situations that are safe and appropriate. So today I am announcing that the Centers for Medicare and Medicaid Services will be providing administrative guidance to the States to enable greater use of single-task workers in transporting nursing home residents from one area of the facility to another, under supervision and under training. CMS will issue a proposed regulation to address other types of single-task as well.

But even with these improvements in nursing care, States are still facing the barriers in the development and implementation of community-based care systems, including the Medicaid program itself.

Medicaid seems to have a bias toward institutional care, a bias rooted in the experience of earlier years when nursing homes were almost the only alternative. That is apparent in kinds of services that are offered, as well as in determining the eligibility.

But institutional care is only one of several options. As Governor of Wisconsin, I had the opportunity, under the supervision of the Federal Government, to get a waiver to pilot another approach, the Family Care, the Pathways to Independence Program.

As we redesigned our own State's long-term care system, we introduced the Family Care benefit to our Medicaid programs. This benefit offers State coverage of long-term care services for elderly Wisconsin citizens, as well as other adults with disabilities.

Aging and disability resource centers were then established in each participating county. Seniors, as well as others eligible for the benefit, are now able to go to the centers to obtain program information, seek counseling and be enrolled in a care-maintenance organization, the entities responsible for managing those benefits.

The Family Care Program allows seniors to choose their own personal care setting and integrates personal and family as well as physician assessments into a care plan, which is individualized for each individual senior.

Its principles are simple: Give people the information they need to make the positive decisions. Do it in a way that they can understand it, and in a one-stop shop environment so they can go there and get the necessary treatments that they need. And make the funds flexible so that they follow the individual, not the funds flowing to the institution, so they follow the person to the most appropriate setting, paying for what that individual person needs.

Another initiative, which is called the Program of All-Inclusive Care for the Elderly, or PACE, also offers very good promise. PACE operates from a managed-care model and provides comprehensive and high-quality medical, social and long-term care services to the frail elderly eligible for nursing home care. This helps these older citizens maximize their autonomy as well as their continued community residence.

Finally, we should support those families that provide the majority of long-term assistance to the loved ones requiring help due to injuries, accident of birth, disability, or long-term illness. Their efforts are providing those in need with what is usually the best care available.

The Caregiver Support Program, which was recently announced by our Administration on Aging, is a dynamic new initiative. And I hope our efforts with community-based long-term care will continue to reveal additional ways that the Federal policies are able to be made more family friendly.

Personal savings are going to become an increasingly important component of long-term care financing as our elderly population continues to grow. We must take the steps today that will encourage people to start saving for tomorrow.

Specifically, the president has proposed that individuals be allowed to deduct the cost of purchasing eligible, private long-term care insurance. This will provide, hopefully, the incentive, or an additional incentive, for people to take greater financial responsibility for their long-term care needs and will encourage the use of long-term care insurance.

By providing tax deductibility for policies that meet the eligibility standards, quality long-term care insurance will play a larger role in the financial security of older Americans. And by making such incentives available, more employers will join the trend in offering long-term care benefits to their employees.

This concept recognizes that individuals have a responsibility to plan for their future and empowers them to do so with the help of their employers.

Employer-sponsored long-term care plans would be subject to ERISA and the protection it affords participants and beneficiaries.

We have also proposed allowing the taxpayers to claim an additional personal exemption for providing long-term care to qualified family members who live in the taxpayer's home. Providing such an exemption would recognize the formal and informal costs to family caregivers that provide long-term care.

Community-based care can be tailored to the needs of the individual and can maximize the independence of the men and women who need assistance. It can also alleviate some of the burdens that our family caregivers are currently facing, enabling more individuals to remain in their homes.

To get started on the enormous task at hand, I have asked Tom Scully, the CMS administrator, to begin identifying issues that we must consider as we evaluate how to improve our long-term care service delivery system.

He will be reaching out to the States and to other parties, and especially to this committee, with interests in long-term care, including ordinary citizens, medical associations, nursing facilities, and senior citizen groups. Mr. Scully will discuss with these groups the critical decisions that must be made as we determine how we can best provide long-term care to those who need it.

We have taken some important steps in helping our States transition to community-based care, and I can assure you that the administration looks forward to working with you on a bipartisan basis as we begin to equip our States for such a shift.

And so, therefore, thank you, Mr. Chairman, for your concern, your passion for this important issue. And at this time, I am pleased to answer your questions and those of other committee members.

[The prepared statement of Secretary Thompson follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

The Assistant Secretary for Planning and Evaluation
Washington, D.C. 20201

STATEMENT

BEFORE THE

SENATE SPECIAL COMMITTEE ON AGING

TOMMY G. THOMPSON

SECRETARY

DEPARTMENT OF HEALTH AND HUMAN SERVICES

JUNE 28, 2001

Good morning, Chairman Breaux, Senator Craig, and distinguished Members of the Senate Special Committee on Aging. Thank you for this opportunity to speak before you today regarding the Administration's efforts to address the long-term care needs of our nation's elderly and disabled.

At the turn of the 20th century, life expectancy at birth was 49 years. In the course of one hundred years, we have added nearly thirty years to the life expectancy of a newborn. Think of the changes witnessed by a person who was born in 1900. There are indeed about 65,000 people age 100 years or older. Now consider that Medicare and Medicaid have been around for about one-third of their lifetime. Yet the fundamental design of these programs has not really changed in the past 35 years. Yes, Medicaid will pay for your care in a nursing home, but if a state wants to pay for non-Medicaid services that may help keep families together such as respite care, it has to come to Washington for a waiver.

It is past time to modernize the Medicare and Medicaid programs. To address the needs and innovative care options of the 21st century, fundamental improvements in these programs are overdue.

Long term care used to mean nursing homes spending for the elderly exclusively. But today, home and community care spending accounts for one quarter of total Medicaid long-term care expenditures. There are now more choices than ever before for persons who are elderly or have a disability. Helping individuals stay in their own home for as long as possible is generally the best choice for beneficiary and taxpayer alike. The states are operating about 250 home and community-based waivers that serve more than one million individuals at a federal cost of approximately $7 billion. But, as I said, to do these things, states must apply for waivers. And the waivers themselves are time-limited.

Government must do a better job of preparing for the future. Tax incentives, home and community-based waivers, state-level buy-in programs – all of these are important components of any discussion on long-term care solutions. New proposals such as those outlined in the President's New Freedom Initiative will give our elderly and disabled the freedom to participate more fully in the community and the workforce – a goal that is shared by all.

Impact of the "Baby Boomers"

The members of this Committee know so well the statistics about the rapidly rising growth in the number of Americans who are aged 65 years and older. Today, the 35 million people aged 65 or older account for about 13 percent of the total population. It is projected that by 2030, one in five people will be age 65 or older. Preparing for the future requires us to rethink the strategies of the past. Innovative approaches to long-term care service delivery have the potential to preserve the independence and the quality of life of our seniors in a most cost-efficient manner.

Even though the first of the baby boom generation will turn 65 in 2011, the likely use of nursing homes does not really begin until a person reaches age 75. But the impact of the baby boomers is already being felt, as they are demanding access to care and more choices for their parents.

Government now provides nearly 60 percent of the funding for nursing home care. The ability to provide cost-effective care in a manner that maintains the high quality of services and preserves individual dignity will become increasingly important as our Baby Boomers continue to age. Community based care as an alternative to placement in institutions clearly presents the potential to save the individual, the family, the taxpayer and the government money. Working towards developing and implementing such systems prior to the retirement of our Boomer Generation will allow us to both maximize and leverage our current and future resources.

Quality of Care in Nursing Homes

While today's hearing is focused on community-based alternatives to nursing homes, it is appropriate to touch briefly on the subject of nursing homes as well. Nearly three million Americans spend at least some portion of the year in our nursing homes. We all want to be assured that our vulnerable senior citizens are receiving quality care. Today, I can give you a glimpse of the progress we have found in compiling the second annual report on nursing home quality that will be released later this year.

There is no question that the nursing home industry has been struggling in recent years. The industry has faced a number of challenges, but there seem to be a number of positive emerging trends on a few quality indicators.

- Since 1998, there has been a 35 percent decrease in the proportion of deficiencies for care problems resulting in actual harm to nursing home residents.

- Nursing homes cited for immediate jeopardy represent fewer than two percent of all nursing homes.
- Improper use of physical and chemical restraints has declined.
- The prevalence of involuntary weight loss is on a downward trend.

This news is indeed encouraging and we want to continue to build upon these trends.

Worker shortage will continue to be a major pressure point on the long term care industry generally and especially the nursing home industry. We must look for creative solutions to this problem, in addition to improved methods of recruitment and retention in nursing homes and for care in the community. Currently, we are planning to undertake a collaborative effort with states, foundations, and several other stakeholders to develop innovative ideas to address the issue of worker shortage in community care settings. We are also working to identify and publicize promising state-developed practices.

For example, in Wisconsin, we have successfully utilized "single task workers" for several years in situations that are safe and appropriate. Today, I am announcing that the Centers for Medicare and Medicaid Services will provide administrative guidance to the states that will enable greater use of signle task workers in transporting nursing home residents from one area of the facility to another. CMS will also issue a proposed regulation to address other types of single tasks as well.

New Approaches to Community-Based Care

Despite the benefits of community-based long-term care, the states still face some barriers in the development and implementation of such a service delivery system, including the Medicaid program itself. It has been said on a number of occasions that the Medicaid program has an inherent "bias" towards institutional care. There is no question that law requires that each state offer nursing home services under the Medicaid program, while allowing states the option of providing community based services. The good news is that, working together, the states and the federal government are making real progress in developing and offering community based services with these services outstripping institutional growth every year.

A critical component of developing a community-based system is making it both manageable and understandable. One particular area that is receiving a great deal of attention but as of yet, not much action, is serving the population referred to as the "dually eligible." These aged or disabled individuals are eligible for both Medicare and Medicaid. The 6.4 million individuals who are enrolled in both

Medicare and Medicaid represent only 19 percent of the Medicaid population but account for 35 percent of Medicaid spending.

States are interested in learning more about how to make all available services work together in the community, and do so in a fashion that will make sense to an elderly person or an individual seeking public help for the first time.

As Governor of Wisconsin, I had the opportunity to pilot one such approach – the Family Care. In order to redesign our state's long-term care system, I signed legislation that introduced the Family Care benefit to our Medicaid program. This program offers state coverage of long-term care services for Wisconsin elderly and other adults with physical or developmental disabilities. Aging and Disability Resource Centers will be established in each participating county, where seniors and others eligible for the benefit can obtain program information, seek counseling, and be enrolled in a Care Maintenance Organization – the entities responsible for managing the benefit.

The goal of Wisconsin's new program is to keep seniors in their community longer, involve them more in the decision-making process regarding their care, and reduce the costs to both families and the state for long-term care. Family Care allows seniors to choose their care setting – be it at home, in an assisted living facility, or in a nursing home – and integrates personal, family and physician assessments into a care plan individualized for each senior. Its principles are simple: (1) give people the information they need to make decisions about their lives; (2) do it in a way they can understand , and do it in a "one-stop shop" so that they don't need to run around; and (3) make the funds flexible so that they follow the person to the most appropriate setting, paying for what the person wants.

Also embracing the merits of providing our seniors with care in the community is the Program of All-Inclusive Care for the Elderly, commonly known as the PACE program. Operating from a managed care model, these programs provide comprehensive, high quality medical, social and long-term care services to frail elderly persons eligible for nursing home care to maximize their autonomy and continued community residence.

Further examples of community-based care can also been seen in Florida, where managed long-term care delivery models are being piloted to provide individuals with feasible alternatives to nursing home care. Project services are based upon the needs of each project participant, and are designed to maximize home and community-based alternatives. Additionally, Florida is piloting the CARES program – Comprehensive Assessment and Review for Long-Term Care Services. This is a nursing home pre-

admission assessment program, where a CARES nurse or social worker, as well as a physician, assesses persons applying for Medicaid nursing home care prior to approval. The goal of this program is to prevent unnecessary or premature admission to a nursing home.

States are also interested in ensuring this system is a responsive one – one in which available funds will follow the person to the most appropriate and cost-effective setting of their choice. Today's systems are not designed in this way. However, we are currently working with states – such as Florida, Wisconsin and Michigan – to pilot waivers that allow for a more coherent system.

Finally, we should support those families who are today providing the majority of long-term assistance to their loved ones who require help due to injury, accident of birth, disability, or long-term illness. Their efforts are providing those in need with what is usually the best care available. I am pleased with the new Caregiver Support Program recently announced by our Administration on Aging, and I hope that our efforts with community-based long-term care will continue to reveal additional ways that our federal policies can be made more family-friendly.

An Early Start to Long-Term Care Saving: Tax Incentives

Personal savings are going to become an increasingly important component of long-term care financing as our elderly populations continue to grow. We must take steps today that will encourage people to start saving for tomorrow. To that end, the Administration has developed a pair of tax proposals that will: (1) induce people to begin investing in long-term care; and (2) reduce the financial burdens that providing in-home long-term care is placing on family caregivers.

Specifically, the President has proposed that individuals be allowed to deduct the cost of purchasing eligible private long term care insurance. This will provide an additional incentive for individuals to take greater financial responsibility for their long-term care needs and will further encourage the use of long-term care insurance. With the incorporation of tax deductibility for policies that meet eligibility standards, quality long-term care insurance will play a larger role in the financial security of older Americans. By making such incentives available, more employers will join the trend in offering long-term care benefits to their employees. This concept recognizes that individuals have a responsibility to plan for their future, and empowers them to do so with the help of their employers. Also, employer-sponsored long-term care plans would be subject to ERISA and the protections it affords participants and beneficiaries.

Additionally, the Administration has proposed that taxpayers be allowed to claim an additional personal exemption for providing long-term care services to qualified family members who live in the taxpayer's home. Providing such an exemption would recognize the formal and informal costs to family caregivers that provide long-term care.

Conclusion

Given the many steps that must be taken before a community-based long-term care system can be fully implemented, it is vital that we begin our partnership with the states immediately. We can shift our focus and our resources away from automatically placing people in institutional settings and towards empowering those who are able to reside in settings that are community-based. And, this is a transition that our citizens support.

Community-based care can be tailored to the needs of the individual, as well as maximize the independence of our elderly and disabled. Further, it can alleviate some of the burdens that our family caregivers are currently facing, enabling more individuals to remain in their homes. We have taken important steps in helping our states transition to community-based care, and I look forward to working on a bipartisan basis with this Administration and this Congress as we begin to equip our states for such a shift.

At this time, I am pleased to answer any of your questions.

The CHAIRMAN. Mr. Secretary, thank you very much for a very detailed and very fine statement about the principles and things you are trying to accomplish, as well as what you have done also in your State of Wisconsin.

We have been joined by our ranking member, Senator Larry Craig.

Senator Craig, do you have any comments you would like to make?

Senator CRAIG. Well, Mr. Chairman, first let me ask unanimous consent that my statement be a full part of the record.

The CHAIRMAN. Without objection.

[The prepared statement of Senator Craig follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Good morning. I am pleased to join John today in helping launch what promises to be a valuable series of hearings examining the challenges of assuring affordable, accessible, and flexible long-term care to America's seniors—particularly now, as the first of the massive Baby Boom generation approach retirement age.

Medicare prescription drugs and Social Security may be getting more ink at the moment, but the looming demands of our faltering long-term care system are perhaps of equal weight and concern. By the time all the Baby Boomers have retired, in approximately 2030, more than 70 million older Americans will be in need of some form of long-term care. And perhaps even more alarmingly, the number of Americans 85-and-older, those most likely to need daily assistance, will nearly double by 2020.

As we prepare to meet this challenge, one issue of particular concern to me—and, I know, to Senator Breaux—is the reality that despite decades of well-intentioned talk, this country continues to devote the lion's share of its limited long-term care funding to institutional nursing home care, rather than to assisting seniors in living independently in their own homes and communities. In addition to being more cost-efficient than nursing home care, home and community based care is vastly preferred by America's seniors and their families.

When a mother or a spouse is only one bad fall away from permanent institutionalization, just a few hours of simple in-home assistance with difficult tasks can make a tremendous difference, not only to the older person's quality of life, but also to his or her family and to the taxpayers. It is families and taxpayers, of course, who often must shoulder the cost of long-term institutionalization—a cost that now averages a staggering $40,000 per year per resident.

Initiatives such as the Older Americans Act Family Caregiver program, which I strongly supported, and which this Committee recently examined, offer modest steps in the right direction. But much more remains to be done. For example, a look at efforts undertaken by many states—including Secretary Thompson's Wisconsin—offers much in the way of encouraging innovation. I understand that state experimentation with long-term care solutions will be the focus of our next hearing, one I am very much looking forward to.

Finally, I would just add that no serious review of our long-term care system will be complete without a serious effort to simplify the current disjointed hodgepodge of long-term care programs and benefits. Navigating the current maze of Medicaid, Medicare, Older Americans Act, block grants, and other long-term care programs is a daunting challenge even for well versed policy experts, not to mention seniors themselves.

We have our work cut out for us, and I am eager to get started. Thank you.

STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Welcome, Mr. Secretary.

We are extremely pleased you are with us today. And I am extremely pleased that John has started a series of what I think are most valuable hearings on the issue of long-term care.

And of course you have outlined some of the concerns, my concerns, about affordability and accessibility and flexibility and all

those kinds of things that really begin to fit as we recognize this massive wave coming at us out there in our demographics.

I am part of that wave, ultimately, as many in this room are. And if we don't have the sense to shape it now or help begin to shape it, I think it is a very, very real problem.

Obviously, Medicare and prescription drugs and Social Security are the items that get the bulk of the ink today. But out there in our future is this long-term care issue that you have clearly recognized and are beginning to take action on it.

I look at these numbers that, by 2030, 70 million older Americans will be in that status of long-term care, and then you keep looking outward and seeing those numbers double, and it says to us so loudly. And that is why we in this committee, I think, can effectively use the committee as a bully pulpit, not only to get attention to and to help you all, but, most importantly, to dramatize the importance of moving in this direction.

Mr. Chairman, I do have some questions.

The CHAIRMAN. OK.

Senator CRAIG. But let me ask you to proceed with questions, and I will come back to them, because I am anxious——

The CHAIRMAN. That will be fine.

Senator CRAIG [continuing.] To see where the Secretary is going and where we might assist him.

The CHAIRMAN. That will be fine. Thank you, Senator.

Let me start by asking maybe sort of a generalized question. I am interested in, how do we as a Nation compare, if you know, with how other developed nations treat their elderly?

It seems to me that in other countries that are developed countries around the world that it seems to be that there is more at-home care for seniors then we do in this country. Is there any indication of what other nations are doing in this area that we can compare with and get some ideas?

Secretary THOMPSON. I am sure there are, Senator. I am not that familiar with what other countries are doing. I haven't taken enough study. I have certainly done a lot of study about what we are doing in the United States, and I just don't think we are doing enough.

I think the way the system was set up in the mid–1960's with Medicare and Medicaid, it was very much, as you have indicated, a bias toward institutionalized care, and we have continued to do that.

And only recently in the 1990's have we started to address alternative care, respite care, and stay-at-home, and setting up programs for that. And it is so much more important for us to continue to do so, and to modernize Medicaid to allow us to provide for the services at home rather than just an institutionalized setting.

And so I think that we have to do a better job. But I can't point to a country that is doing that much better job, but I am sure there are some examples.

The CHAIRMAN. I think particularly in Asia it is sort of a cultural thing that is very important. I like the idea.

I am one of the sponsors of the tax credit for long-term care insurance. I think that is a no-brainer; we should be encouraging that.

I like the idea that you talked about; the Administration has proposed that taxpayers be allowed to claim an additional personal exemption for providing long-term care services to qualified family members who live in the taxpayer's home.

If you think about it, we do that for children. I mean, you have the child tax credit if you are taking care of children. And now if you want to encourage people to help take care of parents or perhaps grandparents in a home setting, is it not appropriate to also have some type of assistance to provide for that?

And I think the concept of a grandparent credit, if you will, whatever you want to call it, would be something that would be good public policy.

Let me just ask, you talked about the waivers, that you have all these States that have applied for 250 waivers to use their Medicaid dollars to do things other than just place people in nursing homes, and you talked about home and community care and the PACE program.

Explain to the committee exactly what do you mean when we are talking about alternatives other than nursing homes, your community-based type of things that the department is allowing States to use their money to do. What are we talking about them doing?

Secretary THOMPSON. Well, there are so many programs out there.

There is the Cash and Counsel program, that has just set up a waiver in four States, in which the money is going to be able to be used for individuals to come in. And they are being counseled and to be able to actually get the cash to purchase services in the community.

There is the COP program, Community Options Program, in which elderly citizens can make the option of staying home. It used to be only with State dollars that you could do it, but then the Federal Government allowed us to come in and get waivers and to be able to use the Medicaid waiver dollars to be able to purchase services.

And what I tried to do in Wisconsin is to set up so that caregivers in the Community Options Program are put into an overall comprehensive program, where, if your uncle or aunt or your mother or father needed services, you would go to a central place and get the information, and actually have the doctor make an assessment, have the parent or brother or sister or son or daughter make an assessment of what that individual needs.

And then the community, that collection point, that center, would purchase the services, whether it would be food, come in; maybe it would be nursing home nursing care for 3 or 4 days a week; maybe come in and just take care of the parent or parents one night a week so that the son and daughter could get out and get away.

It depends upon the individual, but it makes it much more localized, much more individualized, and allows the dollars to follow the individual instead of just flowing to the institution.

The CHAIRMAN. I take it, Secretary, now the State really has to go through a waiver process to be able to use any of that.

Secretary THOMPSON. Absolutely.

The CHAIRMAN. And you would recommend that we would amend the Medicare law when we are doing the reform and modernization, to not make that a necessary step?

Secretary THOMPSON. That is absolutely correct, and allow for the flexibility to do so in order to get the job done, because States have got a lot of things going, and we should allow and encourage that kind of flexibility to look for alternatives to provide long-term care.

The CHAIRMAN. You have given us two good ideas: change the waiver process to allow more flexibility for the States and local communities to do more; plus the so-called—I would call it the grandparent tax credit for caring for people in the home, which are two good, helpful ideas.

Secretary THOMPSON. I think it is good, common sense, Senator.

The CHAIRMAN. OK.

Governor Senator Carper. [Laughter.]

Senator CARPER. Thank you, Senator Chairman Breaux. [Laughter.]

Secretary Thompson, when you were chairman of the NGA, I think you started something, really kicked into gear something called Center for Best Practices to identify those practices within the States which serve as laboratories and showed the way for the rest of us.

Are there any States that come to mind, including your own, any States that come to mind where they are doing an especially good job, a creative job, in approaching these challenges? And how we might incent those States, how we might spread that word, how we might build on those successes?

Secretary THOMPSON. There are a lot of States doing a lot of things, but I am not sure that any one State is doing everything.

Oregon has got some good programs and has taken a leadership role in long-term care. Minnesota has got some good programs. Arizona has got a family care program like we have in Wisconsin. Delaware has some programs.

The new Cash and Counsel waivers that were just granted, three States and one more is coming in. I think it is Arkansas is doing a good job under Governor Huckabee. I believe it is Florida and Arkansas have got these waivers.

But to point out the best State, besides Wisconsin. [Laughter.]

I would be a little bit hard-pressed to do that. But there are good examples out there, and we should encourage that.

Senator CARPER. Are there any arguments against the kind of change in waivers that you have called for?

Secretary THOMPSON. Am I against it?

Senator CARPER. No, are there any arguments—what would be the arguments against doing what you have suggested?

Secretary THOMPSON. Well, you are going to have competition from the nursing home industry, for sure.

And you are going to have competition and opposition from people that think the Federal Government should set all of the standards and make all the programs fit one mold.

I just don't think that is the right—especially in this area. You have to encourage a lot of things.

Louisiana, for instance, under Senator Breaux's leadership, got a nice waiver through at the beginning of the year for children. I think about—if I remember correctly—3,900 children were able to live at home, if I am correct about that waiver.

You know, if it was just the Federal Government, Louisiana would not have been able to get that waiver. If we had just, you know, a one-size-fits-all, Wisconsin could have not tried this Family Care plan that I think is going to be a model for the country.

Senator CARPER. About a year and a half ago, almost to the day, my sister and I were down in Florida at my mother's home. And my mom, we had just moved my mom to this nursing home, I mentioned earlier, up in Ashland, KY, close to where my sister lives.

And we were going through my mom and dad's home, packing things up, a lifetime of memories. One of the things we came across as we were going through—my dad died about a decade ago.

But one of the things we came across as we went through all these boxes and things and papers and through the attic and all, we found an insurance policy. "What is this?" It turned out to be an insurance policy for long-term care that my mother had purchased several years earlier for herself.

And my mom was one of those people in Florida who got phone calls all the time from others who were trying to sell her things—a vacuum cleaner that I remember she paid three times more than it was worth. [Laughter.]

Getting the roof replaced on the house, which was perfectly fine.

But she bought this long-term care policy, which was now about to expire but lasted a couple of years.

You talked earlier about providing some incentives through the tax code to encourage employers to provide and people to acquire. I want you to just go back and just talk about this a little bit more.

My mom did it without the incentive, even without the encouragement of my sister and me. But it was a stroke of genius on her part.

Secretary THOMPSON. Yes, it was.

Senator CARPER. But, what—could you go back and talk a little bit more about the kind of incentives we need to provide through the tax code for employers to offer and for individuals to take advantage of long-term care.

Secretary THOMPSON. What we need to do, Senator, we need to—first off, we need to get information out there.

I don't think we do a very good job of advising seniors, you know, about what is available under Medicare, what is available under Medicaid, what is paid for and what isn't. And to tell them that it is not—if they really want to do what is necessary, they need to have a long-term care insurance policy. And we should be doing more of that.

And, you know, until this committee started holding hearings, I don't think that subject was ever discussed. But to use the tax code, you know, to be able to deduct it.

It is really an investment by the Federal Government, because that long-term care insurance, as your mother had, it certainly helps you and your sister, but it is also helping the Federal Government, because if she didn't have that—or the State governments, through Medicare and Medicaid. It is just an investment,

you know, that is going to save the Federal Government future expenditures.

And so we should use the tax code to encourage them. We should use it so that employers see this is an opportunity for them to give expanded coverage for their employees, to be able to take care of their employees, you know, in their retirement years.

These should be the best years for everybody. They should be beyond their worries. They have raised their children, paid their debts to society. And they should be able to pick and choose where they are going to live and be able to have the opportunity to have long-term care insurance that is going to help subsidize and give them the independence and the quality of life that they deserve and that you certainly want them to have, Tom.

Senator CARPER. Do you have any idea if a dollar sign has been put on this particular proposal, or the other one that you laid on the table, with respect to what was the extra exemption for those who take into their home——

Secretary THOMPSON. That is for the Caregiver program.

Senator CARPER. Any ideas what the price tag on those might be?

Secretary THOMPSON. I did have that figured, and I—but I will send it to you, Tom.

Senator CARPER. Thank you.

Secretary THOMPSON. Thank you, Governor Senator. [Laughter.]

The CHAIRMAN. Thanks so much, Governor.

Questions, Senator Craig?

Senator CRAIG. Well, I think most of them have been covered.

Obviously, to create these kinds of flexibilities, waivers can be granted now to some extent.

Mr. Secretary, are there other legal, structural obstacles within the law that you think we ought to focus on, beyond creating new components, as the chairman was delineating, from a tax credit or deduction?

Have you scanned the law, as it relates to Federal involvement today, to see what other obstacles might be out there that we could reform or adjust to deal with this?

And of course with your, you know, Family Care Program in Wisconsin and the flexibility it gave, what might you suggest?

Secretary THOMPSON. Well, it took us 2 years to set the stage in weekly discussions with the former HCFA, now CMS.

And then, once we had the knowledge base and the discussions how far we could go, then the waiver only took about 90 days to get approved, which is fairly rapidly, but it took 2 years of preparatory time to get there.

And the big obstacle always has been is that when Medicare was set up, it was to pay for nursing care services in a nursing home. And it never really realized or expected that our elderly were going to live as long as they did or that there would be other alternatives—respite care in the community. And so the system pays for the services in a nursing home.

And they now provide for home-care services, but you still get a waiver for it. And Medicaid does not provide for respite care unless you get a waiver. And so what you need to do, is you get the waiver.

We are very, very much—we are eager to give these waivers, because they allow for new alternatives. You have provided a grant, you and the Federal Government, of $70 million for States to apply for this money to make changes, and that is a wonderful program.

I went to the National Governors Conference and told them that there was $50,000 planning grants and all they had to do was fill out—and I made up a two-paragraph form that all you had to do was sign. And out of the 56 States and territories, 54 have already since February applied for the $50,000. And so we have only got one territory and one State left to do it.

But it tells me there is a tremendous degree of excitement out there at the local level that wants to do something in this area. And that $70 million, I am sure, you know, when they get all their applications in, is going to go very rapidly.

Senator CRAIG. Sure.

Secretary THOMPSON. And I think we are going to get some innovative ideas.

And I would like to come back to you with some of those ideas and discuss with you, you know, how we are going to be able to fund them and how we should be able to distribute this money.

Senator CRAIG. Good. Thank you.

The CHAIRMAN. Secretary, thank you very much. I think you have been very helpful, and we clearly think your ideas that you have suggested are very, very positive.

And this begins the dialog, which we do need a national dialog on this issue, and your presence has been very helpful.

Thank you very much.

Secretary THOMPSON. Thank you.

The CHAIRMAN. We would like to invite up a panel, consisting of our good friend and former colleague, former Senator David Durenberger, who is chairman of Citizens for Long-Term Care, which I have had a chance to review their publication and find it to be most interesting and very helpful; also, Ms. Carol O'Shaughnessy, who is a specialist in social legislation for the Congressional Research Service, which is always very helpful to us; and Mr. Bob Blancato, who is executive director of the 1995 White House Conference on Aging.

We welcome all of you.

And, Senator Durenberger——

Senator CRAIG. Mr. Chairman.

The CHAIRMAN [continuing.] Glad to have you back.

Yes, sir?

Senator CRAIG. Before David starts, let me apologize. I am going to have to step out.

I also received the brochure and read it, and it is an impressive concept. And I will look forward to further input on it.

But I apologize to the panelists.

The CHAIRMAN. It is a busy day, I understand.

Senator CRAIG. Command calls, but thank you.

The CHAIRMAN. We have several different things going on at once, as you can imagine, and we certainly understand that.

David Durenberger.

STATEMENT OF DAVID F. DURENBERGER, CHAIRMAN, CITIZENS FOR LONG-TERM CARE

Mr. DURENBERGER. Mr. Chairman, Mr. Mainstream, thank you very much. It is a pleasure to be here.

Larry Craig, it is a pleasure to see you as well.

Let me begin by thanking you for the invitation to testify. I think it is very significant. Not as an invitation to me but I think what you propose doing here, now and in the future has a great deal of significance.

It is good to be on the other side of the table. I already know the answers to the questions, as well as the questions. [Laughter.]

Today I am not here representing the 4.5 million Minnesotans, who actually invented what someone said earlier, "Republican, Democrat, and Independent," as in our Governor, but rather, represent a confederation of dozens of membership organizations from aging, insurance, long-term care providers, disability advocates, professionals, unions. We call it Citizens for Long-Term Care.

And I am here to briefly, on their behalf, offer a bit of history, a word of encouragement, and a promise of help.

I have special respect for the members of, and in the role of this committee, having served on this committee as well as on the Finance and what is now called HELP Committee. The issues here are complex, the stakes are high, the competing priorities are many.

Change comes hard, but this committee is uniquely positioned by its nature and its history to make the crucial contribution to long-term care reform.

Steven Covey creates two categories, which are instructive in this context. They are dealing with issues which are urgent and important, and those which are not urgent but important.

As a member of the Senate, I always struggled with the idea that if something was not urgent, it couldn't be important. And I came to realize that a tyranny of the urgent kept me from attending, as you illustrated by your late arrival here today, to some very, very important things. It is almost the plague of service in the Senate and the Congress today.

But one exception has been this committee. Over the years that I am familiar with, going back to 1979, the people of America have been extremely well-served by this committee. The leadership of people like John Heinz, David Pryor, Chuck Grassley, before you, and now you, Mr. Chairman, is really something that is in the nature of an undervalued national opportunity.

So God knows we need this kind of leadership now on this issue.

Citizens for Long-Term Care is an additional resource to the deliberation of ideas about long-term care issues. I dearly hope that a rich dialog between all the viewpoints that Citizens represent—and I will tell you, we represent every one of them will benefit from your work.

Most of these people used to be adversaries in this business. They have now found a way to come to make common cause and to find common ground. And I think Larry Minnix from AAHSA was in here to see you last week and delivered some of our reports.

We believe that we can be helpful to you, Mr. Chairman and members of the committee, to create a work product that will lead

the Nation to a comprehensive approach to the most important social health and welfare issue of the next three decades.

Long-term care, as Governor Senator Carper said earlier, is either a patchwork or a crazy quilt of services, providers, caregivers, and other supports that people have to access in times of crisis to help them manage the crisis.

The greatest failure in long-term care is an antiquated public policy that impedes personal planning, preparation, and decisions.

On the acute medical care side, we see an industry that has been defined by advances and innovations in care because public policy has placed a primacy on developing policies that help people address their medical needs. People are encouraged and they are supported in making advance decisions about financing their acute care needs, even though they don't know what they might be.

An overwhelming number of people in America have insurance, a primary care physician, other important protections against catastrophic medical costs. And the medical profession has always had a financial incentive to innovate. Public policy does not do the same thing for long-term care.

In Minnesota, 95 percent of our citizens have health insurance; 94 percent do not have long-term care insurance.

Too often, people are forced to make their decision about long-term care in a crisis. When a loved one is faced with a need for supportive care, we find that people are unprepared to address the issues involved.

It happened to me with my dad; it happened with my mom.

They are unaware of what the most appropriate type of care is, where to get it, and what other services might be available.

Finally, they don't understand how to finance the needed care, because they assumed it was paid for by Medicare, and they fail to address the potential need for long-term care. People are forced to make critical decisions in a time of crisis.

With all kinds of honorable intentions, government then steps in to assist people, and we just heard that in the testimony. Whether it is Federal or State government, government steps in to assist people who are unable to pay for care themselves.

But in the end, the recipients, in a sense, become victims, not only of poverty and a spend-down, but of the system which takes away their ability to be anything but.

The goal too often is relief, not recovery. For many, especially aged persons and families, the disablement of the spirit is as tragic as the disability of Alzheimer's, spinal cord injury, or cerebral palsy.

Long-term care has been based on such a public assistance or welfare model for too long. Society does not want to abandon the disabled or the elderly. Our members in CLTC who represent people with disabilities recognize their members' need for it, but they believe there can be a better system.

The compassionate alternative is developing an insurance-based system that supports all people in times of crisis.

And just for purposes of record, Mr. Chairman—I see my time has expired—I need to, not to remind you so much as probably to remind others that we have been here before.

Part of my comments relate to the dependence on State governments in this joint Federal-state responsibility. Yet Americans are Americans wherever they may live. I have never been able to understand why their choices are limited by their place of residence when it comes to long-term care.

President Reagan recognized that in 1982, and he proposed as part of his New federalism program the Federalization of the Medicaid program. And you can imagine the consequence if we had done that.

In 1985, Ron Wyden and I and John Chafee introduced long-term care insurance tax reform.

In 1987 and 1988, as you will recall, we did the Medicare Catastrophic Act, and we included in there changes in the social insurance approach to long-term care.

In 1990, the Pepper Commission said you can't do this on welfare, you cannot do this on savings; you have to build yourself a social and a private insurance system.

So, Mr. Chairman, I cannot adequately express on behalf of the millions of people that are represented by our 63 association members how grateful we are to you personally, to your staff, and to the members of this committee for beginning this national dialog, which I understand you will probably take across the country over time. And we are all pledged to make it successful. Thank you.

[The prepared statement of Mr. Durenberger follows:]

Submitted Testimony of the Honorable David F. Durenberger
Chairman, Citizens For Long Term Care
To the United States Special Committee on Aging
June 28, 2001

Many of life's most critical hazards are those that unexpectedly reduce the sources of income, significantly strain one's financial security or greatly affect one's health. Saving for retirement or protecting one's financial security during working or younger years is subject to all kinds of events or risks. Many events, like the cost of college tuition, can be planned for. But some risks like an accident or a birth related impairment or the onset of a chronic disease, which can necessitate years of costly care, are not expected nor very often planned for. During retirement, events such as higher than expected inflation, longer than expected life or the need for long term care can impede the best of plans and threaten financial and retirement security.

What has emerged to help families protect financial security is a base of social insurance, upon which private insurance and publicly encouraged deferred compensation arrangements have been built. For most people, financial security is principally derived from earnings and then Social Security, Medicare, employer-provided pensions and benefits, and savings, all of which seek to help protect individuals and families from unexpected risks associated with health care or loss of income.

There is a safety net of public assistance both for those workers who were unable to adequately save or acquire insurance and for those who did not or could not work.

Public assistance is a traditional state and local government response to financial need. In the middle of the last century our national government began to fund the safety new as well. Over time, as our less advantaged grew in number, and the cost of meeting their needs expanded, national government financing, especially Title 19 and other provisions of the Social Security Act became critical. Today, it is impossible to determine where responsibility and accountability begin or end.

As the numbers of people who are elderly or disabled increase, more people will face greater risks to their financial security from long term care costs. This gaping hole in our system of ensuring financial security needs to be addressed.

What is long term care and how is it delivered?

Long term care services and support encompasses a broad range of assistance to people who need ongoing help to function on a daily basis. These services may range from assistance with daily activities such as bathing, dressing and eating to more complex services such as meal preparation, shopping, money management, medication management, and transportation. Long term care cannot be relegated to specific hours, days of the week or to fixed settings.

For the twelve million people who need help now and for the millions of family members who are their caregivers, there is no national, cohesive or uniform long term care system. Long term care is provided in a range of settings encompassing home, community and facility based settings depending on the recipient's needs and preferences, the availability of formal and informal support, and the type of reimbursement. In essence, we have a patchwork of programs that vary from state to state and community to community. Each program has its own standards for eligibility and provides different services. This patchwork of efforts is inefficient, inequitable and often ineffective. The lack of a cohesive national policy to assure access to long term care has left people with disabilities and the elderly without a consistently dependable and predictable system of support for their long term care needs.

Why we need financing reform

Long term care is an essential component of individual and family financial security. To disregard the financial impact of long term disabilities on individuals and on society leaves a gaping hole in our nation's economic security. The current system for enhancing economic security is principally derived from earnings, Social Security, Medicare, employer-provided pensions and benefits, and savings, none of which adequately address long term care for a majority of Americans.

Everyone is at risk not only of having a family member in need of long term care, but also of needing assistance themselves. About 45 percent of the long term care population is under the age of 65. Yet, although the need for health insurance to cover a patient's medical expenses in case of catastrophic illness is widely recognized, few people are insured against the costs of providing long term support services for that same person. This lack of insurance coverage jeopardizes the financial security of families and diminishes the economic security of the country.
At more than $4,500 a month, the cost of even a short stay in a nursing home or other facility has the potential to exceed the financial resources of many Americans, especially those no longer able to work. A long stay in a nursing home or extensive use of home and community-based services can easily (and quite often does) consume a lifetime of financial resources. Upon exhausting their own private resources, individuals and families must turn to the federal-state Medicaid program as the payer of last resort. The current Medicaid based financing system, which is the largest single payer of long term care, dictates that people must effectively impoverish themselves in order to receive government assistance.

The federal-state design of the Medicaid system is a product of its times-the early 1960s. It divides financing between the states and federal government. As a result reimbursement and service delivery vary widely from state to state. Moreover, although most people prefer to be cared for at home, Medicaid's preference towards institutional care has left Americans with few alternatives and tremendous confusion over how best to arrange the options that are available to them. Families are often forced to balance a loved one's needs and desires with financial realities.

Demographic change, including the 77 million aging Baby Boomers, increased longevity due to medical advances, and declining family size, not only calls attention to the inefficiency and inequity of our current system, but also raises a clear alarm about the future. The costs of long term care, which are already economically devastating to most families, will only become more expensive as the population ages. Other demographic changes, including families living farther apart, two-wage earner families, and smaller families indicate there will be relatively fewer adult children upon which elderly parents or siblings in need of long term care will be able to depend.

As the pool of potential unpaid caregivers shrinks due to demographic and economic trends, paid professionals will play an increasingly greater role in delivering long term care. However, the relative size of the paid long term care workforce is not likely to increase with the anticipated demand for paid long term care. Under funded staffing levels, unrealistic workloads, insufficient government reimbursement rates, along with the need for additional training and support, as well as labor shortages have resulted in high staff turnover. Recruitment and retention problems create an unstable workforce and are a barrier to high-quality care. In addition, our current financing system does not support today's wages, and therefore raises serous questions about the ability to recruit future paid caregivers.

The fragmented services and supports available to people with disabilities is the result of how long term care has been funded in the past. Changing long term care financing will change how long term care is organized and delivered. A rational approach to financing will improve the efficiency and equity of the system, it will recognize people's desire to receive care where and when they need it, and it will improve the quality of the care.

Pillars of reform

Citizens For Long Term Care's members have agreed upon a set of core beliefs that are fundamental to beginning of any discussion on long term care and long term care financing reform. We called them the Eight Pillars of Financing Reform. They are:

- Every American must be assured access to needed long term care services.
- A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.
- The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.
- Eligibility for the social insurance benefit should be based on functional limitations as an entitlement benefit.

- Private and public policies should be developed to educate and encourage individuals and families to plan for the financing of care prior to the onset of disability.

- Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.

- Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.

- The financing system must support choices across the continuum of care and help maximize personal independence, self determination, dignity and fulfillment.

An American approach to pooling risk

The need for long term care is an insurable risk. This means that the risks are relatively low, but the financial consequences are not. As an insurable risk, the most efficient way for individuals to finance long term care is to pool the risks relative to the expected costs. That is, saving for this contingency is not efficient either for the individual or for society as a whole. Reliance on public assistance as the primary source of financing long term care should be reserved for those whose asset levels necessitate such public assistance.

Nevertheless, government has a critical role in ensuring that every American has access to long term care and that the service infrastructure be adequate to the need. Universal access to care must be maintained by a social commitment expressed through a combination of social insurance and tax subsidized incentives to support and encourage private insurance; a Medicare program that adequately addresses chronic illness, preventive medicine, acute and episodic care needs; and publicly financed safety net protections for those who are not supported by these other means.

Based on lessons from the national debate on health care reform, Henry Aaron suggests "...reform will have to build on existing U.S. institutional arrangements – modifying, improving, and extending them, but not scrapping them in favor of some entirely new system." This statement reflects the American approach to pooling risk and ensuring financial security. It also acknowledges that it would be difficult to create a wholly new, separate long term care system. Instead we must build upon existing institutions and programs.

The American approach to pooling insurable risks has been a combination of social insurance and tax-encouraged private insurance, both of which are tied to earnings. Social Security, including the life and disability insurance, and Part A of Medicare are earned rights derived from employment for the worker or the worker's dependent. Most private insurance is organized through group purchases made by employees or by employers on behalf of their employees and their dependents. Relatively common employer-provided benefits include health insurance, disability insurance, and life

insurance. Retirement income is also enhanced through employer-provided pensions and deferred compensation plans such as 401(k) type arrangements. These employee benefits as well as many individual savings plans are encouraged by preferential tax treatment.

Clearly, there are gaps in these arrangements as well as gaps between these arrangements. Savings are used to bridge those gaps. But in the absence of sufficient savings, public assistance is often available. Public assistance benefits are targeted to those in specific categories with the least financial means.

Building on the foundation these polices have laid but shifting the emphasis from public assistance to earnings and insurance provides the opportunity and means to guarantee all Americans access to needed long term care. It is upon this system that we must build better options to help people secure access to long term care services.

Towards reform

The pillars of reform developed by Citizens For Long Term Care, taken in concert with our established American system of pooling risk, provide a basis for discussing reform options. Citizens For Long Term Care agrees that there must be a new social insurance benefit that finances a minimum floor of financial protection combined with a program of incentives for the early acquisition of private insurance. The social insurance component would provide a new floor of protection based on functional need with appropriate eligibility and benefit level qualification standards. Public assistance must be available to ensure that those whose needs exceed all other public and private resources are helped. There must be a clear national commitment to finance long-term care based on principles of social and private insurance. Without specifying the details of this framework, there are areas of clear agreement that must be a part of reform proposals. These include:

The New Social Insurance Benefit

- A new social insurance benefit with appropriate eligibility and benefit level qualification standards must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.

- The financing system should be as flexible as possible, not only to meet different and changing needs of individuals, but also to assure appropriate consumer choice in settings across the continuum of care. Two people with the same level of functional need should receive the same level of assistance but be able to use that assistance differently.

- There needs to be a new publicly financed program that provides a national, uniform system of disability assessment and assistance, which offers both information and assistance in arranging for appropriate services

- There needs to be a critical examination of the development of guidelines for disability and long term care to help ensure integrated coverage for supportive services over the course of one's lifetime.

Private Insurance and Employers

- The acquisition of private insurance, especially at a younger age, for those for whom it is most appropriate must be encouraged and supported through publicly supported tax incentives.

- Insurers have a responsibility to help educate consumers and work with employers, the government, and consumer groups to develop ways to expand the pool of privately insured risks, ensure adequate consumer protections, and to ensure that private resources are used to improve the organization and delivery of long term care.

- Employers have a critical role to play. Employers, working with government, have a responsibility for helping people to better understand the financial consequences of long term care and their options to plan for this risk. Employers are also in a better position than individuals to choose and organize disability and/or long term care insurance options.

- Individuals and their families have a responsibility to plan for the financial consequences of needing long term care. For some people, at various stages of their life, the only effective way to plan for the future will be by working and paying taxes. Others, however, will have the opportunity to build on the protections provided by the social commitment and use tax incentives to purchase private insurance or to finance other options that insure long term care needs.

Medicare

- Medicare needs to be reformed to cover the most appropriate level of support for the health care needs of those with chronic illness and disabling conditions.

- Medicare must also be reformed in ways that ensure more beneficiaries are able to either avoid or delay the onset of chronic and disabling conditions. In addition, Medicare must better define the difference between chronic health care and long term care services so that the health needs of those with chronic conditions are better met.

Medicaid

- Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.

This approach establishes a national framework to improve the financing, organization, and delivery of long term care. It offers the potential to pool public and private resources towards the development of an efficient and equitable market of long term care providers, and has the potential to help families better organize, coordinate, and integrate needed care with their own efforts.

Call For a National Dialogue

The transition from the current welfare-based system of financing long term care to this new national public/private system will be difficult; it will take time and it will require the skills of our nation's most respected and visible leaders. As Hubert Humphrey said "[t]he moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped." Today, with respect to long term care, we fail that moral test. We fail the test, not out of willful conduct, but rather, as the result of long ago adopted policies and programs that never recognized the nature and cost of long term care.

There are questions on which Citizens For Long Term Care has not yet reached agreement. Answering these questions will require a national dialogue about long term care. Only by engaging the people of this nation will our leaders serve to educate the public and move beyond the concerns of the interest groups represented in this process. Therefore, it is imperative that our nation's leaders, led by the President, undertake a national dialogue with the people to address the size, scope and cost of our commitment to long term care financing. This public dialogue, which must take place as part of our current dialogue on Social Security and Medicare reform is the only way we can educate people about the need and cost of long term care. At stake are the financial security of families and the economic security of the nation.

By developing a national dialogue that recognizes long term care financing reform as an integral part of financial security, we can close the gaping hole in our financial safety net. In doing so, we can develop a financing system that supports an integrated system of care. Such a change would ensure that those not capable of caring for themselves can maintain the highest quality of life, according to their preferences, with the greatest degree of independence, autonomy, participation, personal fulfillment, and dignity.

We have the opportunity to develop a financing system that supports the varying goals of a diverse population with diverse long term care needs. In order to seize this opportunity we must commit ourselves to a national dialogue today, before the demographic tidal wave of aging Baby Boomers overwhelms us.

Thank you, Mr. Chairman, and Members of the Committee, for your commitment to begin this dialogue.

Defining Common Ground:

Long Term Care Financing Reform in 2001

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Citizens For Long Term Care

February 2001

The following organizations are members of Citizens For Long Term Care's Board of Directors. As the guiding forces behind this paper they actively support and affirm its conclusions.

- AARP
- Aetna Inc.
- Alzheimer's Association
- American Association of Homes and Services for the Aging
- American Health Care Association
- The Arc of the United States
- National Association for Home Care
- National Committee to Preserve Social Security and Medicare
- Service Employees International Union

Citizens For Long Term Care would like to thank Dr. Robert Friedland and Lee Shirey of Georgetown University's Center on an Aging Society for their tireless efforts in helping Citizens For Long Term Care develop this report.

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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.

10k-2001

Contents

Letter from the Chairman iv

Executive Summary 1

Defining Common Ground 7

- **Introduction** 7
- **Principles of Reform** 9
- **Background** 11
- **Why Financing Reform is Necessary** 15
- **The Demographic Imperative** 17
- **A Call for a National Dialogue** 21
- **The Road to Reform** 23

Letter From the Chairman

As a United States Senator from 1978 to 1995 I was privileged to serve for 16 years as a member of the Senate Finance Committee and, for two years in 1989-90, as a Vice Chair of the United States Bipartisan Commission on Comprehensive Health Care, which was tasked with reforming access to acute and long term care for all Americans. Named for Representative Claude Pepper, the nation's champion for the aged and people with disabilities, the Pepper Commission affirmed the need to use an insurance-based system to reform the financing of long term care.

In the 10 years since the Pepper Commission released its report, *A Call to Action,* our population has gotten older, disability has increased, and care has become more expensive. Yet no one has responded to *A Call to Action.* Our national debates over Social Security and Medicare reform ignore long term care financing just as most people ignore it in their private lives until a loved one needs supportive care.

In 2001, a new Congress and a new President provide unprecedented opportunity to make a commitment to reform long term care financing. As is often observed about the election of 2000, "Americans live in times of unprecedented prosperity." But the election also underlined a sense of unease on the part of our people about the future. The unease comes for many people, in large part, from the knowledge that their economic resources are insufficient to provide extended care in the face of a debilitating incident or health condition. This is best reflected in the generation of Americans born in the years immediately after WWII, referred to as the Baby Boom generation. Most "Boomers" have parents whose retirement savings and security are beyond that of any previous American generation, but whose medical and long term care needs have the potential to eat quickly into the value of that savings and security.

Throughout the last 65 years we have developed a system of social commitments, such as insurances, tax incentives, and health programs which were designed to assist people ensure their financial and retirement security. Unfortunately, long term care, which today poses a real and significant threat to that financial security, has never been integrated into our policy debates on individual financial or national economic security. Ninety percent of Americans are insured against medical expense and only 6% against long term care expenses. In our financing systems, both private and goveramental, resource allocations favor acute medical needs over long term disability. Despite more deaths from chronic disease than acute incidents, Medicare still is geared towards providing coverage for acute illness rather than chronic or long-term care.

As the great mass of our population ages we are witnessing rising speculation about the nation's financial security programs' ability to fulfill their promises. This speculation is the combination of fairly predictable demographic and cost impacts that will severely constrain those public policies built in the 1930's (Social Security) and 60's (Medicare/Medicaid) that were meant to help support financial security among are our elderly. People living longer with more chronic illnesses, coupled with an increasing number of people under 65 utilizing long term care supports and services, demands we address long term care financing as a key component of the financial security, Medicare and Social Security reform debates.

Given all of this, over sixty of the major national associations of long term care providers, insurers, and patient advocacy groups representing aging and disability concerns began meeting in 1998-99 in a search for common ground on which to build a national mandate for change. I was asked to chair the effort and together we

created Citizens For Long Term Care in April 1999. CLTC began with common ground on a set of principles, which should characterize a system of long term care that would benefit all Americans.

Since July 2000, representative members of CLTC have been meeting together to find common ground on financing policy solutions. We rejected a consolidation of existing long-term care funds into a distinct long-term care program funded either publicly or privately. The delivery system that comes closest to assuring the principles on which we have agreed is one in which goods, services, innovations in professionalism and practice are constantly evolving. Only markets that support people making advanced financing decisions and personal choices in time of need meet these criteria.

The financing system that best optimizes market performance and evolving services while supporting people to make advanced decisions is an elaboration of the employment-based income security system that has evolved in the United States through the 20th century. Not all employment is equal and as a result people have different resources and capacities to provide or pay for care. For that reason, CLTC advocates a base of financial support in the social insurance system to which every American contributes with their first paycheck. But with that first job should also come an opportunity and responsibility to invest in private insurance supported by judicious tax incentives to protect both earnings and savings capacity from an early life or aged related disability.

The transition from a Medicaid based assurance for Americans to a social/private insurance security system built over a lifetime will require time. The impact of shifting tens of billions of dollars from the federal/state Medicaid program to a program of social insurance and tax subsidies has intergovernmental consequence. That is why the leaders of America's long term care associations believe all Americans, not just elected representatives, must be part of the solution; therefore, CLTC calls for a national dialogue to advance this issue led by the President of the United States.

A Congressional commission is *not* a national dialogue. Not since the Social Security crisis of 1983 has a bi-partisan commission's recommendations been converted to popularly supported legislative actions. For example, the Pepper Commission's 1990 recommendations were totally bipartisan and nothing happened. The National Bipartisan Commission on Medicare in 1998-1999 was bipartisan and it fell apart—not only failing to enact change but also refusing to include long term care in its recommendations.

The President of the United States must use the powers of the Presidency to focus attention on the need for this critical reform. The power of presidential leadership can be seen in our debate over a prescription drug benefit for Medicare. Only with similar leadership can we expect to help the tens of millions of families that are coping with the devastating costs of long term care.

In releasing this paper Citizens For Long Term Care and its members stand ready to work with our new President, members of the 107th Congress, and with Governors and Legislators from the 50 states. Together we can work to educate and inform America about the need for long term care financing reform. Together we can help to safeguard the financial and retirement security of tens of millions of Americans. Together we can help protect the elderly, people with disabilities and the chronically ill. Together we can find a better way.

Sincerely,

Sen. David F. Durenberger 1978-1999
Chairman,
Citizens For Long Term Care

Long term care is an essential component of individual and family financial security. To disregard the financial impact of long term disabilities on individuals and on society leaves a gaping hole in our nation's economic security.

Executive Summary

The member organizations of Citizens for Long Term Care have come together in agreement over the need to change the way in which long term care is financed for people of all ages. The coalition represents insurers, providers of institutional care, providers of community and home-based care, professional caregivers, family caregivers, and people with physical or cognitive impairments who need long term care. For the first time these groups have reached agreement on the need for reform, on the principles that must guide that reform, and on a way in which reform can be achieved.

What is long term care and how is it delivered?

Long term care services and support encompasses a broad range of assistance to people who need ongoing help to function on a daily basis. These services may range from assistance with daily activities such as bathing, dressing and eating to more complex services such as meal preparation, shopping, money management, medication management, and transportation. Long term care cannot be relegated to specific hours, days of the week or to fixed settings.

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Everyone is at risk not only of having a family member in need of long term care, but also of needing assistance themselves. About 45 percent of the long term care population is under the age of 65. Yet, although the need for health insurance to cover a patient's medical expenses in case of catastrophic illness is widely recognized, few people are insured against the costs of providing long term support services for that same person. This lack of insurance coverage jeopardizes the financial security of families and diminishes the economic security of the country.

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to work. A long stay in a nursing home or extensive use of home and community-based services can easily (and quite often does) consume a lifetime of financial resources. Upon exhausting their own private resources, individuals and families must turn to the federal-state Medicaid program as the payer of last resort. The current Medicaid based financing system, which is the largest single payer of long term care, dictates that people must effectively impoverish themselves in order to receive government assistance.

The federal-state design of the Medicaid system is a product of its times—the early 1960s. It divides financing between the states and federal government and as a result reimbursement and service delivery vary widely from state to state. Moreover, although most people prefer to be cared for at home, Medicaid's preference towards institutional care has left Americans with few alternatives and tremendous confusion over how best to arrange the options that are available to them. Families are often forced to balance a loved one's needs and desires with financial realities.

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As the pool of potential unpaid caregivers shrinks due to demographic and economic trends, paid professionals will play an increasingly greater role in delivering long term care. However, the relative size of the paid long term care workforce is not likely to increase with the anticipated demand for paid long term care. Under funded staffing levels and hence unrealistic workloads, exacerbated by insufficient government reimbursement rates, along with the need for additional training and support, as well as low wages and benefits have added to labor shortages and resulted in high staff turnover. Recruitment and retention problems create an unstable workforce and are a barrier to high-quality care. In addition, our current financing system does not support today's wages, and therefore raises serious questions about the ability to recruit future paid caregivers.

The fragmented services and supports available to people with disabilities is the result of how long term care has been funded in the past. Changing long term care financing will change how long term care is organized and delivered. A rational approach to financing will improve the efficiency and equity of the system, it will recognize people's desire to receive care where and when they need it, and it will improve the quality of the care.

Pillars of reform

In the course of the "Common Ground" dialogue, Citizens For Long Term Care agreed upon a set of core beliefs. These beliefs evolved from Citizens For Long Term Care's Principles of Reform, which its member organizations agreed upon as a set of basic principles that would shape the development of an ideal long term care system. From the Principles of Reform, which are set out in the accompanying document, we developed the Eight Pillars of Financing Reform. They are:

- Every American must be assured access to needed long term care services.
- A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.
- The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.
- Eligibility for the social insurance benefit should be based on functional limitations as an entitlement benefit.
- Private and public policies should be developed to educate and encourage individuals and families to plan for the financing of care prior to the onset of disability.
- Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.
- Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.
- The financing system must support choices across the continuum of care and help maximize personal independence, self determination, dignity and fulfillment.

An American approach to pooling risk

The need for long term care is an insurable risk. This means that the risks are relatively low but the financial consequences are not. As an insurable risk, the most efficient way for individuals to finance long term care is to pool the risks relative to the expected costs. That is, saving for this contingency is not efficient either for the individual or for society as a whole. Reliance on public assistance as the primary source of financing long term care should be reserved for those whose asset levels necessitate such public assistance.

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Based on lessons from the national debate on health care reform, Henry Aaron suggests ". . . reform will have to build on existing U.S. institutional arrangements—modifying, improving, and extending them, but not scrapping them in favor of some entirely new system." This statement reflects the American approach to pooling risk and ensuring financial security. It also acknowledges that it would be difficult to create a wholly new, separate long term care system. Instead we must build upon existing institutions and programs.

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Clearly, there are gaps in these arrangements as well as gaps between these arrangements. Savings are used to bridge those gaps. But in the absence of sufficient savings, public assistance is often available. Public assistance benefits are targeted to those in specific categories with the least financial means. Building on these programs that emphasize shared social responsibility for those with insufficient personal or family resources, provides the opportunity and means to guarantee all Americans access to needed long term care. It is upon this system that we must build better options to help people secure access to long term care services.

Towards reform

The pillars of reform developed by Citizens For Long Term Care, taken in concert with our established American system of pooling risk, provide a basis for discussing reform options. Citizens For Long Term Care agrees that there must be a new social insurance benefit that finances a minimum floor of financial protection combined with a program of incentives for the early acquisition of private insurance. The social insurance component would provide a new floor of protection for all based on functional need with appropriate eligibility and benefit level standards and requirements. Public assistance must be available to ensure that those whose needs exceed all other public and private resources are helped. There must be a clear national commitment to finance long-term care based on principles of social and private insurance. Without specifying the details of this framework, there are areas of clear agreement that must be a part of reform proposals. These include:

The New Social Insurance Benefit

- A new social insurance cash payment benefit with appropriate eligibility and benefit level standards and requirements must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.
- The financing system should be as flexible as possible, not only to meet different and changing needs of individuals, but also to assure appropriate consumer choice in settings across the continuum of care. Two people with the same level of functional need should receive the same level of assistance but be able to use that assistance differently.
- There needs to be a new publicly financed program that provides a national, uniform system of disability assessment, which offers both information and assistance in arranging for appropriate services.
- There needs to be a critical examination of the development of guidelines for disability and long term care to help ensure integrated coverage for supportive services over the course of one's lifetime.

Private Insurance and Employers

- The acquisition of private insurance, especially at a younger age, for those for whom it is most appropriate must be encouraged and supported through publicly supported tax incentives.

- Insurers have a responsibility to help educate consumers and work with employers, the government, and consumer groups to develop ways to expand the pool of privately insured risks, ensure adequate consumer protections, and to ensure that private resources are used to improve the organization and delivery of long term care.

- Employers have a critical role to play. Employers, working with government, have a responsibility for helping people to better understand the financial consequences of long term care and their options to plan for this risk. Employers are also in a better position than individuals to choose and organize disability and/or long term care insurance options.

- Individuals and their families have a responsibility to plan for the financial consequences of needing long term care. For some people, at various stages of their life, the only effective way to plan for the future will be by working and paying taxes. Others, however, will have the opportunity to build on the protections provided by the social commitment and use tax incentives to purchase private insurance or to finance other options that insure long term care needs.

Medicare

- Medicare needs to be reformed to cover the most appropriate level of support for the health care needs of those with chronic illness and disabling conditions.

- Medicare must also be reformed in ways that ensure more beneficiaries are able to either avoid or delay the onset of chronic and disabling conditions. In addition, Medicare must better define the difference between chronic health care and long term care services so that the health needs of those with chronic conditions are better met.

Medicaid

- Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.

This approach establishes a national framework to improve the financing, organization, and delivery of long term care. It offers the potential to pool public and private resources towards the development of an efficient and equitable market of long term care providers, and has the potential to help families better organize, coordinate, and integrate needed care with their own efforts.

Call For a National Dialogue

The transition from the current welfare-based system of financing long term care to this new national public/private system will be difficult; it will take time and it will require the skills of our nation's most respected and visible leaders. As Hubert Humphrey said "[t]he moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped." Today, with respect to long term care, we fail that moral test. We fail the test, not out of willful conduct, but rather, as the result of long ago adopted policies and programs that never recognized the nature and cost of long term care.

There are questions on which Citizens For Long Term Care did not reach agreement. Having found common ground on the need to use a sys-

tem of both social and private insurance, we did not attempt to reach agreement on the extent of, or limits to the new social insurance benefit, nor on the scope and structure of what role private insurance should play. Answering these questions will require a national dialogue about long term care. Only by engaging the people of this nation will our leaders serve to educate the public and move beyond the concerns of the interest groups represented in this process.

Therefore, it is imperative that our nation's leaders, led by the President, undertake a national dialogue with the people to address the size, scope and cost of our commitment to long term care financing. This public dialogue, which must take place as part of our current dialogue on Social Security and Medicare reform is the only way we can educate people about the need and cost of long term care. At stake are the financial security of families and the economic security of the nation.

By developing a national dialogue that recognizes long term care financing reform as an integral part of financial security, we can close the gaping hole in our financial safety net. In doing so, we can develop a financing system that supports an integrated system of care. Such a change would ensure that those not capable of caring for themselves can maintain the highest quality of life, according to their preferences, with the greatest degree of independence, autonomy, participation, personal fulfillment, and dignity.

We have the opportunity to develop a financing system that supports the varying goals of a diverse population with diverse long term care needs. In order to seize this opportunity we must commit ourselves to a national dialogue today, before the demographic tidal wave of aging Baby Boomers overwhelms us.

Defining Common Ground: Long Term Care Financing Reform in 2001

Introduction

Many of life's most critical hazards are those that unexpectedly reduce the sources of income, significantly strain one's financial security or greatly affect one's health. Saving for retirement or protecting one's financial security during working or younger years is subject to all kinds of events or risks. Many events, like the cost of college tuition, can be planned for. But some risks, like an accident or a birth related impairment or the onset of a chronic disease, which can necessitate years of costly care, are not expected nor very often planned for. During retirement, events such as higher than expected inflation, longer than expected life or the need for long term care can impede the best of plans and threaten financial and retirement security.

What has emerged to help families protect financial security is a base of social insurance, upon which private insurance and publicly encouraged deferred compensation arrangements have been built. For most people, financial security is principally derived from earnings and then Social Security, Medicare, employer-provided pensions and benefits, and savings, all of which seek to help protect individuals and families from unexpected risks associated with health care or loss of income. Most of this structure is for workers and their dependents; however, there is a safety net of public assistance both for those workers who were unable to adequately save or acquire insurance and for those who did not or could not work.

Unfortunately, long term care has never been factored into these programs as a possible threat to financial security. As the numbers of people who are elderly or disabled increase, more people will face greater risks to their financial security from long term care costs. Citizens for Long Term Care believes that this gaping hole in our system of ensuring financial security needs to be addressed.

Of the more than 42 million Americans of all ages who have a disabling condition, over 12 million are dependent upon others for basic tasks such as eating, bathing, toileting, dressing, and getting in and out of bed (Adler, 1995).[1] An estimated 11.5 million Americans perform these daily caregiving services for family members with little financial or community support. Although many people assume that these long term care support services are only required by the elderly, about 45 percent of the long term care population is under age 65.

People of all ages are at risk for not only having a family member in need of long term care, but also of needing assistance from others themselves as a result of illness or injury. Although the need for health insurance to cover a patient's medical expenses in case of catastrophic illness is widely recognized, few people are insured against the costs of providing long term support services for that same person.

The current system of financing long term care has not worked well for those who need supportive services, nor for the family members who often act as caregivers. As biomedical advances extend life for the elderly and people with disabilities, the physical and financial burdens of long term care will only increase. In

relative terms, there will be fewer adult children to care for elderly parents. Further, employers will see an increasing number of their employees struggle to balance caregiving responsibilities with work.

For the past 60 years, Americans have relied on a combination of social insurance and private means to pool risk and support financial security.[2] The basis for our social insurance programs and most of our private means of pooling risk and enhancing financial security is tied to employment. Social Security, including the life and disability insurance portions of Social Security, and Part A of Medicare are earned rights derived from employment for the worker or the worker's dependents. Most private insurance is organized through group purchases made by employers on behalf of their employees and their dependents. Relatively common employer-provided benefits include health insurance, disability insurance, and life insurance. Retirement income is also enhanced through employer-provided pensions and deferred compensation plans such as 401(k) type arrangements. These employee benefits as well as many individual savings plans are further encouraged by preferential tax treatment.[3]

Thus, the American approach to pooling insurable risks and protecting financial security has been a combination of social insurance and tax encouraged private insurance. Clearly, there are gaps in these arrangements as well as gaps between these arrangements. Savings are used to bridge those gaps. In the absence of sufficient savings, public assistance is usually available. Public assistance benefits are targeted to those in specific categories with the least financial means.

Unfortunately for those who need extended long term care services, public assistance remains the primary financing mechanism. It is time for a national dialogue on reforming the financing of long term care. Citizens for Long Term Care, representing 63 diverse organizations, has come together in agreement over the need for reform and the principles that must guide reform efforts. The organizations that comprise Citizens For Long Term Care represent insurers, providers of institutional care, providers of home-based and community care, professional caregivers, family caregivers, and people who need long term care, as well as people who do not yet need such care.

Notes

[1] The more than 42 million Americans is based on a broad definition of disability, defined as difficulty with certain activities, such as attending school or walking, due to a physical or mental health impairment. The 12 million Americans is based on those who need help with basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

[2] Social insurance refers to more than just the public financing of private insurance. Social insurance programs often have many goals that are transparent from the stated objectives, but the most important goal is to provide universal coverage and access. The best examples of social insurance are the Old Age, Survivors, and Disability Insurance program (OASDI), and Part A of Medicare. These programs are a part of the Social Security Act.

[3] Tax incentives can also be viewed as tax expenditures. That is, forgone revenues assuming the activity would have occurred without the tax incentives. Tax incentives or preferences are of higher value to those with higher taxable income.

Principles to guide long term care

Upon its inception in 1999, Citizens For Long Term Care member organizations agreed upon a set of basic principles which would shape the development of an ideal long term care system. We believe that all efforts to enact change must incorporate and reaffirm our basic principles.

Independence

Services should promote individual dignity, maximize independence and self-sufficiency, and be provided in the least restrictive setting possible, and reflect the overwhelming preference of individuals to remain at home.

Choice

People should be able to choose from a full range of home, community-based, facility-based health and social services so they can get the types of services that will meet their individual needs and preferences.

Role of Families

The central role families play in planning for and providing long term care should be recognized and supported.

Access

People of all ages and income levels should have access to long term care services and supports.

Eligibility

Eligibility for services should be based on functional criteria and social needs that take into account cognitive, physical, and behavioral limitations and the need for support, supervision, or training.

Financing

Costs should be spread broadly and progressively, so that out of pocket costs are affordable. This goal may involve tax policy, Social Security, Medicare, Medicaid, private health insurance and pensions, social services and housing policies. Both public and private financing mechanisms should be strengthened toward this goal.

Accountability

Systems for assuring the quality of care should be built into all long term care programs. These systems should assure quality and value based on outcomes and consumer protections enforced through appropriate government regulations.

Standards

The highest standards of professionalism and quality are essential for caregivers and systems. This must be supported by thorough training, appropriate supervision and fair compensation.

Coordination

Systems should coordinate services for people with multiple needs that change over time, providing a seamless continuum of care.

Efficiency

Incentives and controls in public and private programs must maximize quality and control costs.

Citizens For Long term Care believes that the organization and delivery of long term care must be based on a desire to ensure that those needing assistance can maintain the highest quality of life.

I. Background

What is long term care?

Long term care, services, and supports encompass a broad range of assistance to people who need ongoing help to function on a daily basis.[4] These services may range from assistance with daily activities such as bathing, dressing and eating to more complex services such as meal preparation, shopping, money management, medication management, and transportation. Long term care represents the extra set of eyes and hands necessary for dependent persons to function from day to day. Long term care is integral to the lives of those who are frail, cognitively impaired, disabled, or whose chronic illness requires supportive care.

People who need long term care may also require a variety of medical services such as preventative, primary and acute medical care or rehabilitation services, such as occupational, speech and physical therapies.

Long term care cannot be relegated to specific hours or days of the week or to fixed settings. People who need long term care need to receive the care in the setting where they live, and may move frequently between home, hospital and nursing facility while others receive long term care in one place for a long period of time.

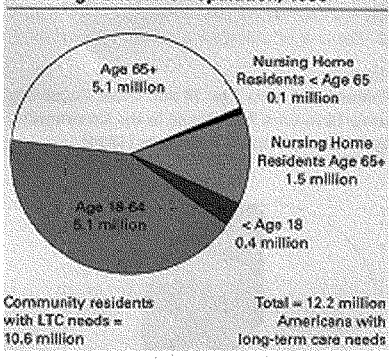
Citizens For Long term Care believes that the organization and delivery of long term care must be based on a desire to ensure that those needing assistance can maintain the highest quality of life, according to their preferences, with the greatest degree of independence, autonomy, participation, personal fulfilment, and dignity.

Who needs long term care?

Over 12 million people of all ages need long term care.[5] The risk of needing long term care increases with age, but 46 percent of the long term care population is under age 65. Children (ages 5-17) who need long term care account for 3 percent of the long term care population (see Figure 1).

The majority—87 percent—of the long term care population resides in the community. The scope and extent of their needs are diverse, however. Among the 10.2 million adults age 18 and older residing in the community, almost 60 percent need help from another person to perform

Figure 1
The Long-Term Care Population, 1995



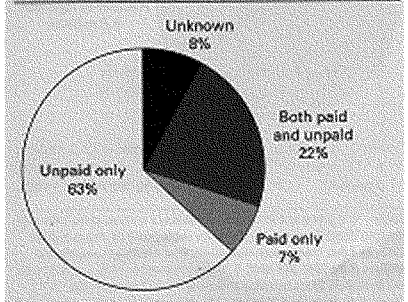
Source: H. Komisar and M. Niefeld, unpublished analysis of the 1994-1995 National Health Interview Survey on Disability (NHIS-D), Phase II (April 2000); M. Adler, "People with Disabilities: Who Are They?" unpublished analysis of the 1994-1995 NHIS-D, Phase I (November 1996); and N. Krauss and B. Altman, *Characteristics of Nursing Home Residents 1996*, MEPS Research Findings No. 5 (Rockville, MD: Agency for Health Care Policy and Research, December 1998).

basic activities of daily living (ADLs) including eating, bathing, dressing, toileting, and getting in and out of bed. The remainder of the population residing in the community needs help with instrumental activities of daily living (IADLs) only, such as shopping, managing money, and housekeeping. Almost all of the adults residing in institutions need help with ADLs.

Who provides long term care?

An entire "community of caregivers" including family and friends, community supports, and paid direct-care professionals struggle to organize, coordinate, and provide long term care. But families are clearly the heart of the long term care system, providing unpaid care to 63 percent of adults needing long term services. About 22 percent of adults receive care from a mixture of unpaid and paid providers, while 7 percent of the long term care population age 18 and older rely exclusively on paid assistance. (see Figure 2). The task of caring for a person with a disability, the frail elderly, or someone who is chronically ill is an emotionally and physically challenging job. In addition to the skills necessary to complete one's job, the caregiver must possess a level of patience and understanding that helps them treat society's most vulnerable with the dignity and respect they deserve. For parents in some states, the challenge of providing care is magnified when they find that they must give up custody of their children in order to order to obtain assistance for them.

Figure 2
Percent of Adults Age 18 and Older Receiving Long-Term Care Assistance in the Community, by Paid and Unpaid Providers (1994)



Source: The Urban Institute and CRS (2000). Long-Term Care Chartbook.

Citizens For Long Term Care

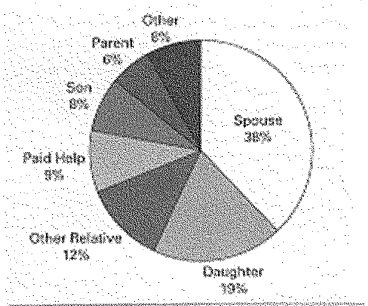
Families and friends are critical

Family members provide most long term care, particularly spouses, daughters, and daughters-in-law (see Figure 3). Most people who need long term care rely on one or two key family caregivers, but there are often other family members involved in ancillary aspects of caregiving. In 1997, the value of informal caregiving was estimated at $196 billion, compared to $83 billion for nursing home care and $32 billion for home health care.[6]

Among the long term care population age 15 or older living in the community, spouses and adult children were the key caregivers, providing some 65 percent of the unpaid care received by those in the community. In 1994, an estimated 120 million hours of care were provided by more than 7 million family members to elderly people that need long term care (R. Stone 2000). More than 3.9 million family members provided assistance to people under the age of 65 who need long term care.

One-third to one-half of primary family caregivers are also employed outside the home. Working family caregivers provide care an average of 18 hours a week, while struggling to meet the demands of their work and other family obligations.[7]

Figure 3
Relationship of the Care Provider to People Age 15 and Older Receiving Personal Assistance



Source: 1991-93 Survey of Income and Program Participation

Paid professionals

Direct-care workers provide the majority of paid long term care. Paid workers include registered nurses, licensed practical nurses, as well as certified nursing assistants, qualified medical aids, personal assistants and other direct support professionals who deliver care and assistance in facilities and as at home care workers. Of the 2.2 million workers in long term care, some 1.9 million are women, which often makes them more susceptible to injury from the physical rigors of providing care.

In addition, professionals that provide skilled care often do not receive the same status or value as professionals in acute care medical professional-patient relationships. The American medical model, which favors acute care and subspecialty emphasis, prioritizes technological and professional values in ways that are detrimental to the values and the professional skills required for long-term care. Too often, patients needing long term care develop relationships with institutions instead of medical professionals.

Some groups are concerned that improved financing of professional caregiving will crowd out family members' unpaid caregiving, and increase the strain on an already overloaded system. Evidence shows that although public financing does change how unpaid caregiving is organized, families tend not to decrease the amount of care they provide. Furthermore, even though current public financing of home and community-based long term care is greater than it has ever been, family members today are providing more care for longer than families have ever needed to in the past (Tennestedt, 1999; D. Stone, 2000; and R. Stone, 2000).

How is long term care financed?

Long term care, which includes nursing home and other facility based care, home health care, home and community-based waiver services, and personal care, is financed through a wide mix of public and private sources (see Figure 4). Public financing, which funds 62 percent of all services, is delivered through Medicaid, Medicare, state programs, the Veterans Administration, and the Administration on Aging. Private financing includes private insurance, philanthropy and out-of-pocket payments by individuals and families in need of care.[8]

Medicaid, the largest public payer of long term care services, accounted for 45 percent of all long term care expenditures, 46 percent of nursing home revenues and 38 percent of home care revenues in 1998. Some 73 percent of Medicaid's long term care expenditures, however, are for nursing home care. Medicaid expenditures for long term care have grown substantially in recent years, largely due to a growing elderly population.[9]

Medicare is often described as the second largest public payer of long term care, financing 16 percent overall. Medicare finances 12 percent of all nursing home care and 27 percent of all home (health) care. Medicare's coverage of nursing home care, however, is tied to a patient's need for skilled services subsequent to a hospital discharge. These payments are limited by law to short term post acute and rehabilitative services. In the strictest sense they do not *truly* represent long term care because they are time limited as opposed to ongoing. When a person living at home requires skilled service, Medicare covers only chronic care and supportive services incidental to the need for a skilled service.

Figure 4

Expenditures for Long-Term Care Services, by Type of Service and Payer
(Billions of 1998 Dollars)

	Nursing Home Care	Home Care	Total
Public			
Medicaid*	$40.6	$14.8	$ 55.4
Medicare	10.4	10.4	20.8
Other public	2.1	0.1	2.2
Total public	**53.1**	**25.3**	**78.4**
Private			
Private insurance	4.7	4.0	8.7
Out of pocket	28.5	6.0	34.5
Other private	1.6	3.7	5.3
Total private	**34.8**	**13.7**	**48.5**
Total	**$87.9**	**$39.0**	**$126.9**

*Medicaid dollars include both federal and state. Home care under Medicaid's primarily provided through home and community-based waver programs.

Note: Nursing home care includes intermediate care facilities for the mentally retarded (ICFs/MR). Home care includes home health care, personal care and home and community-based waiver services.

Sources: Burwell, B. (2000). *Medicaid Long-Term Care Expenditures in 1999.* The Medstat Group: Cambridge, MA. National Health Expenditures Tables, HCFA.

The largest source of private financing and the second largest source overall are the individuals' families. Families financed 27 percent of long term care out of pocket in 1998. Altogether, payments from families account for 15 percent of home care revenues and 32 percent of nursing home revenues.[10] Private long term care insurance finances less than 7 percent of long term care.

Notes

[4] In an effort to move away from the "care" model and towards one that emphasizes independence, the disability community uses the phrase "long term services and supports" instead of long term care.

[5] People with long term care needs receive or need help from another person with one or more of the following activities of daily living (ADLs): walking, getting in or out of bed or a chair, bathing, using a toilet, dressing, and eating; and/or people who because of a health or physical condition have difficulty with and receive or need help from another person with at least one of the following instrumental activities of daily living (IADLs): preparing meals, shopping, managing medication, using the phone, light housework, and getting outside of walking distance.

[6] Arno et al., (1999).

[7] The NAC/AARP Family Caregiving Survey (1997) found that 54 percent of employed family caregivers have made changes at work to meet their caregiving responsibilities.

[8] National income estimates of private expenditures include home health care only. Excluding the value of personal or custodial care at home dramatically understates individual out-of-pocket expenditures, since it is personal care that is the bulk of paid long term care provided in the community.

[9] The elderly population has more than doubled since the time Medicaid was first enacted.

[10] Some of this out-pocket spending may be attributable to those on Medicaid. Medicaid beneficiaries in nursing and other facilities are able to retain about $30 a month for their personal needs. The rest of their income, including Social Security and Supplemental Security Income, is turned over to the facility.

II. Why financing reform is necessary

At a national average cost of more than $4,500 a month, the cost of a short stay in a nursing home or other facility exceeds the monthly income of most Americans, especially those no longer able to work. A long stay in a nursing home, other facility or a similar period of in-home care can easily consume a lifetime of savings or prevent the accumulation of savings in the case of families where a child has a significant disability. Extensive use of home and community-based services can easily rival the cost of care in a nursing facility. Families exhaust themselves physically, mentally and financially to provide care at home often turning to a nursing or other facility when they are no longer able to provide at home care. As a result, more than 85 percent of long term care is either publicly financed through public assistance, primarily Medicaid, or directly out of the pockets of those who need help and their families (Feder et al., 2000). As our population rapidly ages, we are faced with the potential for long term care costs to explode. We must act now to help protect the financial security of families and the economic security of the federal and state governments. Additionally, financing reform will dramatically improve the delivery and quality of care.

The consequences of fragmented financing

The current system of financing long term care through a blend of public, private and out-of-pocket payments is inefficient and inequitable. Financial assistance is often contingent upon impoverishment, but not every American who is impoverished is eligible for assistance. Furthermore, the type and amount of assistance varies. Someone eligible for Medicaid in one state may not be eligible in another, and two people eligible for Medicaid in the same state with the same level of functional impairment may not be eligible for the same services. Extensive use of home and community-based services can easily rival the cost of care in a nursing facility.

Another consequence of this fragmented system is that one in five adults with long term care needs—about 2 million people—report that their needs are unmet, often with serious consequences (Feder et al., 2000). Although over 361,000 people with mental retardation or developmental disabilities are receiving residential services, there are about 66,250 people on a waiting list for these services (Prouty and Lakin, 2000).

Our patchwork long term care system has resulted in a confusing array of choices that rarely match families' needs. Families are forced to do the best they can with poor information and often-imperfect sources of professional assistance. In addition to shouldering a heavy financial and emotional burden, families must undertake a massive on-the-job education in organizing and delivering long term care to their loved one.

Impoverishment bias

With individuals paying such a large portion of long term care costs, it is not surprising that many people are nearly impoverished by the health care needs of a family member. About one-third of discharged nursing home residents and one-half of current nursing home residents entered as private pay residents but spent down to Medicaid (Weiner et al., 1996). Individuals

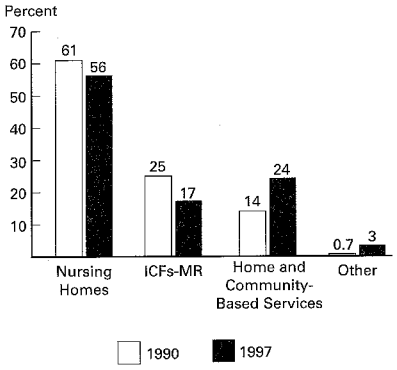
who are eligible for Medicaid are forced into a lifetime of impoverishment in order to continue receiving assistance. This double-bind leaves families in an extremely difficult position, especially families with a younger disabled person.

Institutional care

While Medicaid must cover nursing home care, states are not required to provide home or community-based care (other than home health care). State Medicaid programs can choose to provide personal care as a statewide benefit or to establish a home and community-based program under a Medicaid "waiver." A waiver allows a state to experiment with specific program designs and also target assistance to either a particular category of Medicaid eligibility or a limited area in the state, or both. All states have one or more Medicaid waiver programs, but only 30 states and the District of Columbia have elected to provide statewide personal care to their Medicaid beneficiaries (Doty, 2000). Coverage under the personal care benefit is often limited and insufficient to remain in the community.

Nevertheless, Medicaid spending on home and community-based care services has increased substantially since 1990. Most of the growth has been directed at younger persons with disabilities, especially those with mental retardation or developmental disabilities (Wiener et al., 2000). In 1997, some 77 percent of total spending for Medicaid home and community-based waivers was for people with mental retardation or developmental disabilities, compared to 21 percent for the aged and elderly disabled populations (Harrington et al., 2000). As a result, the proportion of total Medicaid spending for intermediate care facilities for people with mental retardation or related conditions (ICFs/MR) has declined substantially (Figure 5).[11] For the elderly, however, more than half of the growth in home and community-based expenditures occurred in four states. (Wiener et al., 2000). Thus, for people who need long term care, the one option that is available through Medicaid in all states is nursing home care.

Figure 5
Medicaid Spending for Long-Term Care, 1990 and 1997



Source: The Urban Institute and CRS (2000).

Note

[11] The trend toward deinstitutionalization of persons with mental retardation and developmental disabilities in favor of care in community-based settings began in the 1970s. In 1982, for example, the number of Medicaid beneficiaries with MR/DD in a waiver program was 1,381. In 1999, that number had increased to 261,930. And in that same period the number of beneficiaries in an ICF/MR decreased from 140,682 to 117,917 (Prouty and Lakin, 2000).

III. The Demographic Imperative

Demographic trends indicate that in the future more people will need long term care, and that relatively fewer people will be available to provide this care. Longer life expectancies have resulted in the need for long term care at all ages for longer periods of time. Current difficulties in locating, organizing, and paying for long term care will only be exacerbated by the aging of our society.

Disability rates

The Elderly Population

Disability rates among the elderly have declined.[12] However, a growing absolute number of elderly people, coupled with increasing life expectancy, means that the number of people who need assistance is expected to increase. Projections of the number of elderly persons needing long term care by 2030 range from 10.8 million to almost 14 million (Friedland and Summer, 1999).

The Non-elderly Population

On the other hand, disability rates for children and young adults have risen considerably since 1990. Before 1990, however, disability rates for both groups remained steady for two decades. Among children under age 18, disability rates increased from 5.6 percent to 7.9 percent for boys, and from 4.2 percent to 5.6 percent for girls between 1990 and 1994. These changes can be partially attributed to the increase in the prevalence of asthma, mental disorders, mental retardation, and learning disabilities (Kaye et al., 1996). Among younger adults, ages 18 to 44, disability rates increased slightly for both men and women between 1990 and 1994, in part due to the increase in orthopedic impairments and mental disorders.

Among adults age 45 to 64, disability rates remained fairly constant from the 1970s through the early-1990s.[13] Work disability rates have also remained fairly constant; some 11 percent were unable to work and 7 percent were limited in the type or amount of work they can do (1994). Work disability rates are much lower for adults age 18 to 44, but have been increasing. Between 1990 and 1994, for example, the proportion of those unable to work increased from 2.9 to 3.7 percent (Kaye et al., 1996).

The impact of the aging population

The aging of our population will have a significant impact on the demand for care and hence, the future of both paid and unpaid caregiving. The relative size of the paid long term care workforce in the future is uncertain. The overwhelming preference for home care by people with disabilities and the elderly population has greatly increased the demand for paid professionals, but the number of people choosing this type of work is not increasing as quickly as the demand for their services.

Changes in family structure will also affect the pool of potential unpaid caregivers. The elderly of today have fewer adult children than did previous generations and the elderly of tomorrow will have even fewer children upon which to depend. Adding to the complexity is the fact that adult children are increasingly less likely to live near their parents. Furthermore, the population most likely to require long term support services, age 85 and over, is growing faster than any other age group. Thus, the elderly needing care in the future will be among the "oldest old," and hence their caregivers, primarily spouses and adult children, may also be elderly.

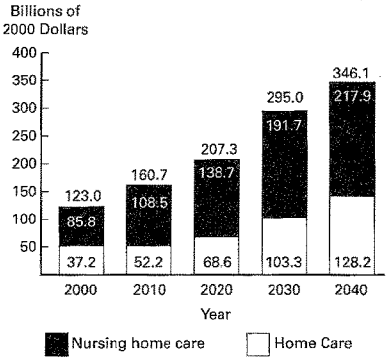
The paid long term care workforce is declining

It is clear the size of the paid long term care workforce will not be able to keep up with the anticipated demand for workers unless the system changes. The recruitment and retention problems that providers face, primarily due to the low-wage rates that are being offered in today's competitive labor market, will only be exacerbated as our population ages. High turnover rates in facilities and in the home care industry, exacerbated by insufficient government reimbursement rates are a major concern because they create an unstable workforce and are a barrier to high-quality care. The Institute of Medicine (IOM) reported that nursing home caregivers average turnover rates of 105 percent per year (1994). Turnover rates for home care workers, however, are generally lower (Wilner and Wyatt, 1998).

Growth in long term care expenditures

As our population ages, long term care expenditures are expected to increase dramatically. Estimates by the Congressional Budget Office (Hagen, 1999) suggest that for the elderly alone, long term care expenditures are expected to increase from $123 billion now to $346 billion in 2040 (in 2000 dollars) (see Figure 6). Given the relative newness of the long term care insurance market, the impact of private insurance on the financing of these costs remains uncertain. The Congressional Budget Office, however, estimates that regardless of how much private long term care insurance expands between now and 2020, Medicaid spending will still increase substantially. Assuming an increase in private long term care insurance spending, Medicaid spending would have to increase from $43 billion today to $75 billion in 2020 (in 2000 dollars) to maintain current levels of service to low and middle-income elderly people. If there is no appreciable expansion in private insurance spending, Medicaid long term care expenditures for the elderly is estimated to increase to $88 billion by 2020 (Hagen, 1999).

Figure 6
Projected Long-Term Care Expenditures for the Elderly, by Type of Care



Source: Projections from CBO, March 1999.

Increasing demand on states

Most publicly financed long term care services and supports are funded through the federal-state Medicaid program. Recently, a number of state-funded long term care programs have been developed to supplement the public funding provided by Medicaid. The establishment and expansion of such programs demonstrates a response to unmet need by states. More than $1.2 billion was spent on state-funded long term care programs for the elderly in 1996 (Kassner and Williams, 1997). Today, 36 states report that they have state-funded multi-service programs that provide home and community-based care to people of all ages in 2000 (Summer, forthcoming).

It is unclear how much the demand for Medicaid long term care services will increase as our population ages. It is clear, however, that in the absence of long term care financing reform, states' roles in providing long term care services and supports will expand. As Medicaid competes with Social Security and Medicare, which are also affected by the aging of the population, there is likely to be pressure to restrain growth in Medicaid spending (Merlis, 1999). Thus, the burden of long term care financing will increasingly be placed upon states and local communities.

Notes

[12] From the National Long term Care Survey (NLTCS), the annual rate of decline in disability between 1982 and 1994 was about 1.3 percent per year among people age 65 and older. This resulted in 1.2 million fewer elderly persons with disabilities in 1994 than if the disability rate had not declined.

[13] The rates were about 25 percent for men and 23 percent for women before 1982, and 22 percent for men and 23 percent for women after 1982. (In 1982, however, the NHIS question on disability was changed substantially.)

Motivated by concerns over the current state of long term care and in agreement on the need to pool long term care risk, Citizens for Long Term Care calls for a national dialogue on reforming the financing of long term care.

IV. A Call for a National Dialogue

Pillars of reform

Citizens For Long Term Care's Principles of Reform, which described a set of basic principles that would shape the development of an ideal long term care system have served as an important point of reference in discussions. From the Principles of Reform, Citizens sought to be more specific and develop the Eight Pillars of Financing Reform, which would help guide the national dialogue on long term care financing reform.

- Every American must be assured access to needed long term care services.
- A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.
- The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.
- Eligibility for the social insurance benefit should be based on functional limitations as an entitlement benefit.
- Private and public policies should be developed to educate and encourage individuals and families to plan for the financing of care prior to the onset of disability.
- Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.
- Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.
- The financing system must support choices across the continuum of care and help maximize personal independence, self determination, dignity and fulfillment.

Motivated by concerns over the current state of long term care and in agreement on the need to pool long term care risk, Citizens for Long Term Care calls for a national dialogue on reforming the financing of long term care. To help guide that dialogue Citizens For Long Term Care developed a set of goals for a new system. The system must: be a public/private long term care system; it must assure access to care; support individual preferences and family caregivers, and build on the current financial security framework; and, the system must be financed by a clear national commitment based on principles of social and private insurance.

Most specifically, Citizens For Long Term Care agreed that there must be a new social insurance benefit that finances a minimum floor of financial protection for all. This benefit will be based on functional need with appropriate eligibility and benefit level standards and requirements. The new social benefit is to be combined with a program of tax incentives for the purchase of private insurance earlier in one's life. Citizens also strongly believes that public assistance must be available to those whose needs exceed all other public and private resources. The member organizations agreed that certain key elements should be a part of long term care financing reform. They are:

The New Social Insurance Benefit

- A new social insurance cash payment benefit with appropriate eligibility and benefit level

standards and requirements must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.

- The financing system should be as flexible as possible, not only to meet different and changing needs of individuals, but also to accommodate regional variations and to assure appropriate consumer choice in settings across the continuum of care. Two people with the same level of functional need should receive the same level of assistance but be able to use that assistance differently.

- There needs to be a new publicly financed program that provides a national, uniform system of disability assessment, which offers both information and assistance in arranging for appropriate services.

- There needs to be a critical examination of the definition of guidelines for disability and long term care to help ensure integrated coverage for supportive services over the course of one's lifetime.

Private Insurance and Employers

- The acquisition of private insurance, especially at a younger age, for those for whom it is most appropriate must be encouraged and supported through publicly supported tax incentives.

- Insurers have a responsibility to help educate consumers and work with employers, the government, and consumer groups to develop ways to expand the pool of privately insured risks and to ensure that private resources are used to improve the organization and delivery of long term care.

- Employers have a critical role to play. Employers, working with government, have a responsibility for helping people to better understand the financial consequences of long term care and their options to plan for this risk. Employers are also in a better position than individuals to choose and organize disability and/or long term care insurance options.

- Individuals and their families have a responsibility to plan for the financial consequences of needing long term care. For some people, at various stages of their lives, the only effective way to plan for the future will be by working and paying taxes. Others, however, will have the opportunity to build on the protections provided by the social commitment and use tax incentives to purchase private insurance or to finance other options that insure long term care needs.

Medicare

- Medicare needs to be reformed to cover the most appropriate level of support for health care needs of those with chronic illness and disabling conditions.

- Medicare needs to be reformed in ways that ensure more beneficiaries are able to either avoid or delay the onset of chronic and disabling conditions and to better define the separation between chronic health care and long term care services so that the health needs of those with chronic conditions are better met.

Medicaid

- Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.

This approach to reform establishes a national framework to improve the financing, organization, and delivery of long term care. It offers the potential to pool public and private resources towards

the development of an efficient and equitable market of long term care providers, and provides the potential to help families better organize, coordinate, and integrate needed care with their own efforts. As outlined, individuals are encouraged to take responsibility for their future long term care needs while the government provides necessary consumer protections, a base social insurance program that can be built upon, and long term care for those whose needs exceed their resources.

While often not recognized as a key element of financing reform, the intergovernmental aspect of the Medicaid program dictates that reform of the financial, regulatory and oversight interchange between local, state, and federal governments will be an integral aspect of long term care financing reform. To solve long term care financing reform will require an intensive re-examination of the intergovernmental relationships that currently govern long term care financing. These include:

Intergovernmental:

- The federal government must be responsible for establishing the operating principles; policies and public financing for the national long term care system.
- State and local governments have a responsibility to work with the federal government to design and implement measures of quality outcomes.
- State and local governments have a responsibility to work with the federal government to encourage the development of local capacity to help people based on national standards of care.
- The federal, state, and local government must share responsibility for educating consumers about long term care risks, helping them make informed choices about insuring those risks and making sure long term care insurance has adequate consumer protections.

There are still many critical questions for which Citizens For Long Term Care did not reach agreement. First and foremost is the question of the size and scope of the floor of financial protection. Others include appropriate levels of support for tax incentives for the purchase of long term care insurance or necessary changes to Medicare and Medicaid. The answer to these questions will require a national dialogue about long term care.

The Road to Reform

The need for long term care is an emotionally and financially draining experience that can affect a family through the birth of a child with developmental disabilities, accident, chronic disease or as the result of the frailties of old age. People of all ages and economic stratum are at risk of being impoverished by its expense. For the last sixty years we have developed and refined a combination of social insurance and private mechanisms to help people achieve some level of financial security. In doing so we have strengthened the economic security of our country and developed a uniquely American approach to financial security.

Unfortunately, changing demographics threaten to undermine this system of support unless reform is undertaken. As we enter the 21st century we can foresee the retirement of 77 million Baby Boomers many of whom will join their parents in a lengthy retirement brought on by advances in medicines and healthier living. As their parents get older and the Baby Boomers begin to suffer from the inexorable increase in chronic health conditions we can predict with reasonable certainty the greater need for long term care supports and services. Moreover, scientific advances

in preventing developmental disabilities, helping with accident rehabilitation or curing chronic illnesses have not proceeded as quickly as we would like, thus ensuring a steady increase in need from these users of long term care.

As the cost of long term care continues to outpace inflation, we can safely assume that there will be a tremendous explosion in costs associated with long term care. For families this means greater threats to financial security. For retirees it can mean impoverished golden years. For the states and federal governments it will mean long term care costs will crowd out other priorities. For America it means we must begin addressing long term care financing reform now to prevent these possibilities.

The transition from the current welfare-based system of financing long term care to a new national public/private system will be slow and difficult. It will not happen overnight, but fortunately we have several years to begin the process before the full force of the retiring Baby Boomers is upon us. In order to begin the transition our country's highest leaders must take the initiative. We need, and expect, the President of the United States, with help and support from business and elected leaders, to begin a national dialogue on long term care financing reform. We have started the dialogue on the other aspects of financial security; Medicare, Social Security and tax reforms: long term care financing reform must now be part of the dialogue. To ignore this threat imperils the financial security of every American and the economic prosperity and security of our nation.

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The CHAIRMAN. Thank you, Senator Durenberger, very much for your statement, but also for your long and continued involvement in these types of issues. It is encouraging to see that once you leave this place, you can still make a big difference. And we thank you for that.

Mr. DURENBERGER. Thank you.

The CHAIRMAN. Ms. Carol O'Shaughnessy.

STATEMENT OF CAROL V. O'SHAUGHNESSY, SPECIALIST IN SOCIAL LEGISLATION, CONGRESSIONAL RESEARCH SERVICE

Ms. O'SHAUGHNESSY. Senator Breaux, good morning, and thank you for the opportunity to testify before you today. I have had the pleasure of working with the staff of the Senate Special Committee on Aging for many years.

Today, I will give an overview of long-term care consumers, providers, and spending, and will summarize my written statement.

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness or frailty.

You had asked about what kinds of services comprise long-term care. Services range from care in nursing homes, assisted living, and boarding care facilities to home and community-based services through home health and homemaker services, adult daycare, and home-delivered meals.

The cost of care is related to the type, intensity, and duration of care that is needed by an individual, as well as the availability of informal supportive services from family and friends.

Researchers and policymakers have debated the question of whether or not home and community-based services are cost-effective. This question is very complex, and many factors must be considered, including how best to target home and community-based services, the effective mix of services to divert persons from institutional care, and how to assist informal family caregivers in their responsibilities.

I will say just a few words on a long-term care population. About 9 million adults receive long-term care assistance, but the vast majority, or 80 percent, are in community-based settings, not in nursing homes.

Persons aged 65 and older represent about 60 percent of all adults who receive assistance, but the need for long-term care affects persons of all ages.

About 3.5 million adults receiving care are under age 65.

The CHAIRMAN. Let me interrupt you, if I can.

You said, 80 percent of the 9 million are in nursing home facilities——

Ms. O'SHAUGHNESSY. Are in home and community-based settings, not in nursing homes.

There is a disproportionate expenditure. We are spending so much money on institutional care, but really there are more people in home and community-based settings, receiving care mostly from family and friends.

The CHAIRMAN. I had heard it was even higher than that. I had heard the figure 95 percent.

Ms. O'SHAUGHNESSY. Well, this data comes from the most recent data from the national interview survey on disability.

The CHAIRMAN. OK, please continue.

Ms. O'SHAUGHNESSY. OK.

About one-third of elderly persons who receive care at home and in community-based settings have severe impairments. That is, they have limitations in at least three activities of daily living, such as bathing, dressing, toileting, or getting around inside the home. And without home and community-based support, these persons might require care in nursing homes.

The likelihood of needing care increases dramatically with age. Over half of persons age 85 and older receive long-term care assistance.

However, regardless of age, persons are more likely to be in community-based settings rather than in nursing homes. And there is a chart in the written testimony that displays this for you, chart 1.

The demand for long-term care, as we heard from the Secretary, is expected to grow substantially in the future and will be driven by the aging of the baby boom generation. Estimates show that the number of elderly persons alone who need long-term care assistance could grow by 35 percent over the next 20 years and by 82 percent over the next 40 years. And in the testimony, chart 2 displays the growth and the need over the next several decades.

Rapid growth in the number of people over age 85 presents special challenges, because they have the greatest risk of needing care. And demand will also increase as a result of the recent Supreme Court decision in Olmstead and advocacy efforts on the part of younger persons with disabilities.

These factors will present challenges for some long-term care providers, who even now face difficulties in meeting demand for services in certain areas.

I just want to make a point about the role of families and informal supports. Most long-term care assistance is provided by unpaid family members, and almost 60 percent of the functionally impaired elderly receiving care rely exclusively on informal, unpaid assistance.

Many have argued that while public programs should not and cannot replace family caregiving, targeted initiatives to assist family caregivers are needed.

A number of Federal programs—and I have displayed them in the testimony—support persons with disabilities. However, none focus exclusively on long-term care.

It is as Senator Durenberger and the Secretary mentioned, is a patchwork quilt of programs.

Many observers believe that the current system is flawed because of its overreliance on institutional care, the impoverishment of many persons as a result of paying for care, the heavy reliance on informal caregivers, and the uneven availability of home and community-based services.

In terms of spending, the Nation spent $134 billion on long-term care in 1999. And this represents about 13 percent of total personal health care expenditures and amounts to slightly more than Na-

tional spending on prescription drugs. And in the testimony, that is displayed on chart 5.

Of the total long-term care spending, 67 percent is for institutional care and one-third is for home and community-based services.

And if you look at the chart on your far right, it displays the sources of long-term care funding. We see that Medicaid is the major payer. Personal out-of-pocket spending represents about 25 percent, with Medicaid at 44 percent. And Medicare and private insurance play much smaller roles.

I will say a few words about Medicaid. Medicaid's role, as we heard this morning, is primarily through its financing of institutional care. And of total Medicaid spending in fiscal year 2000, 73 percent was for institutional care and just 27 percent was for home and community-based care.

And if you look at the second chart, you see that Medicaid's long-term care spending is still dominated by spending for nursing home care, even though home and community-based services spending has risen over the last decade very rapidly. In fact, home and community-based has risen seven times as opposed to about a doubling in institutional care expenditures.

Many States consider their home and community-based waiver programs, that the Secretary mentioned as key components in developing long-term care systems.

And despite the rapid growth, however, many analysts consider the program to be only a partial step in providing comprehensive long-term care services because of the restrictions on eligibility and limitations in service availability throughout the Nation and within individual States.

We have done some analysis of fiscal year 2000 expenditures and found that at least half of the States spend most of their money on institutional care in fiscal year 2000. Twenty States spent 75 percent or more of their Medicaid dollars on institutional care, despite the rapid increase in the waivers.

Changing the way long-term care is financed has drawn attention of Congress for more than two decades, and proposals have included both incremental and large-scale approaches. A wide range of proposals has been advanced including social insurance, the tax incentives that you mentioned, grants for expanding home and community-based services, and combinations of these.

To date, Congress has taken incremental approach. Obviously, the significant challenge for Congress is to reconcile the cost, as well as the relative roles of public and private sectors, in ways to assist family caregivers.

Thank you, Mr. Chairman, and I would be happy to answer any questions.

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

Long-Term Care: Consumers, Providers and Spending

Testimony Before Senate Special Committee on Aging
Carol V. O'Shaughnessy
Specialist in Social Legislation
Congressional Research Service

June 28, 2001

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Statement of Carol O'Shaughnessy
Specialist in Social Legislation
Congressional Research Service

Long-Term Care: Consumer, Providers and Spending
Testimony Before the Senate Special Committee on Aging
June 28, 2001

Good morning, Mr. Chairman and Members of the Committee. My name is Carol O'Shaughnessy. I am a Specialist in Social Legislation at the Congressional Research Service.

This morning I will provide an overview of long-term care for the elderly and persons with disabilities. I will briefly describe the need for long-term care services, the role of families in providing care, and the role of federal programs in financing services.

Defining the Need for Long-Term Care Services

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care due to illness, frailty, or a disabling condition. Need for long-term care services is measured by the need for assistance from others in performing basic daily activities, referred to as *activities of daily living* (ADLs) and *instrumental activities of daily living* (IADLs). ADLs are basic human functions, and include bathing, dressing, getting around inside the home, toileting, and eating. IADLs are tasks necessary for independent community living, such as shopping, light housework, and meal preparation.

Legislation to finance long-term care services frequently limits eligibility to persons having limitations in a specific number of ADLs, and, for the cognitively impaired, persons with a similar level of disability. This approach allows policymakers to target people with greatest need and to control costs.

Long-term care services include a continuum of health and social services, ranging from care in nursing homes to care at home through home health, personal care, homemaker services, and services in the community,

such as adult day care. Long-term care may also be delivered in a variety of other settings that provide health and supportive services along with housing, such as intermediate care facilities for the mentally-retarded (ICFs/MR), assisted living and board and care facilities.

The cost of care is related to the type, intensity, and duration of services needed by clients, as well as the availability of informal assistance from family and friends. Costs may be modest to provide home-delivered meals to a frail older person living at home, for example. Cost of providing more intense home care services to a very severely impaired older person without family or community supports may be higher. Costs for 24-hour care in nursing homes or intermediate care facilities for the mentally retarded (ICFs/MR) can range from over $40,000 to almost $80,000 annually. Researchers and policymakers have debated whether expanded access to home and community-based care for the Nation's long-term care population is less costly than institutional care. This question is very complex and many factors must be considered, including how best to target home and community-based services, what is the most effective mix of services to divert persons from institutional care, and how to assist informal caregivers who often make a difference in keeping their family members from entering an institution.

The Long Term Care Population.[1] About 9 million persons over age 18 receive long-term care assistance. The vast majority – over 80% – of these persons are in home- and community-based settings, *not* in nursing homes. Only about 1.6 million persons – less than 20% of all adults receiving assistance – reside in nursing homes.

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[1]Data for this section come from an analysis of the 1994 Disability Supplement to the National Health Interview Survey (NHIS) and the National Long-Term Care Survey, *The Characteristics of Long-Term Care Users*, prepared for the Committee on Improving Quality of Long-Tem Care, Institute on Medicine, by William D. Spector, et.al., 1998.

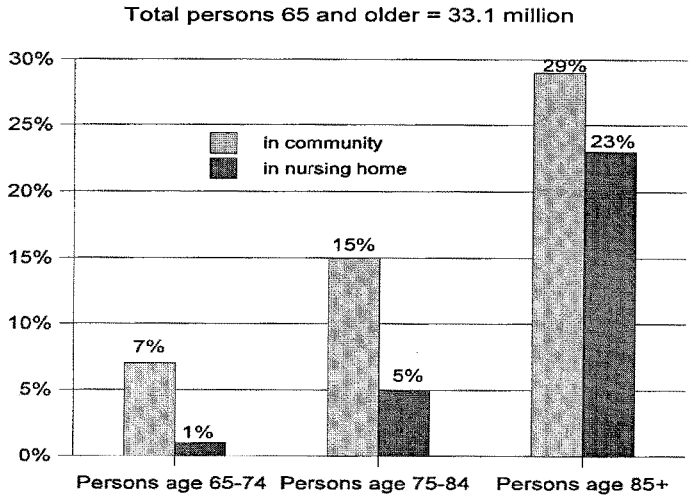
Estimates of the number of persons who need long-term care vary depending upon the number and types of ADL and IADL limitations and other factors used for measurement. Therefore, other research may show slightly different estimates.

Persons age 65 and older represent about 60% of all adults who receive assistance (almost 4 million persons in community settings and about 1.4 million of the 1.6 million persons in nursing homes). But the need for long-term care affects persons of all ages. Of the 9 million persons receiving long-term care assistance, about 3.5 million are adults under the age of 65. In addition, almost 500,000 children living in the community have difficulty performing activities of daily living.

Almost one-third of the elderly, and about one quarter of adults of all ages, who receive care at home and in community services settings have **severe** impairments – that is, they need assistance with three or more activities of daily living. Without home and community support, these persons might require care in nursing homes. In addition, almost 40% of the elderly, and about half of adults of all ages, who receive assistance at home and in community settings have diminished ability to carry out tasks necessary for independent community living.

The likelihood of receiving long-term care assistance increases dramatically with age. Over half of all persons age 85 and older receive long-term care assistance, either in community settings or in nursing homes, compared to only 28% of persons age 65-84. However, regardless of age, older persons are more likely to receive long-term care at home or through community services, rather than in nursing homes. (Chart 1)

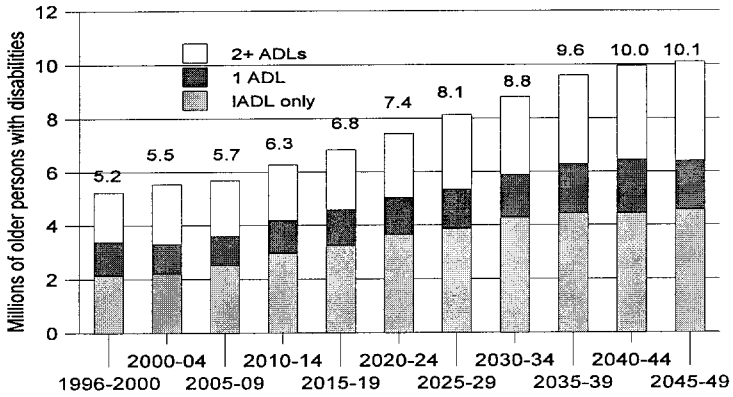
Chart 1. Persons Age 65 and Older Receiving Long-Term Care Assistance, By Age and Setting, 1994



Source: 1994 National Long-Term Care Survey from W. Spector, et. al. *Characteristics of Long-Term Care Users.* Prepared for the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.

Demand for Long-Term Care. The need for long-term care is expected to grow substantially in the future, straining both public and private financial resources. Growth in demand will be driven by large increases in the elderly population as a result of the aging of the baby boom generation and general increases in longevity throughout the population. The first of the baby boom generation will turn 65 in just 10 years. Estimates show that the number of elderly persons alone who need long-term care assistance could grow by 35% over the next 20 years, and by 82% over the next 40 years. (Chart 2)

Chart 2. Projected Growth of the Long-Term Care Population, Age 65 and Older



Source: *The Long-Term Care Financing Model.* Prepared by the Levin Group, Inc. for DHHS, 2000. The projected number of older persons with disabilities represents the average for each time period.

ADLs = activities of daily living
IADLs = instrumental activities of daily living

While estimates vary, increases in longevity and in the number of older persons are certain to affect the demand for services. Rapid growth in the number of people over age 85 presents special challenges because the "old-old" have the greatest risk of needing care. The demand for home and community-based services is expected to grow as a result of the recent Supreme Court decision in *Olmstead v. L.C.* and advocacy efforts of younger persons with disabilities.[2] These factors will present challenges for long-term care providers, who even now face difficulties in meeting demand for services. Some research has found that about one in five disabled elderly persons living in the community report some unmet need. Persons with

[2]In *Olmstead*, the Court held that Title II of the Americans with Disabilities Act (ADA) requires states to place individuals with mental disabilities in community settings rather than in institutions, when the state's treatment professionals have determined that community placement is appropriate, community placement is not opposed by the individual with a disability, and the placement can be reasonably accommodated. The scope of the *Olmstead* decision applies broadly to all individuals with disabilities protected by Title II the ADA.

income below the poverty level and those with income from 150% to 200% of poverty are about equally as likely to have some unmet needs.[3]

The Role of Families and Informal Supports

Most long-term care assistance is provided by unpaid family members. About 37 million caregivers provide informal care to family members of all ages. Typically, this care is provided by adult children to elderly parents and by spouses to one another.

Almost 60% of the functionally impaired elderly receiving care rely *exclusively* on informal, unpaid assistance. (Chart 3) Research has documented the enormous responsibilities that families face in caring for relatives who have significant impairments. For example, caregivers of the elderly with functional limitations provide an average of 20 hours of unpaid help each week. Some estimates have shown that unpaid work, if replaced by paid home care, would cost an estimated $45 billion to $94 billion annually.[4] Some estimates have placed the economic value of caregiving even higher.[5]

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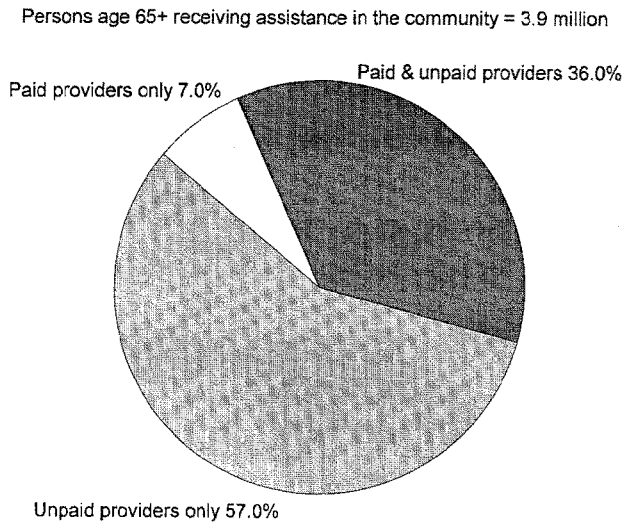
[3]Komisar, Harriet and Marlene Niefeld. *Long-Term Care Needs, Care Arrangements and Unmet Needs among Community Adults: Findings from the National Health Interview Survey on Disability*. Working Paper No. IWP-00-102. Georgetown University, Institute for Health Care Research and Policy, 2000.

[4]Doty, Pamela. *Caregiving: Compassion in Action*. U.S. Department of Health and Human Services, 1998. p. 13. This estimate is based on elderly persons who need assistance with ADL or IADL limitations.

[5]Arno, Peter, et. al. The Economic Value of Informal Caregiving. *Health Affairs*, March/April 1999.

Chart 3. Percent of Persons Age 65 and Older Receiving Long-Term Care Assistance in the Community, 1994



Source: 1994 NHIS-DS, from W. Spector, et. al. *Characteristics of Long-Term Care Users.* Prepared for the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.

Many have argued that while public programs should not and cannot replace family caregiving, targeted initiatives to assist family caregivers are needed. For example, last year Congress enacted the National Family Caregiver Support Program as part of the Older Americans Act. The intent of the program, funded at $125 million this year, is to provide information, assistance, and respite care services to families in their caregiving efforts.

Federal Programs. A number of federal programs directly or indirectly support a wide range of services for persons with disabilities. (Chart 4) None focus exclusively on long-term care. Eligibility requirements, services authorized, and administrative structures vary among the programs, making coordination difficult. Services provided by Medicaid and other federal programs that support long-term care vary widely by state, leading to uneven access to services across the Nation.

Chart 4. Selected Federal Programs for Persons with Disabilities

Medicaid
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests
- *Services:* Nursing facility, home health, personal care services, and adult day care
- *Administration*: State

Medicaid Home and Community-Based Service Waivers
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet income and asset tests, and who would otherwise be in an institution
- *Services*: A wide array of non-medical support services excluding room and board
- *Administration*: State

Medicare
- *Eligibility*: Persons age 65 and older and certain younger persons with disabilities
- *Services*: Short-term skilled nursing facility and home health care
- *Administration*: Federal

Social Services Block Grant
- *Eligibility*: Determined by states
- *Services*: A wide array of home and community-based services
- *Administration*: State

Older Americans Act of 1965
- *Eligibility*: Persons age 60 and older
- *Services*: Nutrition, home care, adult day, respite, transportation, and preventive health services, among others
- *Administration*: State

Supplemental Security Income (SSI) State Supplemental Program
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet state income and asset tests
- *Services*: Cash payments may be used by beneficiaries for home and community care
- *Administration*: State

Rehabilitation Act of 1973
- *Eligibility*: Adults who have a physical or mental impairment that results in a substantial impediment to employment and who can benefit from vocational rehabilitation (VR) services
- *Services:* Vocational rehabilitation, employment training, education, and independent living services among others
- *Administration*: State

Supportive Housing (Sections 202, 811) and Congregate Housing Services Act of 1978
- *Eligibility*: Certain adults with disabilities
- *Services*: A variety of supportive housing options
- *Administration*: Federal

Department of Veterans Affairs (DVA)
- *Eligibility*: Based on statutory priorities, including service-connected disabilities and/or other factors
- *Services*: A range of institutional, residential, and supportive services
- *Administration*: Federal

- *Medicaid* provides coverage for nursing home care and a wide range of home- and community-based services for persons of all ages who meet income, asset, and categorical eligibility criteria prescribed by federal and state law. Many people qualify for Medicaid benefits not by being poor, but rather, by depleting most of their assets and income to pay for care. Although nursing home care coverage is mandated by federal law, states have great discretion in deciding the extent of coverage for home and community-based care.
- *Medicare* pays for medically necessary, part-time skilled nursing and rehabilitation therapy services at home; it also pays for up to 100 days of care in a skilled nursing facility following hospitalization for individuals who need daily skilled nursing care. Medicare does **not** cover long-term care services for persons with chronic care needs or who require only assistance with ADLs.
- The *Social Services Block Grant (SSBG)* program provides a range of home and community-based services to low-income persons of all ages who meet state-defined eligibility requirements. Home care services must compete with a variety of other services for funding.
- The *Older Americans Act (OAA)* supports home and community-based services to persons aged 60 and over.
- *Tax benefits* for long-term care include a limited deduction for long-term care expenses and insurance premiums (provided the taxpayer itemizes deductions), tax-exempt insurance benefits, and the dependent care tax credit.

Other programs, such as state supplements to *Supplemental Security Income (SSI)*, support a range of home- and community-based services for persons with long-term care needs. Federal programs or benefits that support persons with disabilities or their caregivers include the *Family and Medical Leave Act* and the *Senior Companion Program (SCP)*, which supports volunteer assistance to frail older persons.

Despite the range of federal programs and benefits that exist, many observers believe that federal programs do not significantly support the care

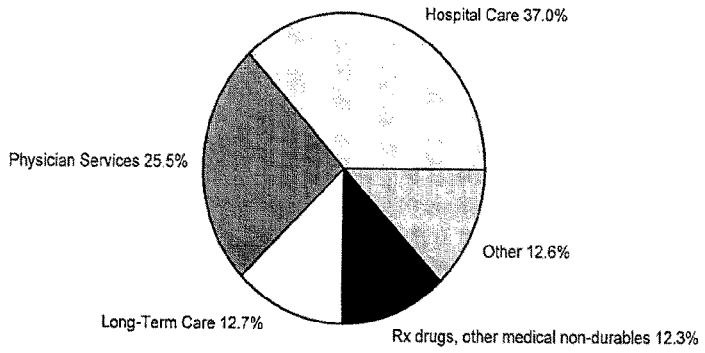
most people want, that is, home and community-based services. They argue that the current system is flawed because of an over-reliance on institutional care and the sometimes poor quality of such care, the heavy reliance on informal caregivers who bear most of the burden of care, and the uneven availability of home and community-based services that most people prefer over care in institutions.

Public and Private Spending on Long-Term Care

The Nation spent $133.8 billion on long-term care for persons of all ages in FY1999. This represents almost 13% of total personal health spending and an amount slightly more than the Nation's spending on prescription drugs and nondurable medical supplies combined. (Chart 5)

Chart 5. Long-Term Care Spending as a Share of Total Personal Health Care Spending for All Ages, 1999

Total personal health care spending = $1.06 trillion

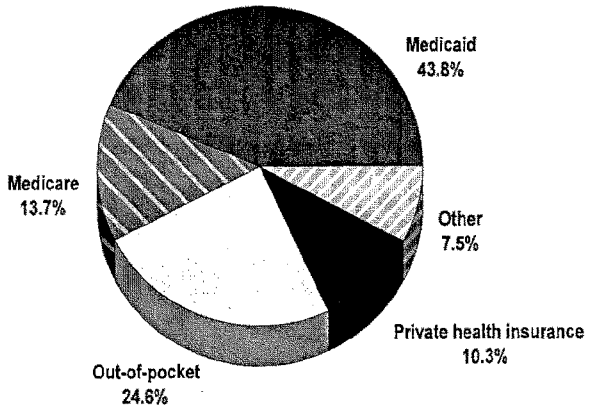


Source: Health Care Financing Administration, Office of the Actuary, National Health Statistics Group.
Note: Percentages do not sum to 100% due to rounding.

Of FY1999 long-term care spending, 67% was for institutional care and one-third was for home and community-based services. Medicaid and personal out-of-pocket spending represent the two major sources of payment, 44% and 25%, respectively. Medicare plays a smaller role,

representing only 14% of total long-term care spending. Private health insurance represents about 10% of the total. (Chart 6)

Chart 6. Sources of Long-Term Funding, 1999
Total long-term care spending = $133.8 billion



Source: Prepared by CRS based on data from Health Care Financing Administration, Office of the Actuary, National Health Statistics Group.
Note: Percentage does not sum to 100%due to rounding. Medicaid spending includes expenditures for nursing homes, ICFs-MR, home health, personal care and community-based waiver services.

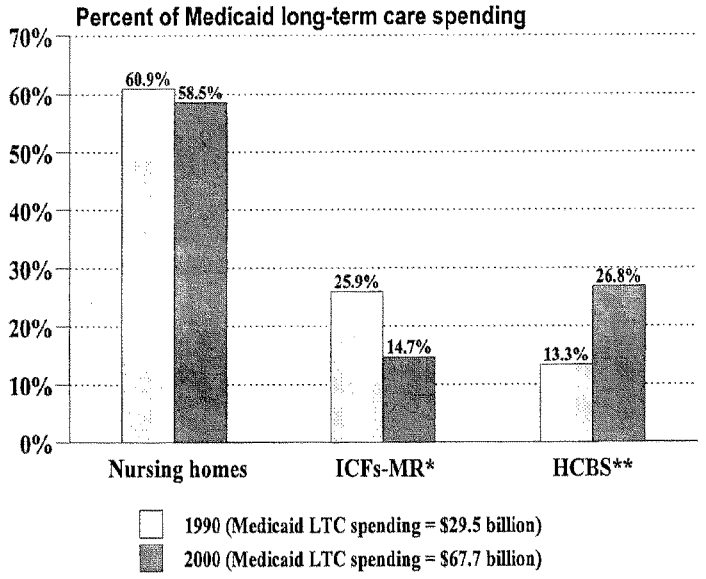
The Heavy Reliance on Medicaid. Federal Medicaid law mandates states to provide nursing facility care. In addition, states may (and all states do) provide institutional care for persons with mental retardation. States are required to provide home health services for persons who are entitled to institutional care. However, other home and community-based services, such as personal care, homemaker services, and adult day care, are provided at the option of each state.

In order for persons to become eligible for Medicaid long-term care services, they must meet strict income and assets requirements that are set by the state within federal guidelines. Medicaid pays for long-term care costs of persons whose income is low enough to receive federal cash payments under the Supplemental Security Income program (SSI) for elderly and

disabled persons ($530 per month), but can also pay part of the costs for persons whose income exceeds specified levels through its "spend down" policies (that is, a person must deplete income and resources to become eligible).

Medicaid long-term care spending in FY2000 was almost $68 billion, more than double the amount spent in FY1990 (almost $30 billion). (See Table 1, below.) While only a small proportion of all persons receiving long-term care services reside in nursing homes, public spending for institutional care, primarily through Medicaid, is higher than expenditures for home and community-based care. Of total spending in FY2000, 73% was for institutional care; in comparison, just 27% was for home- and community-based care. Even though spending for home and community-based services has dramatically increased since FY1990, institutional care still dominates Medicaid's long-term care spending. (Chart 7)

Chart 7. 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.

The shift in Medicaid spending toward home and community-based care over the last decade has occurred primarily as a result of states' initiatives to provide a wide range of services under waiver authority granted by the Department of Health and Human Services (under Section 1915(c) of the Medicaid statute). In order to be served under these waiver programs, persons must meet institutional level of care requirements and states must assure that the cost of home and community care not exceed the cost of institutional care that would otherwise be provided to recipients. From 1990 to 1998, the rate of increase in Medicaid spending for home and community-based services has outpaced the rate of increase in spending for institutional care. Institutional care spending rose by 94%, while home and community-based care spending rose seven times over the 10 year period.

Table 1. Medicaid Spending for Long-Term Care Services, FY1990- FY2000

($ in billions)

	FY1990	FY2000	Percent change, FY1990-FY2000
Institutional care	**$25.6**	**$49.6**	**93.8%**
Nursing facility care	18.0	39.6	120.0%
Intermediate care facilities for the mentally retarded (ICFs/MR)	7.6	10.0	31.6%
Total home and community-based services	**3.9**	**18.1**	**364.1%**
Home and community- based waiver services	1.2	12.0	900.0%
Personal care services	1.9	3.8	100.0%
Home health care services	0.8	2.3	187.5%
Total long-term care expenditures	**$29.5**	**$67.7**	**129.5%**

Source: *CRS calcuations based on Medicaid Long-Term Care Expenditures in FY2000,* compiled from HCFA 64 data. The MEDSTAT Group, Inc.

Many states consider their Medicaid home and community-based waiver programs as key components in developing long-term care systems. Despite rapid spending growth nationwide, however, many analysts consider such programs to be only a partial step in providing comprehensive long-term care services because of restrictions on eligibility and limitations in service

availability throughout the Nation and within individual states. Moreover, most states spent at least half of their FY2000 Medicaid long-term care funds on institutional care; and 20 states spent 75% or more on institutional care.

Future Directions

Changing the way long-term care is financed has drawn congressional attention for more than two decades. Previous Congresses did not reach any consensus on what policy directions to take. Broad policy approaches advanced in the past have included proposals for social insurance coverage of long-term care costs, expanded public commitment for home and community-based care, tax incentives for private financing, and combinations of these, among others. Proposals have included both incremental and large scale approaches.

Some believe that the federal government should assume the major role in expanding access to services through a new or expanded entitlement program. For example, the 1990 U.S. Bipartisan Commission on Comprehensive Health Care[6] recommended social insurance for home and community-based care and for the first three months of nursing home care. Under this proposal, the federal government would subsidize costs of care for low income persons; others would contribute toward the cost of care. Another approach advanced was a Clinton Administration proposal for capped grants to states for home and community-based care for severely disabled persons, regardless of age and income.

Others believe that costs of a new or expanded social insurance program would be prohibitive and that private sector initiatives, such as private long-term care insurance and other means of self-financing, should be promoted. Still others believe that a strategy combining both public support and private financing, such as proposals to create tax incentives for the purchase of long-term care insurance, should be pursued.

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[6] *A Call for Action. The Pepper Commission U.S. Bipartisan Commission on Comprehensive Health Care.* September 1990.

To date, Congress has chosen an incremental approach to changing the federal role in long-term care. A significant challenge for policymakers is to reconcile the concerns about the costs of these proposals, the relative roles of the public and private sectors, and ways to assist family caregivers.

Note: CRS staff Rachel Kelly and Gary Sidor made key contributions to this statement.

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

Next, Bob Blancato.

Bob, welcome. Welcome back.

STATEMENT OF ROBERT B. BLANCATO, EXECUTIVE DIRECTOR, THE 1995 WHITE HOUSE CONFERENCE ON AGING; AND PRESIDENT, MATZ, BLANCATO & ASSOCIATES, INC.

Mr. BLANCATO. Mr. Chairman, thank you. Nice to be here.

I commend you for calling these hearings on long-term care and getting ready for the boomers. You are right, we do need a plan of action. You will have my complete statement, so let me make five quick points.

First, this is not a new issue, but there is new urgency. In 1977, I began work with the House Select Committee on Aging. We held hearings on long-term care. Fourteen years ago, our chairman, Claude Pepper, went to the House floor with a long-term care amendment.

In 1994, to prepare for the White House Conference on Aging, we went to the American people to set the agenda. Their top priority issue was comprehensive health care, including long-term care. And at the conference, five of the top 10 resolutions were on long-term care.

Fourteen years ago, long-term care was an issue with some foresight; today it is one of urgency. The reasons are many.

Demographics is certainly one. Today our medium age is the highest ever at 35.3. One key reason: Boomers between 45 and 54 grew by 49 percent between 1990 and 2000.

Second, Boomers and long-term care, public education, and personal experiences: Long-term care is not a mainstream issue compelling enough boomers into action. Why? In part because boomers delayed planning for their future, in part because of denial about aging.

Also, boomers have a false sense of security that Medicare will take care of their long-term care. Public education and awareness efforts must be intensified and improved. Before we tackle the complicated issues of financing and coverage, let's get everyone on the same page about what long-term care is, who pays now, and how.

I hope that the ongoing work of OPM dealing with the Long-Term Care Security Act will help educate boomers. This committee should also look at the many private groups who are doing great work in consumer education on long-term care. It must be a priority in the plan of action.

Maybe we just need a message. Americans, and especially boomers, have always responded to messages. One message is, you never know when.

My example, I have been a boomer all my life. I have spent more than 25 years in national aging policy, including long-term care. When did I focus on long-term care in a personal way? One year ago, because of a long-term care health crisis affecting my mother.

My take away? The cost of care for her in 2001 dollars is staggering. What about 20 years from now?

Too many boomers wait for the crisis to land on the doorstep. That is wrong. Crisis planning is an oxymoron.

Third, a call to action with a timetable: Let's set a timetable to move long-term care legislation in 2001. Top on the list is the bill you mentioned, S. 627, the Long-Term Care and Retirement Security Act.

As president of Americans for Long-Term Care Security, we strongly support this bipartisan bill and commend you, Mr. Chairman, for being an early cosponsor.

This is the kind of public-private incentive package that is needed. ALTCS views all the main pieces of this bill as critical; they must all stay together and be passed together.

Also this year, let's inventory all Federal programs in long-term care. How many are there? Are they working? Can we achieve cost-savings by reducing duplication? What successes can we build on? Are there State and Federal programs that have produced what we really need, long-term care service systems with a continuum of care?

And as work on comprehensive Medicare reform continues later this year, let's move to a Medicare that does what boomers want it to do: provide more long-term care coverage, provide more preventative coverage.

Fourth, family caregivers are key: Let's keep emphasizing family caregivers in all future long-term care policy. It was a strong start in 2000 with the National Family Caregivers Support Program.

Long-term care affects many constituencies—boomers, seniors, women, families, persons with disabilities. But the crosscutting issue, especially for boomers, is family caregiving.

We need to build more policy around caregivers. And if we do, we will get more of a buy-in from boomers.

It is not only a health issue, it also is an economic issue. In 1997, a MetLife study revealed that caregiving costs American businesses as much as $29 billion a year. That is a wakeup statistic.

And five, long-term care, a Federal investment: Future long-term care policy decisions will take some political courage. It is easy to score a bill, get shocked when it is high, and walk away. But with some long-term care legislation, the question is, is it in fact an investment that will achieve future savings, especially for Medicaid?

You know, next year we celebrate the 30th anniversary of the Older Americans Act nutrition programs. They were set up to help at-risk seniors from having to be institutionalized because of poor nutrition.

Has it worked? Absolutely.

Seniors have been in the congregate or home-delivered meal programs for 20 years or more. This means they are still in their homes, still in the community, and not in nursing homes.

That was a new appropriation in 1972. It was a good investment. The same thing with funds spent on research, especially Alzheimer's research. These are good investments.

Our goal should be long-term care that features universality, financial security, service availability, a real commitment to quality care, and a sensitivity to the needs of different constituencies. And it should specifically change the existing funding bias of Federal programs toward institutional care.

The time to act is now. Other timetables are not going to wait. In 2010, retirees grow from 13 to 20 percent of our population. And

as you well know, in 2011, the first wave of boomers turns 65 and are Medicare-eligible.

Mr. Chairman, certainly when it relates to boomers, long-term care, it may not be our issue today, but it could be tomorrow.

Thank you very much.

[The prepared statement of Mr. Blancato follows:]

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NEW YORK • WASHINGTON, D.C.

Written Testimony of

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Executive Director, 1995 White House Conference on Aging

Submitted to the

Special Committee on Aging
United States Senate

June 28, 2001

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MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE:

Thank you for the invitation to testify this morning. My name is Bob Blancato. I am President of Matz, Blancato and Associates, Inc. I also had the pleasure of serving as the Executive Director of the last White House Conference on Aging held in 1995.

I commend you for calling these hearings on long-term care and Baby Boomers. I especially support using these hearings as a necessary call to action on developing and moving the various elements for this nation to have a comprehensive national long-term care policy.

I would propose at the outset that we go beyond a call to action. We can go one step farther and aim for a specific timetable when we achieve a genuine national long-term care policy for Boomers and the many other individual constituencies who will confront long-term care challenges in their lifetime.

It is a special honor for me as a former House Select Committee on Aging staff member to be asked to testify before the more senior and still flourishing Senate Special Committee on Aging. Yet there is also a relevant historical tie between the House Committee and this hearing today. I had the good fortune of being on the staff when Claude Pepper was our Chairman. Imagine it was almost 14 years ago when Claude Pepper had the vision that America needed a national long-term care policy. He went as far as proposing such a policy and even got it to the House floor for a vote. He followed this with the landmark work of the Pepper Commission, which went further in developing a framework for a long-term care policy. Back then, as today, there were two primary directions for long-term care policy at the federal level: more Medicare coverage of long-term care, and providing more alternatives to institutionalization with federal long-term care funds.

There is also a tie between the work and products of the 1995 White House Conference on Aging and this hearing today. The Conference, which was the 4th in our history and final one of the 20th century, was called by President Clinton but was chaired by the distinguished former Chairman of this Committee Senator David Pryor. Our mission was to be intergenerational: to have a conference that did not just focus on the aged but on aging, a process that affects all generations. We also did something unique. We went to the American people and asked them to identify what should be on the agenda of this Conference.

After conducting more than 1000 local, state, and regional events in all 50 states in a one-year period with more than 125,000 persons in attendance, the top issue was comprehensive health care including long-term care. What more classic intergenerational issue is there than long-term care? Presently, it is estimated that 40 percent of those persons receiving long-term care are not seniors, but are those between 18 and 64. So it was evident that this was a top concern of the grassroots of this nation.

The question then became, would these grassroots come to Washington as delegates and adopt resolutions on long-term care? The answer was yes. In fact five of the top ten resolutions, based on votes of delegates, were on long-term care. I am submitting the text of these resolutions in my written statement for the record. The reality is that these resolutions comprise the provisions of many of the important long-term care bills that have either passed since 1995 or are pending today. There are also other outstanding ideas that could comprise future legislation. Two prime issues in these resolutions that are still relevant today are that long-term care policy, public or private, must feature genuine choice and that home- and community-based long-term care must get more support.

I am pleased to note that thanks to the support of all of you on this Committee that a fifth White House Conference on Aging will be held not later than December 31, 2005. It should be noted that the first wave of Boomers will be 59 for this conference and one can predict that long-term care will be an important issue.

What has happened relative in the development of national long-term care policy since 1988 or since 1995? It has gone from a hypothetical, almost foresighted issue 14 years ago to a far more imminent issue today. One good reason is that the oldest Boomers were only 42 in 1988, but now they are 55. It has also gotten more complicated to achieve a comprehensive solution because the health care market place has gotten more complicated. Yet I am concerned, as this Committee is, that long-term care is not enough of a mainstream issue that compels large numbers of people into action. This is especially true among Boomers.

We know based on past history that where Boomers do become engaged, they have a profound impact. Consider the impact Boomers have made on fast food, telecommunications, health clubs and, as they get older, sports medicine. Clearly the sheer number of Boomers contributes to them having an impact. We know Boomers are America's largest generation. The aging of the Boomers in the past decade has contributed significantly to the U.S. now having the

highest median age ever in its population. It is now, according to the Census Bureau, at 35.3 years up from 32.9 years in 1990. Further, and perhaps more significant in the short-term, were findings of an article in the Christian Science Monitor of May 15, 2001. The author, Laurie Belsie, noted that over the past ten years the number of 18 to 34 year olds actually declined four percent. By contrast, the front half of the Boomers—those aged 45-54—increased by 49 percent in that same time period.

How do we get more of a Boomer buy-in to the reality that they need to be more focused on planning for their long-term care needs in the future? Also, how do they become more engaged in developing long-term care policy? This is a challenge indeed, especially when you consider the rap on Boomers. They suffer from the "three D" syndrome; Boomers delay, especially with respect to saving and planning for later years; Boomers deny that they are aging; and Boomers demand action when they do get something up on their radar screen.

For many Boomers, involvement in long-term care is very personal. Let me give an example. I confess, Mr. Chairman, that I have been a Boomer all my life. I have spent more than half of my life working in national aging policy. But, guess when I first focused on long-term care. About one year ago. And guess why. Because of a long-term care crisis affecting my mother. It made the issue real from two distinct perspectives. One was addressing the crisis—learning about options for long-term care services first at home and later in a long-term care facility. The second was, what would I do if confronted with a similar situation when I got older?

On the care side we experimented with a number of options and thankfully have found the right one. But make no mistake about one thing; we were only successful with my mother's plan of care because my parents were fiscally prudent. My dad made a good income, saved and invested wisely. Therefore, we have the resources to pay.

Have I been as prudent in terms of saving and planning in my working life? I am afraid not. But at least I took one step and purchased long-term care insurance.

The hard reality is, the way I as a Boomer first confronted long-term care is the way too many people in my generation confront it. They wait until the crisis in on the doorstep and then move into action. Lets face it, "crisis planning" is an oxymoron. There is no reason why individuals, or this Congress, should wait for the long-term care crisis to land on the doorstep before having a plan. That is why your plan of action makes so much sense at this point in time.

One critical component of this plan of action on long-term care and Boomers must be to redouble our efforts on doing aggressive, targeted and relevant public education and awareness about long-term care. This Committee and these hearings will certainly contribute to this effort. While this hearing's focus is on Boomers, the public education and awareness efforts must be targeted to address the special issues of the individual constituencies in long-term care: women, families, seniors, the disability community, minority communities, and those in rural America. They all have a stake in long-term care.

Whether it is in policy or public awareness, with respect to long-term care, one size does not fit all. Especially for Boomers, future public education and awareness efforts have to be as localized and as humanized as possible—and they need a message. Americans respond to messages. Political races at all levels are won and lost based on the quality of message. Products are sold based on quality of message or slogan. We might need the same kind of creativity in crafting a message on long-term care and Boomers and we must use the most advanced technology to get that message out. At the end of the day, the message should be one that opens eyes, but does not beat one over the head. It should provide a wake up call, but should not scare people into hasty and unwise actions.

Too often there is a false sense of security on the part of Boomers regarding Medicare and long-term care. A poll done in 1999 by Fabrizio and McLaughlin had a number of findings, but two in particular bear note. Fifty-six percent of those Boomers surveyed were unable to correctly say that Medicare does not cover extended stays in nursing homes. Eighty-five percent of Boomers cannot name the primary funding source for the majority of nursing home residents. To the extent that these misconceptions exist, they must be addressed. It seems that in the course of this public awareness and education campaign, we should also begin a process by which Boomers advocate for those long overdue changes in Medicare that might allow it to cover more long-term care services in all settings, but particularly more preventive services.

We are replete with examples of good public education and awareness campaigns that have worked in this nation. Who focused on road rage two or three years ago? Now it is a real safety and prevention issue for drivers. Think also about Choose to Save. It has helped enlighten Boomers and those younger about the need to save for retirement, however that will be defined in the future. It has also contributed to the inclusion of important savings incentives in the just-enacted tax cut bill.

Here we might be succeeding on one side of the public awareness ledger and falling short on another. If these same Boomers and younger Americans are not planning ahead for long-term care needs, they may have nothing other than their 401(k)s or rollover IRAs to turn to. Based on the most recent study done by MetLife on the average cost of a nursing home being $153 a day, this could wipe out those accounts in no time.

Simply put there is just not enough of a connection on the part of Boomers of long-term care security being a critical part of retirement security. It starts for Boomers in their working years. I recall a 1996 study done by First Wave Inc. that polled boomers and by a two to one margin they said they were more worried about losing their job than their health. That carries over to the way retirement is approached: economic security first, and health care will work itself out.

An exciting area of possibility rests with the ongoing work of the Office of Personnel Management in their implementation of PL 106-265, the Long-Term Care Security Act. In the selection of the carriers to provide this insurance to this vast new potential market, estimated to be as many as 20 million in a recent *Washington Post* article, there will be an unprecedented amount of valuable information available to consumers about the need for long-term care and the choice of products that can be available. While I do not have precise statistics on the percentage of new enrollees who are Boomers, one can assume it will be a significant portion. In that vein, it will be incumbent on the carriers to offer as much choice and options as possible in their plans to attract Boomers. It could well be a harbinger of things to come in the market.

As part of the call to action that this Committee is undertaking, I hope it will include continued movement on important individual initiatives on long-term care that are pending in this 107th Congress. It should also maintain important implementation of long-term care legislation passed in the last Congress.

Last year as part of the landmark Older Americans Act amendments of 2000, there was established a new National Family Caregivers Support Act. This became the most significant piece of legislation yet adopted for family caregivers. Today, $125 million in formula grants to states and competitive grants are now available to enhance the scope and quality of services for family caregivers at the state and local level. I know, Mr. Chairman, that you and this Committee have already conducted hearings on the implementation of this program. This first year is so critical and we all hope for its success.

One critically important dimension to your call to action for long-term care policy that helps Boomers is how well this policy helps family caregivers. It is true that the connection between Boomers and long-term care is more remote than we all would want it to be. However when the focus shifts to family caregiving, the dynamics change. Family caregiving is the cross cutting issue with Boomers and most all the constituencies I mentioned earlier that are involved with long-term care.

This Committee has examined family caregiver. You know the data. Yet one aspect of family caregiving that deserves more attention relates to the employed caregiver. The landmark and award-winning study entitled the MetLife Juggling Act Study estimated that employed caregivers could lose as much as $566,000 in total wage wealth. This, coupled with an earlier MetLife/National Alliance for Caregivers study estimating that caregiving's loss to American business was between $11 and $29 billion a year, shows that caregiving and long-term care are far more that just health issues. They are economic issues that could affect future productivity in this nation.

There is one additional point about the importance of family caregivers in terms of your focus on long-term care and Boomers. In terms of advocacy, you end up with better results with connecting Boomers to caregiving. I have the unique experience of having founded in the late 1990s an organization called the Boomer Agenda. It was established as bi-partisan political and policy organization to get Boomers more involved in the policy and political arenas on issues that should motivate them to act. The work included doing some informal canvassing of thousands of Boomers to determine what priority issues belonged on a Boomer agenda. They were quick to respond and of course long-term care was one of those issues. Yet it was more difficult to get them to advocate on some of these issues. They saw no threat. It was not personal enough for them to get involved.

I discovered while doing this work and giving many speeches on aging policy across the country that the one issue that came up the most from audiences related to questions on family caregiving and policy initiatives. So late last year I founded another entity: CaregiversCount.com. It is a website dedicated to advocacy for family caregivers. In the six months we have been operating, the traffic has been impressive, but the interest and commitment of those visiting the site says to me that family caregivers are the political constituency of the future. In fact, I hope as this committee begins to refocus on long-term care that we can also

look more creatively at future policies for family caregivers. I think it is time to take the individual initiatives that are out there and put them under the umbrella of a Universal Caregivers Act. An article I wrote on this is included in this statement and I am happy to report that Senator Jack Reed of Rhode Island is helping in the development of this bill.

Returning back to this 107th Congress and this Committee's launching its call to action on long-term care and the Boomers, there are several important pieces of pending legislation which, if enacted, could constitute real progress on shaping a future national long-term care policy. First is the Long Term Care and Retirement Security Act (S. 627 and H.R. 831 respectively). As President of the 30-member bi-partisan Americans for Long Term Care Security, we enthusiastically support this legislation and especially commend you, Mr. Chairman, for being an early co-sponsor.

It represents the kind of public-private incentive response we must have in real long-term care policy. We of ALTCS view all the major pieces of the bill relating to long-term care insurance deductibility, tax credits for family caregivers and allowing long-term care insurance in employer cafeteria plans, as all being critical and worthy of passage. We are increasingly optimistic about the prospects of this legislation being enacted in this session. The support on the House side is growing rapidly with over 100 co-sponsors and it has always been a bi-partisan initiative.

In addition, let me note with personal support several other important bills. S. 464 was introduced by Senator Bayh and provides for the family caregiver $3,000 tax credit. In addition, S. 775 sponsored by Senator Lincoln deals with the critical issue of providing more health care personnel trained in geriatric medicine. Also H.R. 1041, sponsored by Congressman Peterson, expands the highly successful Long-Term Care Partnership programs.

In this call to action on long-term care, I also recommend that we take time to do an inventory on all federal programs and funds that are being used at the present time for any form of long-term care, whether defined as institutional, home-based or community-based care. Let us first examine the degree to which fragmentation is a problem. In this era of more limited resources, fragmentation is especially unacceptable since it diminishes the value of both federal funds and the programs.

This inventory would also allow us to see what is working and where the success stories are and to build on them. I was pleased to learn that future hearings you are holding will involve

testimony from key state governors on long-term care programs. My hunch is that over the past several years, states have become the laboratories of good ideas for long-term care, especially with respect to home- and community-based services. In rural America, our inventory should have us focus on those systems that have been developed that lead to strong access and delivery of services. Rural America needs special attention in developing a long-term care policy.

As we move forward with this call to action, we must pay attention to certain core principles that must be part of any national long-term care policy for Boomers and for all groups. They were stated quite well by Mal Schetcher in his book "Beyond Medicare." His principles include: universality, financial security, service availability, and thrift. I would add to this access, quality, greater consumer input and direction, and commitment to value in products.

Some of this is incorporated in legislation already pending. Some come from new ideas—concept papers and the like. But if the focus is to reach the Boomers and to have long-term care policy respond to their needs, we really do need to stress choice and options for services, a continuum of care approach, and ease of receiving information. Assisted living, home- and community-based care have to be more prominent in long-term care for it to be relevant to Boomers. Your hearing announcement talks about another key change that is needed to remove the long-standing bias in federal funds toward institutional care. Mr. Chairman, you are a leader in the efforts to reform Medicare. The idea of having Medicare provide more coverage for long-term care with more choices is a fundamental piece of reform. One approach developed in a white paper issued by the National Academy of Elder Law Attorneys calls for a new Part D of Medicare that would finance long-term care. This approach recognizes the responsibilities of both the individual and the national community to care for America's elderly and disabled individuals and expands our Medicare commitment to adequately fund care for chronic and long-term conditions. I will include a summary of this provision as part of my statement.

Hopefully the Committee, in its review, will examine how well Medicaid waivers have been doing especially in providing alternatives to institutionalization. Perhaps an outcome might be making them permanent.

Finally, let me make this point: this call to action, especially when it moves toward legislation, must include some political courage. To simply look at the scoring on a particular legislative proposal and make a judgment for or against supporting it is shortsighted. There is a

difference between an expenditure and an investment of federal funds. Let me cite one example. Next March, the Older Americans Act nutrition programs will celebrate their 30th anniversary. In March of 1972 Senator Ted Kennedy proposed an amendment to the Older Americans Act to set up the nutrition programs both in congregate settings and home delivered. The need was based on those seniors deemed to be at risk for possible institutionalization based on poor diet. In fact, in testimony before the House Select Committee on Aging, it was determined that up to 20 percent of those in nursing homes at that time were there solely due to the inability to maintain a proper diet. To provide these same seniors with one hot meal a day, five days a week at home or in community settings would cost about one-fourth of the costs to Medicaid for these seniors to be in nursing home care.

This required a new expenditure of money. It was presented as an investment that would save money. The results 30 years later speak for themselves. Today, the average age in the congregate nutrition program is in the mid-70s and in the home delivered program it is close to 80. Eligibility is 60 under the Older Americans Act. This means that many of these seniors have been in the program for 15 to 20 years or more. For those who were at risk when they entered, the intervention of this one service succeeded in keeping them at home or in their community at far less cost than Medicaid would have been.

We may well have to go this route again. We have to be willing to invest today and look for the savings tomorrow. Studies have been done both by the Health Insurance Association of America and the American Council of Life Insurers that demonstrate the future savings to Medicaid if a long-term care insurance tax deduction can be provided today.

I commend you, Mr. Chairman, for this hearing and the ones that follow. The urgency of preparing our nation for the long-term care needs of Baby Boomers must be communicated from Washington. It must be communicated to three audiences: the Boomers, policymakers, and the private sector.

This call to action can and should be linked to a timetable for when a real comprehensive, choice oriented, options oriented, quality oriented, consumer oriented long-term care policy is genuinely in effect. We need a timetable because there is another timetable that is not going to wait—the demographic timetable. Our challenge is to beat that clock. The clock says that in 2010 the number of retirees grows from 13 to 20 percent of our total population (Cerrulli

Associates) and the all important 2011 date when the first wave of Boomers turn 65 and become eligible for Medicare.

I look forward to working with you and the Committee as you advance this plan of action on long-term care. Because as it relates to Boomers: long-term care—it may not be your issue today, but it could be tomorrow.

The CHAIRMAN. Thank you, Bob, very much.

I thank all three of our panelists for the beginning of what hopefully will be a national dialog on this issue, to better educate the folks about the need for long-term care.

Bob, let me ask you, I mean, you have been a leader in this. Do you have long-term care insurance?

Mr. BLANCATO. I do.

The CHAIRMAN. Congratulations.

Mr. BLANCATO. I just turned 50, I have to admit. That proves I am not in denial about aging. [Laughter.]

But I did. I researched it, and I purchased it. And part of it was motivated by the fact of my mother's situation; they do not have long-term care insurance, and the cost of care is quite staggering.

The CHAIRMAN. Let me ask anyone on the panel, is there a market out there now? Or is it an infant market? Or is it something that you would find companies are interested in promoting and selling? Or is it not a good market as is currently structured?

If the concept is, like we are talking, in terms of prescription drugs under Medicare, is to have the government help pay for the premium to allow people to buy coverage insurance in a competitive market, can there be a market for long-term care insurance that would be viable and workable and affordable?

Mr. DURENBERGER. Well, I will just make one comment, because our recommendation was a restructuring of social insurance and the incentives for private insurance.

We also made the decision that, as it relates to a previous question that you asked, it is pretty hard for Americans to go to some other country. It is OK to learn from other country's experiences, but we really have to use an American system.

And in America, private insurance combined with social insurance is the tradition. It is usually bought at work, where you get earnings and employee benefits and so forth.

So if you look at it from that standpoint, the places to look probably are at experiments which have taken place, I think, largely at the State level. I know in Minnesota the legislature authorized the State government, for employees of State government, and some other public employees—to offer long-term care insurance. The employee would have to pay the premium.

The response was about twice what they expected. I think they expected something like 5,000 or 6,000 people. And they ended up with 12,000 or 13,000 people enrolling in the program. I think 3M, on the corporate side, has had a similar experience.

But one of the things I am sure we find out, and you will find out from OPM, is it takes an awful lot of analysis of what is long-term care insurance and what is long-term care insurance. And that is one of the roles that an employer, as in a 3M, an employer as in a Minnesota public employees, at the current time I think has to play to sort out what is real need and what is the product that is going to meet that need.

The CHAIRMAN. It may be that we are going to have the insurance folks come in and testify.

But when they provide long-term care insurance, what are they providing the coverage for? Is it for coverage in a nursing home or is it also in some of these alternative settings?

Bob.

Mr. BLANCATO. They're beginning to cover a wider array of services than just nursing homes, assisted living coverage and some home-care coverage.

And I think there is some merit in getting the industry here to talk about the market, because the market is changing, the market is growing.

The question is, is it growing fast enough? Maybe in their mind, it isn't. But I think it is growing in the sense that there is more interest in it.

But I think that the real question is involved in your question. The element of choice is going to be key to that market growing, especially for boomers to go into it, because this is a different generation.

We are used to having more options and choices. And this is going to be necessary for that industry to do. And I think a lot of them are stepping up to do it.

But I think, as the Senator said, what happens in the interim period—of the Federal employees, military personnel long-term care legislation, and how OPM chooses the carriers and goes through the process of selecting them, and the education process that is involved—is going to be immensely important to the whole future of long-term care insurance in this country.

The CHAIRMAN. Carol, do you have a comment?

Ms. O'SHAUGHNESSY. If I could, yes, if I could add something to that.

It is a very fast growing market. I mean, I think the last data I saw was something like 6 million policies have been sold. One of the issues to look at is the issue of affordability of the premiums. Some recent data from HIAA show that the average income of persons who purchased long-term care insurance is around, I think, $42,500; in 1995 it was $30,000. And persons who purchase long-term care insurance tend to have higher assets.

So even if you were to increase the number of policies sold, one would have to look at the people at the very low end of the income spectrum, in terms of how to protect their income and offer protection for them as well. Affordability is the main issue.

The CHAIRMAN. We have Medigap insurance for prescription drugs. Unfortunately, only the people who buy it are the people who have to use high volumes of prescription drugs. Therefore, obviously, the cost is very, very high.

Is that the same thing that is true for long-term care insurance now, do we know?

Ms. O'SHAUGHNESSY. In terms of?

The CHAIRMAN. That you only buy it—of course, I would think that if you live long enough, you are going to need some type of long-term care. It is a question of whether people believe that. And younger people tend not to believe that, so you only buy it right before you need it. And obviously it becomes very expensive.

Is that correct?

Ms. O'SHAUGHNESSY. Well, the recent data on the buyers of long-term care insurance show that there are certain characteristics and demographic characteristics. I think the average age is 67. People tend——

The CHAIRMAN. I mean, buying it at 67 will tell you something.

Ms. O'SHAUGHNESSY. Right. Exactly, exactly.

According to HIAA, people who are planners are more likely to buy long-term care insurance. It is an issue for planning for the future.

It is not like we know we have Social Security, and we have that, but what do we have to do to plan for our future needs.

The CHAIRMAN. It is an educational problem, too; I mean, I think that what we have here is, I think, all of you have said that, and the Secretary has said it. And not enough people know that they are going to need it and realize they are going to need it.

And when they think they are going to need it, they think that Medicare and Social Security pays for it.

Ms. O'SHAUGHNESSY. That is true.

The CHAIRMAN. And then, that is a real educational problem that hopefully this Congress and this committee can help.

How do we get people to move into this market, Dave, without just passing a long-term care insurance mandate?

I mean, the average age of people buying this is at 67, I mean, that really is a problem right there. We ought to be buying it, you know, just as we buy car insurance or anything else or health insurance, because it would be a lot cheaper if more people were in the pool, obviously.

I mean, any thoughts about how we encourage people to get into this much quicker?

Mr. DURENBERGER. I would like to make two observations. They are both personal, as opposed to Citizens for Long-Term Care, because we aren't at this point in our common ground yet.

First, I believe strongly that it is difficult to, in today's confused, crazy quilt, patchwork, whatever-it-is marketplace, to offer as an affordable a product as could be offered, with all due respect, no matter how good they are at it.

If you clean up the system, they are going to be able to offer—the insurance industry will offer you a much more affordable product.

One of the important things there, as you and I have both gone through in the early 1990's, is what role is the social insurance system going to play? I mean, what if we knew what Medicare was going to provide for at least 5 years and not, change benefits, coverage and eligibility as in subacute care every year?

How can you write a good, private insurance policy if you don't know precisely what the national policy on social insurance is going to be? That is the first part of it.

The second one is this, and it is just a question I have that only a few people can answer that I would like to ask the industry, and that is: Why couldn't you sell me or my children a disability policy when I am 21, on my first job, that I can carry until I am, in my mother's case, 89 with Alzheimer's? We have heard a lot of Alzheimer's here today. I don't know that that is unusual.

But why can't I buy a policy at 21 that I can carry all the way through? When I am young, what it does is replaces income to facilitate the growth of my family, because that is what I am doing as an earner. When I am older, it helps to protect my assets.

That, I think, on the private insurance side, is a key question that needs to be asked.

The CHAIRMAN. Well, you know, we are talking about, right now, about adding $300 billion in the budget-allocated amount to reforming Medicare by providing coverage for prescription drugs. That is a huge amount over the next 10 years.

If we were to all of a sudden require that Medicare covered long-term care with some type of an insurance plan, like we are talking about for prescription drugs, do any of you have a ballpark figure about what we would talk about in terms of how much?

Ms. O'SHAUGHNESSY. Well, I guess cost estimates will obviously depend on the range of services and numbers of people who would be covered and the types of services. So it is hard to——

The CHAIRMAN. You say we spend; we spend more on long-term care now than we do on prescription drugs.

Ms. O'SHAUGHNESSY. Slightly more than on prescription drugs. One hundred thirty-three billion on long-term care.

The CHAIRMAN. So the question then becomes, is that a ballpark cost for what it would cost us to do long-term care under Medicare?

Ms. O'SHAUGHNESSY. Well, most of that is from the Medicaid program. A small amount is from Medicare. It depends upon how you shift those resources.

Mr. DURENBERGER. Mr. Chairman, you might take George Mitchell's proposals from back in 1993, 1994, 1995, something like that, and run them by CBO. And I think you will get a part of that.

The CHAIRMAN. Yes.

Mr. DURENBERGER. I forget which one he did, but it was like Medicare is the catastrophic after 18 months and——

The CHAIRMAN. Well, I think that this has been very helpful.

And I think that this is a busy time for the Congress. We are trying to finish up the patients' bill of rights bill by today or tomorrow afternoon, and adjourn for the Fourth of July recess.

But this has been very helpful. All three of you are really expert in this area, and I thank you for your participation. And we are going to call upon you, if it is all right, in the future as we continue this national effort and this national dialog.

Thank you very much.

This will conclude this hearing.

[Whereupon, at 11:53 a.m., the committee was adjourned.]

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