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AFFORDABILITY OF LONG-TERM CARE

HEARING

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SOCIETY'S GREAT CHALLENGE: THE AFFORDABILITY OF LONG-TERM CARE

TUESDAY, MARCH 27, 2001

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:05 a.m., in room 215, Dirksen Senate Office Building, Hon. Charles E. Grassley (chairman of the committee) presiding.

Also present: Senators Graham, Torricelli, and Lincoln.

OPENING STATEMENT OF HON. CHARLES E. GRASSLEY, A U.S. SENATOR FROM IOWA, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. I want to say good morning to everybody and call the hearing to order.

It is a pleasure to welcome our witnesses, and most importantly, those of you from the public who have taken time to come to this very important hearing.

As usual, I should, and I do, express my appreciation to each of the witnesses for taking time out of busy schedules to participate. Those that have had to come a ways to do that, I thank them for the extra bother.

Normally, we would not start a hearing without somebody from both sides of the aisle being here, but I have permission from the Democrat leaders to move ahead with this hearing. So, that is why we are going ahead without more members present.

Today's witnesses, all of whom are experts in their field, will present very important perspectives on meeting the public, private, and personal financial challenges of long-term care.

Can I give you my philosophy of long-term care? Because too often, it seems to me, we think of just nursing homes. But for me, long-term care is a continuum, and I think for most people, it means independence in the home, maintaining that independence with maybe family care giving, supplementing it with home health care. When you cannot live in your own home, assisted living. There are variations of assisted living, all of which have the intention of maintaining the quality of life before somebody enters a nursing home, and then maintaining that quality of life as much as we can within the nursing home.

The goal of today's hearing is to raise awareness about these financial risks to the very costly aspect and the threat to retirement income security with these long-term care needs, and of course to consider the steps that we in the Congress can, and hopefully will,

take this year to assure that Americans are better prepared to meet the long-term care challenges.

Each year, we have millions of American families unexpectedly finding themselves faced with making difficult decisions about how to care for a family member with long-term care needs.

Today, we will hear firsthand about the realities of that decision making process from a gentleman who will share his personal experience in caring for his wife, who suffers from Alzheimer's disease. He will describe the emotional hardship and the financial devastation that can come with long-term care.

It is extremely difficult to pay for long-term care, even when one has worked hard and saved for retirement. Of course, it is nearly impossible if one has not been so prepared.

Consider the challenge today. We have the average cost of nursing home care ranging from $40,000 to $70,000 a year. Most Americans are not able to pay these costs year after year.

When individuals are faced with chronic or disabling conditions in retirement, they often quickly exhaust their resources, as well as that of their family's. As a result then, millions of people end up turning to Medicaid for help.

It is disheartening to me to realize that two out of three people who are nursing home residents are paid for by Medicaid. Not only do these costs result in a big bill for taxpayers, but we have already had the spending down process that families go through to qualify for Medicaid, which is really a fairly traumatizing experience for families.

Long-term care financing challenges are not new to families or to those of us in Congress. But with millions of baby boomers set to retire in the near future, it is crucial for our Nation to better prepare for what will be a dramatic increase in long-term care needs.

Finding solutions is critical if we are going to meet the needs of our parents and grandparents in a way that sustains their health and their independence without destroying their financial well-being.

Unfortunately, public budgets are already under enormous pressure from retirement programs and will probably be unable to meet these needs. As policy makers, we must act with smart policy. That involves thinking creatively.

We should attempt to develop new policies for existing public programs that contribute to more efficient and cost-effective services. Also, we should maximize private, market-based options to help finance long-term care, such as private long-term care insurance.

We should consider ways to bolster the roughly 22 million family care givers who face a chronic shortage of resources. Care giving can take an enormous physical and financial toll, and we are indebted to these family care givers for their efforts to provide the highest quality of care to our Nation's vulnerable population.

Now, the bottom line seems to be that we should do all we can to inform Americans about the importance of planning financially for these potential long-term care needs.

Congress needs to consider steps that it can take to ensure that Americans, especially this baby boom generation, are better prepared to meet the challenges that accompany long-term care.*

I am going to introduce the witnesses now. But if somebody comes from the other side and wants to give an opening statement, I will break in for that to happen. We always have the practice of at least one Republican and one Democrat making opening statements.

I welcome our panel of witnesses this morning. Our first witness is Carol V. O'Shaughnessy, Specialist in Social Legislation for the Domestic Social Policy Division of the Congressional Research Service. So if you hear me talk about CRS, it's Congressional Research Service.

Following Ms. O'Shaughnessy, we will hear from a person that is a regular before this committee. Dr. William J. Scanlon is Director of Health Care Issues for the U.S. General Accounting Office.

Our third witness, Bill Kays, is the husband of an Alzheimer's victim. Following Mr. Kays will be Gail Gibson Hunt, executive director of the National Alliance for Caregiving. The next witness, Lisa Maria B. Alecxih, vice president of The Lewin Group. Our final witness is Steven Lutzky, chief, Office on Disabilities and Aging here in Washington, DC, the city's Department of Health.

We will go in that order. And unless I interrupt you for another member to give an opening statement, we will just go through all the opening statements. Some of you probably have brought longer statements that you want inserted in the record. You will not have to ask permission to do that, because we will do that in whatever form you submit it to us. Then you obviously will summarize, if it is a longer statement.

Then, also, not knowing who will be here or who will not be here, our practice is that we invite members, or even members who are here who could not ask all their questions, to submit questions for answer in writing. We would appreciate it if you would respond to those in about two weeks.

If some of you have never been through that process, my staff or any of the staff of the Senate Finance Committee, Democrat or Republican, will be able to help you through that process. So, we would appreciate your dialogue with us in writing, as well as vocally.

Would you start out, Ms. O'Shaughnessy?

STATEMENT OF CAROL V. O'SHAUGHNESSY, SPECIALIST IN SOCIAL LEGISLATION, DOMESTIC SOCIAL POLICY DIVISION, CONGRESSIONAL RESEARCH SERVICE, WASHINGTON, DC

Ms. O'SHAUGHNESSY. Good morning, Mr. Chairman. Thank you for asking me to testify.

Long-term care refers to a wide range of supportive and health services for persons who have lost the capacity for self-care. Need for long-term care is measured by the need for assistance from others in performing basic daily activities, called activities of daily liv-

*For more information on this subject, *see also*, "Description of Federal Tax Rules and Legislative Background Relating to Long-Term Care", Joint Committee on Taxation staff report, March, 26, 2001, JCX–18–1.

ing, or ADLs. These include bathing, dressing, getting around the home, toileting, and eating.

Legislation to finance long-term care services frequently limits eligibility to persons having limitations in specific numbers of ADLs. This approach allows policy makers to target persons 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 and homemaker services, and services in the community, such as adult day care.

Other services include respite to relieve care givers, case management to coordinate care for clients, specialized housing arrangements, and home-delivered meals.

About 9 million adults receive long-term care assistance. The vast majority, over 80 percent, are in home- and community-based settings, not in nursing homes.

Persons age 65 and older represent about 60 percent of adults who receive assistance, but the need for long-term care affects persons of all ages. About 3.5 million adults who receive assistance are under the age of 65. In addition, there are about 500,000 children aged 5–17 who had difficulty performing activities of daily living and who live in the community.

About one-quarter of adults of all ages who receive care at home and in community settings have severe impairments. That is, they have at least three limitations in activities of daily living.

The likelihood of receiving long-term care assistance increases dramatically with age. However, regardless of age, older persons are more likely to live in the community than in nursing homes.

As you said, the need for long-term care is expected to grow substantially in the future. Demand will be driven by the aging of the baby boom population and general increases in longevity.

Estimates show that the number of elderly persons alone who need long-term care assistance can grow by about 24 percent over the next 20 years.

Over the last decade, research has shown a rather marked increase in the disability levels of persons who receive help, and these trends have implications for caring responsibilities of families, as well as for demands on the home care and nursing home workforce.

The Nation spent almost $134 billion on long-term care for persons of all ages in 1999. This represents about 13 percent of total personal health spending, an amount slightly more than the Nation spent on prescription drugs and medical supplies. This does not include the unpaid work of informal caregivers.

Of national spending, Medicaid and out-of-pocket are the two main sources of spending. Medicaid accounted for 44 percent of the total, and out-of-pocket spending accounted for one-quarter of total spending. Medicare plays a much smaller role, representing only about 14 percent of total spending on long-term care.

While a number of Federal programs directly or indirectly support long-term care, their eligibility requirements, services authorized, and administrative structures vary, making it difficult to coordinate services around individual clients.

Although Medicaid is the major public payor, access is limited due to its eligibility restrictions and varying State policies. Medicare does not cover long-term care services for persons with chronic care needs, or who require assistance only with activities of daily living.

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 its over-reliance on institutional care, heavy reliance on informal caregivers who bear most of the burden of care, and the uneven availability of home- and community-based care.

While only a small portion of persons receiving long-term care services are in nursing homes, as I said, 1.6 million people, public spending for nursing home care through Medicaid is disproportionately high.

Almost three-quarters of Medicaid spending is for institutional care. Although nursing home care dominates Medicaid spending, a shift toward home- and community-based care has occurred over the last decade.

Despite substantial public spending, families provide the major source of long-term care. About 37 million caregivers provide informal or unpaid care to family members of all ages.

Typically, this care is provided by adult children to elderly family members, or by spouses to one another. Almost 60 percent of the impaired elderly, and nearly three-quarters of adults under age 65 receiving care rely exclusively on informal assistance.

To date, Congress has chosen an incremental approach to changing the Federal role in long-term care. For example, last year Congress enacted the National Family Caregiver Support Program.

Policy approaches advanced in the past have included both incremental and large-scale approaches. Among the proposals, of course, are tax credits for persons with long-term care needs and incentives for private long-term care insurance.

Other broad approaches have included proposals for expanded public commitment for home- and community-based care, and new social insurance coverage. A challenge for policymakers, of course, is to reconcile the concerns about costs of these proposals, as well as the relative roles of the public and private sectors.

That concludes my statement, Mr. Chairman. Thank you.

[The prepared statement of Ms. O'Shaughnessy appears in the appendix.]

The CHAIRMAN. Before we continue with the panel, and before I ask either Democrat to give an opening statement for their side of the aisle, I wanted to recognize the fact that, today, Senator Graham and I have introduced a bill that we call the Long-Term Care and Retirement Security Act of 2001.

It is very common-sense legislation that combines aid to help family caregivers today with tax deduction to encourage people to buy long-term care insurance for tomorrow. I would like Senator Graham to take some time to provide the committee with a bit of detail about the legislation.

I would just simply say that it is similar, if not at least exactly the same, in the goals that we sought last year, and probably very

little change in the legislation that I think we introduced last summer.

OPENING STATEMENT OF HON. BOB GRAHAM, A U.S. SENATOR FROM FLORIDA

Senator GRAHAM. Thank you, Mr. Chairman. I want to thank you and Senator Baucus for holding this hearing today. It has been a pleasure, over the last several years, to have worked with you on a number of pieces of legislation, especially legislation that has affected the lives of older Americans.

This legislation that is being introduced today, the Long-Term Care and Retirement Security Act of 2001, has essentially two objectives. First, is to encourage people to buy long-term care insurance by the provision of an above-the-line tax deduction for a substantial portion of that insurance cost. Second, to recognize the immediate needs of persons who are, today, serving as caregivers for an elderly loved one through a $3,000 tax credit.

Mr. Chairman, one of the things that gives me the hope that we will be successful in this Congress passing this legislation is the fact that it has been able to bring together a large and diverse coalition behind its passage.

The CHAIRMAN. Yes. Very important in that respect. Probably two of the most well-known organizations, the AARP, is joining forces with the Health Insurance Association of America in support of this bill, among other organizations that are behind it.

Senator GRAHAM. One of the heartening things, Mr. Chairman, is that frequently these groups are seen more as adversaries on pieces of legislation rather than as allies, so I am encouraged that we have found common ground with this legislation, and maybe we are onto something that will lead to its enactment.

The CHAIRMAN. First of all, I thank you for your working with me on the introduction of this legislation. I particularly thank the Health Insurance Association of America, the AARP, and others who were working to move the legislation forward.

I think the legislation puts us in a very good positive to do something, both for the present and for the future. For the future, I think it is very important to look down the road. We know that there is going to be increasing access, phenomenal growth because of access to Medicare and Medicaid.

The extent through using the dynamics of the private sector to encourage this sort of family care which would come through the family tax credit, or the extent to which we were also going to encourage people to have more risk management of their own through the purchase of long-term care insurance, it uses the dynamics of our economy to supplement, and maybe even outdo, some government programs.

Senator GRAHAM. You are absolutely right, Mr. Chairman. One final recognition, is that a product of all of the emphasis on better health, particularly for older Americans, has been a significant increase in life expectancy.

During the 20th century, life expectancy after 65 increased by almost a year every decade. It is projected to do the same in the 21st century. So we are going to have not only a much larger percentage of our population over the age of 65, we will have a much larger

percentage of the population over 85. It is in those advanced ages that programs like long-term care have the greatest need.

So the need is there. Now is the time to act. I look forward to working shoulder-to-shoulder with you for enactment this year.

The CHAIRMAN. We will. We have one or two different tax bills this year, so I hope we have an opportunity to do that. Only the future will say for sure what we can do along this line. But this ought to have a high priority among the work of this committee.

In addition to anything you said, do you have any opening comments about today's hearing, or Senator Torricelli?

Senator GRAHAM. Thank you, Mr. Chairman. I appreciate the opportunity to briefly discuss our legislation. I apologize that I am going to have to go to the floor to participate in the current debate. But, again, thank you for holding this hearing.

The CHAIRMAN. Senator Torricelli, did you have anything you wanted to say?

Senator TORRICELLI. Mr. Chairman, I would just as soon hear the witnesses rather than myself. Though, no doubt my own comments would be extraordinarily interesting to me, I would rather hear them. [Laughter.]

The CHAIRMAN. All right.

Now we go to Dr. Scanlon.

STATEMENT OF WILLIAM J. SCANLON, DIRECTOR, HEALTH CARE ISSUES, U.S. GENERAL ACCOUNTING OFFICE, WASHINGTON, DC

Dr. SCANLON. Thank you very much, Mr. Chairman, Senator Graham, and Senator Torricelli. I am very pleased to be here today as you discuss the challenges we, as a society, face in financing long-term care needs.

These challenges are already formidable. As you have heard, an estimated 9 million persons aged 18 and over receive long-term care assistance today. While family members provide much of the care, the $134 billion we spent on services in 1999 represents a significant financial burden for many individuals and for public health care programs.

These burdens will be significantly exacerbated as the baby boomers age. While their numbers alone are sobering, as Senator Graham has indicated, their predicted longer life expectancies could mean a disproportionate share will require long-term care.

How we finance long-term care is distinctive compared to other health services. Insurance that assures access to services and protects against financial catastrophe is the exception rather than the rule. Medicaid and Medicare pay the majority of long-term care expenditures. Medicaid, for many beneficiaries, however, is protection after the catastrophe of becoming impoverished from paying for care out of pocket.

Furthermore, what services Medicaid programs support depends on individual States' financial capacity and their decisions to fund long-term care. Their services, both nursing home and in-home care, vary drastically across the States.

While Medicare is not formally a financer of long-term care, the program has come to play a significant de facto role through its home health care benefit. The sharp curtailment of home health

spending and use following the payment changes in the Balanced Budget Act raised questions about how much Medicare will be spending for long-term care in the future.

The new Medicare prospective payment system for home health implemented in October should make funding available for a significant expansion of services, but the system's incentives may limit how much long-term care agencies choose to provide.

Many have hoped that private long-term care insurance could play a significant role in improving how care is financed, both now and in the future. Private long-term care insurance has been viewed as a possible means of both reducing catastrophic financial risk for the elderly and relieving some of the financing burden currently falling on public programs.

Several recent Congressional initiatives are aimed to increase the use of private insurance. These include the group long-term care insurance available to Federal employees, military personnel, and civilian and military retirees that the Office of Personnel Management is sponsoring, as well as the proposal by you, Senator Graham, and others to provide additional tax subsidies to individuals purchasing long-term care insurance.

At this point, though, after approximately two decades since private long-term care insurance began to receive serious attention as a financing option, fewer than 10 percent of the elderly and even fewer near-elderly have purchased a policy, and it represents a very small fraction of long-term care spending.

Although these numbers are increasing, its market share pales in comparison to the two-thirds of the elderly who have private Medicare supplemental insurance coverage for expenses not paid by Medicare, such as co-payments, deductibles, and prescription drugs.

It is important to ask what has impeded the success of long-term care insurance. Questions exist about the affordability of policies and the value of coverage relative to the premiums being charged.

While determining whether a policy is affordable is subject to differing judgments, some studies estimate that long-term care insurance is currently affordable for only about 10 to 20 percent of elderly individuals.

The premium for a policy purchased when a person is in their 40's or 50's may be less than half that of one purchased by a 65-year-old.

But those premiums for a younger person will be paid for a much longer time, and a person in their 40's or 50's may be more skeptical about the need for a policy when other demands for their income seem more pressing.

Concerns about premiums relative to the value of policies may be another factor deterring purchases. Premiums for a similar policy for the same individual can vary widely, raising questions about what is a good deal. For example, a 65-year-old in Wisconsin could pay between $850 and $2,050 annually for a policy with similar terms from different carriers.

If long-term care insurance is to have a more significant role in how chronic health care needs are being addressed, the policies offered must be viewed by consumers as good, affordable products that are easily understandable.

Considerable progress has been made since the days when long-term care insurance was first offered to better assure that available policies offer greater value to consumers—covering a meaningful array of benefits, not containing undue restrictions or charging excessive premiums.

Considerable credit for that progress goes to the National Association of Insurance Commissioners and to the States for their efforts. But credit also should go to those insurers that have chosen to compete in this market by offering better products. Whether this progress is sufficient to instill consumer confidence in this form of insurance, though, is uncertain.

Let me end by noting that much attention is focused on the baby boom generation and its implications for financing future long-term care needs. That is understandable, given their numbers.

However, we should not lose sight of the fact that disability and dependency, and hence the need for long-term care, know no age boundaries. Private long-term care insurance is not likely to be a viable or effective option for most younger persons with disabilities. Consequently, focusing attention as well on how best to assure that their needs are being met deserves our attention.

Thank you very much, Mr. Chairman and members of the committee. I would be happy to answer any questions that you or others have.

[The prepared statement of Dr. Scanlon appears in the appendix.]

The CHAIRMAN. Thank you. I am astonished by how you can always end your statement in exactly the 5-minute time limit. [Laughter.]

Mr. Kays?

STATEMENT OF BILL KAYS, HUSBAND OF AN ALZHEIMER'S PATIENT, VIENNA, VA

Mr. KAYS. You are probably going to notice a slight change of pace here. I do not think I can talk that fast.

Dr. SCANLON. That may be the secret.

Mr. KAYS. I do thank you for having me here today. It is quite an honor to be asked to testify. I was quite surprised when I got a call asking me about it.

The biggest surprise I will ever have in my lifetime, though, was 10 years ago when my beautiful, 60-year-old wife, Pearl, was diagnosed with Alzheimer's. We never thought this would happen. It came a year after I had retired from Bell Atlantic.

With all these wonderful plans that Pearl and I had made about all of the travel and things that we put off until after I retired, it was too late. We were not going to be able to do it.

When Pearl was diagnosed, I did not know how to spell Alzheimer's. I still get it wrong occasionally. But I quickly found that there was no cure, there was no effective treatment, there was no prevention. I will tell you, I was devastated to know that I was going to lose my beautiful wife.

I have two smart children. They talked me into joining an Alzheimer's support group. I cared for Pearl for 6 years alone at home, because I did not want to be a burden on our children and my wife did not want to either. Pearl was my responsibility.

She needed help with all of the activities of daily living that have been mentioned here. It was getting to me, the care. I started looking for other ways to get around this, and I found out about adult day care in Fairfax County.

I put Pearl in 5 days a week. That gave me the respite I needed. It also gave me the time to go looking for what was coming next that I had been told about. It was never going to get any better. I did look. It was costing me $1,000 a month to have her in day care. I thought that was a lot of money.

I did not realize how lucky I was until I started looking for long-term care and found that, in Fairfax County, it was going to cost me $4,000 to $6,000 a month for what Pearl needed. She needed all of the activities of daily living.

I looked for quite a while. Then I struck gold. I looked 57 miles from Washington, DC in Front Royal, Virginia and found a wonderful place called Royal Haven. It costs $1,700 a month for the very care that I would be paying $4,000 to $6,000 for a year, but you have got to drive 57 miles to get there. That is all right. I can do that. The care that she receives up there is outstanding. It matches her needs.

Three months after I put her in Royal Haven, I had a heart attack and had to have quadruple bypass surgery. I am so lucky she was there. I do not know what I would have done.

I asked the surgeon at Fairfax Hospital what caused this, because I have never had a blood pressure problem and I have never had a cholesterol problem. Lord knows why, but I have not. He said, Mr. Kays, caregiver stress did you in. You do not know what it is doing to you.

My support group also told me that I would have to eventually put her there. I would not have known that if they had not told me.

We have heard here about the care, that it is going to get worse. I read in the Fauquier Democrat up in Warrenton, where Pearl and I grew up, just last week in the paper that the population of Fauquier County went up in the last census by 13 percent. The over-65 portion of that went up 40 percent. They are the ones that are going to need it. We have already heard here about, it is going to get worse with the baby boomers. We all know that.

I applaud you, Senator Graham and Senator Grassley, for the legislation that you have put in. It is going to help a lot of people. It is going to be a little late for Pearl and me, because she is already in a nursing home. But it will help people to plan for the future.

We cannot lay it all at your doorstep, we have got to plan some of the expense ourselves. But it will help us buy long-term care insurance. You see, long-term care insurance was not available when I was planning. I would hope that I would have been smart enough to buy it. I wish I had it now. But it really will help.

Taking care of an Alzheimer's patient, or any person in a home, is horribly difficult work. I think we have got to do everything to recognize these people and help them. We have got to pay them enough so they can take care of their own families.

The care that Pearl gets at Royal Haven is absolutely outstanding, and I will tell you why. It is because of the staff they

have. That staff has been there for a long time. They do not have the turnover they have in many others.

But we have got to recognize these people. We have got to pay them enough so they can take care of their own families. We have got to make sure that the workload they are expected to carry is not overly burdensome. We have got to train them in how to deal with the people that they are caring for. They really need that.

I applaud, Senator Grassley, what you have done in the past for staffing and for quality of service to these people. It is so important. I want to thank you for what you have done in that regard. I want to thank both of you for legislation you are putting in now.

I want to thank you for holding these hearings to make your colleagues, and the American people, aware of this urgent national problem that we are faced with. It is tremendous and it is going to get worse. I appreciate you letting me be here today.

Thank you.

[The prepared statement of Mr. Kays appears in the appendix.]

The CHAIRMAN. You went out of your way to come and tell us your story as an example of hundreds of thousands of people that have problems, and as people live to be older into their 80's and 90's, we are going to have a very high percentage of our population with Alzheimer's.

More importantly, we hope that investment in research will help us find a solution and a cure for whatever we can do to extend the independence of people that have the oncoming of Alzheimer's.

Now, Ms. Hunt?

STATEMENT OF GAIL GIBSON HUNT, EXECUTIVE DIRECTOR, NATIONAL ALLIANCE FOR CAREGIVING, BETHESDA, MD

Ms. HUNT. Thank you. Good morning, Mr. Chairman and members of the committee.

The National Alliance for Caregiving is a nonprofit coalition of 25 national organizations that have come together around the issues of family caregiving. We conduct research, develop national programs to support family caregivers and the professionals who work with them, and work to increase public awareness of caregiver needs and concerns.

I am going to talk a little bit about the demographics of family caregiving. According to the 1997 National Caregivers Survey that we did with AARP, there are 22.4 million U.S. households—that is about a quarter of the U.S. households—that contain someone 18 or older who is caring for a family member, friend, or neighbor who is 50 years old or who needs assistance with everyday activities.

What is the national profile of a family caregiver of an older person? It is a 46-year-old baby boom woman. She works full-time and cares for her 77-year-old mother, who has a chronic illness and lives nearby. She spends an average of 18 hours a week caring for her mother, and also, on average, will spend four and a half years doing so.

Another study, the Met Life Juggling Act, showed that people's expectations of how long they would be responsible as caregivers was significantly underestimated from how long they actually spent.

For example, those who thought they might only have to be a caregiver for 6 months or so, after a relative's hospitalization and convalescence, found themselves caregiving for a year or more. Those who expected to do these tasks for a year or two ended up doing them for 4 years or more. Also, keep in mind, nearly one-third of caregivers take care of two or more people over a caregiving career.

The average annual income of the caregiver is roughly equal to Americans as a whole, $35,000. Forty-one percent also have children under 18 living at home, the proverbial sandwich generation.

When asked in a survey what information they want most, caregivers asked for information on how to deal with stress, as Mr. Kays indicated was needed, how to find and evaluate good-quality home care, and how to balance the demands of work and caregiving. They also cited the need for practical, hands-on training in everyday tasks: bathing, transferring from bed to chair, nutrition, et cetera.

Caregiving and money. In 1998, the United Hospital Fund conducted an analysis that estimated the value of caregiving to society at almost $200 billion a year, more than the value of in-home care and nursing home care combined. Without family caregivers, the long-term care system would bankrupt the country, especially as the baby boomers age.

As for caregivers themselves, they spend an average of $171 a month out-of-pocket for groceries, medications, and home modifications. This conservative estimate is roughly equivalent to an IRA that a caregiver might otherwise be able to save for his or her own retirement.

The Juggling Act study of working caregivers calculated that, over a lifetime of intensive caregiving, this out-of-pocket amount could average nearly $20,000.

In another study, though, half of caregivers reported feeling financially unprepared for their own long-term care, even though they, more than most people, are aware of the tremendous financial drain that long-term care can have on a family.

Caregivers and work. Two-thirds of caregivers work full- or part-time, and over half of those who work are making work-related adjustments. That is an important factor because of the implications on productivity.

Workplace accommodations include half of employed caregivers going in late, leaving early, taking time off from work, and 11 percent taking leaves of absences, down to 4 percent choosing early retirement, and 6 percent giving up work entirely.

In the MetLife study on the cost of caregiving to U.S. employers, the estimate of annual cost in terms of lost productivity was between $11.4 and $29 billion a year. The lower figure counts caregiver who are working full time, live nearby their relative, and perform the personal care ADL tasks.

The $29 billion a year in lost productivity included caregivers who worked part time, do long-distance caregiving, and also do the instrumental activities of daily living, such as managing finances and taking mom to the doctor's.

The chances of a caregiver having to make the kinds of workplace accommodations we are talking about increase if the fol-

lowing risk factors are in place: the caregiver helps with two or more ADLs, resides with the care recipient, is the primary caregiver, or if the recipient has Alzheimer's.

Beyond the cost to employees, the total cost to working caregivers over their career was documented in the MetLife Juggling Act study at nearly $660,000. That included lost Social Security, lost pensions, and lost wages.

Finally, there is the issue of caregiving and health. There are many well-documented studies of the impact of caregiving on caregivers' health, especially where the caregiver is older and frailer to begin with, or where the care recipient has Alzheimer's.

In broad-based studies of caregiving, such as the National Caregivers Survey, only about 15 percent of caregivers say they have actually experienced physical or mental health problems as a result of caregiver,.

About a quarter of them say they find caregiving to be emotionally stressful, although that percentage goes up considerably with risk factors such as co-residence, the length of time spent caregiving, and Alzheimer's caregiving.

Almost three-quarters of working caregivers who are doing the more intense personal care say that it has had somewhat, or a lot, of negative impact on their health.

Of these caregivers, half cited making additional visits to their physician as a result, which can translate into higher health care costs for themselves and their employer.

In addition, 40 percent of working caregivers doing the more intense personal care tasks believe that their ability to work productively and to continue to work was affected by their caregiving-related health problems.

Thank you. That concludes my statement.

[The prepared statement of Ms. Hunt appears in the appendix.]

The CHAIRMAN. Thank you, Ms. Hunt.

Now, Ms. Alecxih?

STATEMENT OF LISA MARIA B. ALECXIH, VICE PRESIDENT, THE LEWIN GROUP, FALLS CHURCH, VA

Ms. ALECXIH. Thank you for asking me to come speak with you. I am going to talk a little bit about long-term care insurance. Bill Scanlon provided a very nice overview of the role of the product and general characteristics of the product, but I am going to try to get into a little more of the details of long-term care insurance.

Specifically, long-term care insurance is a very complex product. It is difficult to understand. There are a lot of options when a purchaser comes to try to make a decision about the product.

The primary source of information about those characteristics in decision making is generally a long-term care insurance agent. So, there is some concern about the ability for consumers to get unbiased information about products and the necessary information to make those decisions.

In terms of the insurance companies, they have three main roles in developing the products. They need to screen poor risks, so they do what is called underwriting. Underwriting basically checks for health status. It has health status questions and will exclude people who have current long-term care needs. So, basically, long-term

care insurance cannot meet the long-term care needs of people who currently need it. That protects the company so they can price a product well, but it also limits who might be able to be protected by the product.

Insurance companies also need to set premiums. The premiums for this product are generally designed to be level, meaning they will stay the same throughout the entire life of the product, given that the assumptions used for pricing end up being the ones that actually occur when it comes to claims for the people who bought it.

So, there is a little bit of risk involved in terms of the purchasers. They may be assuming that they are going to have a premium that is going to stay the same across the entire life of the product, but if they end up using more services than the insurance company thought they were going to as a class, then the premiums can go up.

The other piece of the product that is very key for when people are trying to make decisions, is some of the futures, one of which being inflation protection. Products can be bought without any inflation protection, so if you buy $100 a day today, it will be $100 a day in 30 years. That is not worth much after you take into account inflation.

Long-term care inflation has been growing faster than general inflation, so it is highly recommended that people purchase products that have some sort of inflation protection in it. There are different options, whether it is simple or compound.

People's understanding of those concepts and ability to figure out, one, should they pay the additional price to get the inflation protection in the product, and then which form of inflation protection they should purchase, can make it difficult to make those decisions.

Another aspect of long-term care insurance that a lot of people are no aware of, is lapse rates. Basically, you are buying this product for something that is going to occur 20 to 30 years down the road, and you have to continue paying premiums for that entire period or you are not going to have the protection when you need it.

Quite a few people who purchased long-term care insurance discontinue paying premiums, and there are a lot of reasons they might do that. But, basically, that means that they have paid into a product and get no benefit out of it. The estimates are between 30 and 50 percent of people purchase long-term care insurance lapse it within 5 years.

There are features. You can buy a feature that you can get some of the value out of your policy when you lapse, but that makes the initial price much more expensive than otherwise.

Finally, long-term care insurance policies are very flexible, given the current system now. They cover assisted living, they cover nursing facility care, they cover home- and community-based care. But whether or not they are well-suited to adapt to changes in the future, is a question.

Ten years ago, assisted living was not very common. Assisted living was not covered by the yearly long-term care insurance policies. Today's long-term care insurance policies do cover assisted living. But we do not know what is going to be available 20 years from

now, and whether the policies can adapt to that changing system is something that needs to be of concern to purchasers.

The regulation of long-term care insurance is the responsibility of the States. The National Association of Insurance Commissioners recommends specific model regulation, but the States choose what to include and what not to include in terms of their regulation of the product.

State insurance departments vary considerably in both the resources and expertise that they bring to the regulation of long-term care insurance. Some State insurance departments do not use actuaries to review rates.

Given the importance of the premiums in this product and the ability to price the product correctly, it is a key factor in being able to make sure that, down the road, that the benefits that are expected are delivered by the product.

In addition to the State regulation, there is another piece of legislation that influences the long-term care insurance market. It is not a regulation, it was the Health Insurance Portability and Accountability Act of 1996. This Act defined qualified plans for the purpose of tax deductibility.

Basically, it set an eligibility trigger floor, so the minimum number of ADLs that you can use to have the product be available for tax deductibility. Basically, long-term care insurance companies have wholeheartedly switched over their eligibility triggers to meet that tax deductibility requirement.

The interesting thing about that, is that floor is actually higher than the NAIC recommended as a level for eligibility trigger. So, basically, the tax deductibility has put a constraint on the market in terms of the eligibility triggers that are allowed to be used for the product and still meet tax deductibility. People basically do not want a product unless it is tax deductible, because it does not make sense not to take advantage of that.

I guess Bill Scanlon mentioned the Federal offering of long-term care insurance. Employer-based sales are a small part of the current market. I will conclude now, unless you would like me to continue for a minute.

The CHAIRMAN. Well, if you have got a thought or two.

Ms. ALECXIH. I have a thought or two.

Basically, employer-based sales are a small part of the current market. They represent the future if you are going to have long-term care insurance play a large role in financing care. They provide the offering of lower premiums and getting people at younger ages.

Your committee will be considering tax incentives for long-term care. In my full testimony, I talk a little bit about the implications of tax incentives for long-term care, and who they advantage and who they do not reach.

[The prepared statement of Ms. Alecxih appears in the appendix.]

The CHAIRMAN. All right. Thank you, Ms. Alecxih.

Now, Mr. Lutzky?

STATEMENT OF STEVEN LUTZKY, CHIEF, OFFICE ON DISABILITIES AND AGING, DEPARTMENT OF HEALTH, WASHINGTON, DC

Mr. LUTZKY. I am chief of the Office on Disabilities and Aging within Washington, DC, and I have been given the charge of redesigning the District's long-term care system.

How States design their long-term care delivery systems plays a central role in shaping long-term care in the United States, because the majority of people needing paid long-term care services rely on States to fund the care that they need.

As Senator Grassley noted, State Medicaid programs fund care for approximately 1 million of the 1.5 million nursing facility residents. States have recognized this responsibility and they have been taking advantage of the increasing flexibility given by the Federal Government to try to develop cost-effective care delivery systems that better serve our citizens.

States have had the twin concerns of controlling costs and providing services that meet our citizens' needs. In the past, these concerns have often been at odds and States have resisted expanding services designed to keep people in the community, services such as the ones that Mr. Kays was describing. They viewed these services as potentially being so desirable that it would cause demand and costs to escalate dramatically.

To quell these concerns, States placed limits on the number of people who could receive these services, the amount of services that they could receive, and tried to keep the reimbursement for these services as low as possible.

However, the States that have led the way in expanding access to home- and community-based services, also known as HCBS, such as Oregon and Washington have not experienced these runaway costs. In fact, at least one study suggests that expanding HCBS can produce at least modest overall savings.

In the District of Columbia, we are adapting some of the best practices that we have observed in model States to design a cost-effective system that will not only enhance the lives of some of our most vulnerable citizens, but could also help us improve the fabric of our community.

These model States have designed their programs to support individuals and their families rather than replacing them. I would like to briefly describe some of the key lessons that we have learned.

To be cost-effective, a system must maximize the likelihood that HCBS will serve individuals who would otherwise be in an institution. The program must ensure that accessing an HCBS is as easy as accessing an institution. By the time families and individuals get to the point where they seek out assistance, they are often in a caregiving crisis that must be resolved quickly.

If you have a waiting list that takes years or an eligibility process that takes months, you are often forcing institutionalization on individuals who cannot wait for the assistance.

The District is addressing this issue by following the lead of other HCBS Medicaid waiver programs that do not have wait lists and have sped up their eligibility determination process.

Individuals must also be directed to the services that provide alternatives to institutions. In the District, we are following the lead of States like Wisconsin by building a resource center that will empower consumers to make informed choices about long-term care.

Once the District increases access to HCBS, it must design reimbursement and create infrastructure so that the services are provided in a cost-effective manner, and also that we are monitoring quality.

Other States' experience suggests that, to achieve this goal, the District must increase both the flexibility and the ability to carefully monitor costs and quality.

The District is working to achieve this goal by, one, incorporating managed care principles, such as capitated payment mechanisms or other incentives, for providing care costs effective. These can act to move the decisions about how care is made from the State closer to the actual delivery of care.

Two, by broadening the range of services to add more flexible, and potentially cost-saving, services such as attendant care and residential alternatives to institutions.

Three, by implementing an information technology system that will facilitate the delivery of care and also assist the District in monitoring cost and quality very quickly. Four, by adopting outcome-based measures of quality.

I would like to take the remaining time that I have and, first, thank Congress and the Federal Government for the freedom and support necessary to develop these new programs; 1915(c) HCBS waivers, enhanced matches, and other provisions have played a crucial role in transferring long-term care delivery systems. These programs have allowed individuals who have felt helpless to feel in control over their destiny. They have made individuals and their families stronger.

I have been very encouraged by what I have seen thus far from the Bush Administration. The District plans on taking advantage of the opportunities offered under the President's New Freedom initiative.

Secretary Thompson, of the Department of Health and Human Services, understands what States are trying to achieve. In fact, many of the aspects of the system's proposed redesigns are based on programs that were initiated under then-Governor Thompson's watch in Wisconsin.

I would like to briefly mention some barriers that must be overcome in the years ahead. First, States need more latitude in blending Medicare dollars with Medicaid dollars.

Many individuals in populations that we serve are eligible for both programs, and it is very difficult to create the financial incentives for coordination if we can only influence one funding stream.

Second, we need the Health Care Financing Administration to view States as partners. If a State is doing something innovative or if there are concerns regarding quality, consider having HCFA detail somebody to work with us rather than relying on the often endless process of requests for additional information.

Third, consider mechanisms that will allow States to broaden the populations that we serve. Current reimbursement requirements for waivers make it difficult to intervene earlier and prevent indi-

viduals with predisposing conditions from progressing to more severe and costly disabilities.

Thank you very much for offering me the opportunity to testify.

[The prepared statement of Mr. Lutzky appears in the appendix.].

The CHAIRMAN. Thank you very much, each of you on the panel.

We will take 5-minute turns. I would be glad to defer to you, since you have to go, if you would like to ask questions.

Senator TORRICELLI. I need to go to the debate on the floor. Thank you, Mr. Chairman.

The CHAIRMAN. All right. Then I will ask questions, then turn to Senator Lincoln. Five minute turns, please.

I will not be able to cover all of you in my first 5 minutes. But, if we do not have votes, I will be able to stay here, I think, and ask all of my questions.

I am going to start with Ms. O'Shaughnessy. Your description of long-term care included the common measurement system using activities of daily living, ADLs, for short.

As I understand it, there is a general consensus that a person who needs help with two or more ADLs would need long-term care services. I think you also said that many nursing home residents need help with at least three ADLs.

Could you give us an example of a condition that would lead to the loss of independence and require a person to need assistance in activities of daily living?

Ms. O'SHAUGHNESSY. Certainly, Senator. Persons, for example, who have heart disease, where the heart disease has progressed to an advanced stage; persons with Lou Gherig's disease; certainly persons with Alzheimer's would need assistance with some of the activities of daily living. Any disease that is a chronically, progressively disabling condition would lead to the need for assistance with activities of daily living.

There are other examples, too, where, for example, a person may have a broken hip and may need short-term care who may have to go into a nursing home for a short time for rehabilitation, but when the person returns home, he or she might need assistance with mobility and with bathing, for example. So, there are persons who need short-term assistance.

I mentioned that over 80 percent of persons in nursing homes need assistance with three or more activities of daily living. But when you look at the persons in the community, about 25 percent of the persons who are receiving help in the community also need assistance with three or more activities of daily living.

If you take those, that would be over one million people who could have perhaps gone into a nursing home, but who are surviving at home with the assistance that is provided by families.

The CHAIRMAN. Also, as a follow-up, and also, I would ask Dr. Scanlon for comment as well, it sounds like many of these long-term care services are generally non-medical in nature. Many individuals have long-term care needs where the do not have to be in the hospital, they just need help, as you indicated, with bathing, eating, other things.

But there are some individuals whose long-term care needs are much more severe and do require medical attention. Could you pro-

vide some examples of patients who need long-term care services that are non-medical in nature, and how these patients' conditions compare to the acute care population?

Ms. O'SHAUGHNESSY. I think of, perhaps, younger persons with disabilities who are working, for example, who may be quadriplegic, who have mobility through wheelchairs, et cetera, but who are certainly able to work.

Their condition stems from a medical condition originally, but their medical condition has been controlled. They might need assistance with bathing or eating, for example, if they are quadriplegic.

Persons who have an acute flare-up, who have a severe medical condition, for example, cancer patients, might need physician or medical attention more frequently than younger persons with disabilities who are also working. So I think you have got sort of a dichotomy there between the very severe acute flare-up and persons who have long-term, chronic, progressive disease.

The CHAIRMAN. Dr. Scanlon?

Dr. SCANLON. Mr. Chairman, I would agree with Ms. O'Shaughnessy. There are certainly people who need long-term care who may need continuing skilled services, such as a person on a ventilator where the ventilator is going to need to be maintained by someone with professional training, or someone who needs monitoring to make sure that drugs are working properly and that there are no exacerbations of conditions.

Many of these people are going to need extensive assistance with activities of daily living, what we think of more often as the traditional long-term care need.

Both of these types of people are going to differ from those who have an acute episode, where a condition worsens or a new condition develops and there needs to be some significant intervention, such as a person that falls and breaks a hip. That would be an example of someone who would move from needing supportive services to needing some acute medical care.

The CHAIRMAN. Dr. Scanlon, the potential savings to the public program as a result of increased purchase of private long-term care coverage is yet to be seen. Recognizing our limitations in measuring these savings, what can you share with us in the way of potential gains in consumer choice as a result of private long-term care coverage?

Dr. SCANLON. I think private insurance coverage, when a person receives the benefits, can increase the purchasing power of that individual within that family, and it can have some positive effects in a number of different ways.

Services that may be deemed to be unaffordable can become affordable when one has more resources. As Mr. Kays has indicated, respite can be an important aspect of services in that, while families do an incredible job in terms of serving and assisting people needing long-term care, they sometimes need a break. Being able to purchase some services can provide that break.

They also may open an array of options that did not seem to be affordable, such as alternatives to nursing homes like assisted living facilities, that a person may benefit from greatly.

The other thing I think we should not overlook is that these additional resources could potentially preserve some of the resources of surviving spouses. Surviving spouses actually are more at risk of having needs that are unmet as the result of long-term care. When the first spouse uses up some of the resources of the couple, those are gone when the surviving spouse may have long-term care needs.

The CHAIRMAN. Before I go to Senator Lincoln, just to follow up, do you see any good trends in the development of better-quality products of this insurance coverage?

Dr. SCANLON. I think there have been some very positive trends when one compares the current policies to the very early policies that were provided. I do think that a major portion of the credit for this goes to the fact that the NAIC, through the States, has introduced standards in most States that improve policies by making sure that benefits are more understandable, by making sure that benefits are meaningful in terms of covering services that a person might want, and by making sure that potential consumers know more about the policies that are available.

Again, as I indicated in my testimony, insurers have also played a role in this, too. Larger insurance companies have entered this market and have introduced better policies because they wanted to lead in competing for customers on the basis of more quality products. This does not mean that everything, though, is fine and that we do not need to continue to make improvements.

As you know, last year the NAIC revised its model regulation and statute for long-term care insurance in response to problems associated with premium changes that had occurred.

There was a class action suit in North Dakota because people had been dropping policies because of the very extraordinary increases in the premiums. They were not aware, or did not understand, that this might happen.

That kind of situation led NAIC to rethink some of its requirements. I think that is, again, a positive step. We are still too early to know what is going to happen at the State level in terms of those policies being adopted.

The CHAIRMAN. Thank you.

Senator Lincoln?

OPENING STATEMENT OF HON. BLANCHE L. LINCOLN, A U.S. SENATOR FROM ARKANSAS

Senator LINCOLN. Thank you, Mr. Chairman. I would like to give a very, very special thanks to our Chairman. I appreciate the way that he has taken on this issue and has really done an excellent job in bringing about an awareness of it, and allowing us to work on it. I appreciate his leadership. As a very proud original co-sponsor of the Grassley-Graham bill, I appreciate your efforts.

The CHAIRMAN. Thank you.

Senator LINCOLN. I have been a supporter of long-term care tax credits since I arrived in the Senate, and I have appreciated working with Chairman Grassley, both here and on the Aging Committee.

We certainly need to do what we can to encourage individuals to take the responsibility for their long-term care needs. It certainly

is in our best financial interests, as a Nation, to encourage our baby boomers to prepare for their long-term care needs.

If we do not, long-term care needs will bankrupt our Nation. Even though I am one of the younger members of the Senate, I have to say I have an unbelievable paranoia about how ill-prepared we are as a Nation in meeting the needs our long-term care needs.

I appreciate Mr. Kays' testimony, since I have an Alzheimer's patient at home as well. I am a member of the sandwich generation, with small children and to aging parents who have unbelievable needs.

We, as a Nation, must realize that in the next 10 to 15 years we will have an enormous influx of baby boomers into the aging category of our population. If we are not prepared for it, it is not only going to be heartbreaking to us in terms of the lack of quality of life that we can provide for our constituency, but it is going to be an unbelievable financial disaster as well.

So, I appreciate the panel being here and your willingness to work with us to look for solutions that are going to make a difference.

The title of today's hearing, "The Affordability of Long-Term Care," I cannot help but want to inject also, "The Affordability and Availability." Representing a predominantly rural State, a State that has—we are not proud of it, but the fact is—the largest percentage of any elderly group in a State that lives in poverty. A lot of that is due to our rural characteristics.

But also the fact that, with 125 medical schools in this Nation, only three of them offer a residency program in geriatrics. If we are going to be able to provide the kind of long-term care that we want, we are also going to have to have the trained professionals to be able to deliver it and who know what is needed in the long-term care arena, and the health needs of our aging population.

I certainly think that Congress needs to take a balanced approach towards long-term care by looking at tax credits, but also programmatic expansions. Obviously, prescription drugs is going to be a big issue for us in our aging community.

But there will be individuals who will not have access to long-term care insurance because they cannot afford it, or because they have waited too long to purchase it. We experienced that in our own household with one parent who was eligible for long-term care and one that was not when we finally realized how essential it was.

Since the great majority of seniors who need help living independently live in their own homes, States and the Federal Government need to take a fresh look at how to sustain independent living by creating more long-term care options so that older persons have a wide array of options and a true safety net for their long-term care needs.

I would like to ask the panel, any of you all, Dr. Scanlon, certainly Ms. O'Shaughnessy, and others, what you have run up against. What creative measures have States taken that you all have witnessed to increase home- and community-based services to the elderly?

Ms. O'SHAUGHNESSY. Senator, there are a number of States that have taken great advantage of the Medicaid Home- and Commu-

nity-Based Waiver Program. This was a program created in 1981 that, in the recent decade, has seen expansive growth.

While nursing home care still dominates Medicaid, home- and community-based care has expanded tremendously because States are able to waive certain requirements of the Medicaid statute, namely, the fact that a service has to be available State-wide.

Also, States can waive certain requirements for financial eligibility. This is a real issue with Medicaid, since the asset test for Medicaid eligibility is $2,000, and it has been that for many, many years.

Senator LINCOLN. Right.

Ms. O'SHAUGHNESSY. Some States, like Oregon and Washington, have expanded and used their own funds. AARP did a study recently, finding that $2.5 billion was spent of State money only, not including Medicaid match money.

So some States are putting in a lot of their own money, but in rural States and States that are not as well off as some other States, are very dependent upon Federal programs that exist. For example, the Social Services Block Grant Program, that we did not mention today.

Senator LINCOLN. Dr. Scanlon?

Dr. SCANLON. In addition to increasing their commitment to home- and community-based services, I think one of the innovative things that States have done is recognized that, for many people, 24-hour care is really what is required.

They have tried to provide alternatives to institutions by using these home- and community-based dollars to provide services in other settings, such as assisted living facilities, and board and care homes.

This is something that I think bridges the gap between trying to create a home-like environment and provide all the services, while not putting someone into a very strong institutional environment.

Mr. KAYS. Well, when I was faced with my problem with Pearl, I think I was like every other caregiver. You want to keep them at home.

Senator LINCOLN. Absolutely.

Mr. KAYS. The last thing I wanted to do was to send her away. I wanted to keep her at home. One of the things that permitted me to keep her as long as I did, was the fact that I was fortunate enough to live in this large metropolitan area of Northern Virginia, where Fairfax County and the State provide five adult day health care centers, where you can take them during the day and drop them off and they will get wonderful care. I think more of that is needed.

Now, when you get out in the rural areas, out to the west of us, there are very few of them. We need them out there. Those people are not immune to Alzheimer's, unless they have got something in the water out there. They have got Alzheimer's, too, and they are caring for them in the home.

The other thing I wanted to say a little earlier, as I told you, I had that heart attack after I put Pearl away. I am convinced that if I had not been able to drop her off every day, or 5 days a week, and let someone else care for her and get that respite, when I had that heart attack they would not have been carrying me to Fairfax

Hospital. There is another place right down the road from me that specializes in acute cases.

But it is important to have respite care that is affordable. I think the more money that can be poured in by the State, or you ladies and gentlemen, would sure help. Thank you.

Senator LINCOLN. We are very interested in looking into the adult day care issue, and we are hoping that we will be able to have some hearings later on in the year about that. We have seen how productive they can be in providing that respite care to the caregivers, too. Thank you.

Anybody else?

Ms. HUNT. Yes. I wanted to mention, with regard to the caregiver, the caregivers are usually, as we have heard, the people who are allowing the older person to stay in his own home because they are providing 80 percent of the support to the older person.

There are a couple of States that have wonderful programs, California, probably being first and foremost. New Jersey and Pennsylvania are also States that are doing a good job with support to the caregiver. In California, particularly, the whole range of comprehensive services that they offer, from adult day care and respite, to peer counseling, to information and referral, is aimed at supporting the family caregiver and enabling them to continue caregiving longer and keeping the older person out of an institution.

Senator LINCOLN. Thank you.

Mr. LUTZKY. I would agree with that. I would say there are three groups. There are probably some people that you are just not going to keep out of institutions. Some people, no matter what you do, they are going to keep the people in the community and their family is going to care for them. Then there is the large middle group that Mr. Kays represents. Mr. Kays was resourceful enough and had enough of his own funds to be able to keep his wife in the community. For somebody who does not have those resources, they are likely to go into an institution.

We are trying to design our program so that we have a resource center so that people can get the information that they need, not spend down their assets as quickly, and then if they do become Medicaid-eligible, providing some of these services that are supporting people like Mr. Kays rather than paying the full cost for a nursing home.

Senator LINCOLN. Thank you, Mr. Chairman. I will save my next question for the next round.

The CHAIRMAN. Thank you very much.

Before I go on to questioning, just so we put on the record that Congress took a small step in the area of family caregiving last year, we passed a Grassley-Breaux bill—Senator Breaux is a member of this committee—called The National Family Caregiver Support Program.

It was passed as a result of the work of the Senate Health and Labor Committee, as part of the Older Americans Act, to set up within the Area Agency on Aging a management and guidance program for people who would need services like you needed, Mr. Kays, for your wife at the time she first had them. I do not know how many services were available. You got into the support group

you told us about, so I presume there was a lot of expertise there for us.

But we want to provide an opportunity for people to get this advice about family caregiving to know what all the services available are, and to serve as kind of a consultant for families.

I do not know what we ended up funding that program, but I know we asked originally for $125 million. So, I hope that that will be a step towards helping people to know what the community-based resources are, and access to Federal programs that might be available.

I want some advice from you, Mr. Kays. Most importantly, your testimony, more than anybody else on the panel, reminds us why we are here today. The commitment and diligence that you have to get quality care for your wife sets a very high example.

What kind of advice would you offer other families who might be faced with making decisions about long-term care?

Mr. KAYS. First, as you just mentioned, find out what the alternatives are in the community where they live. You mentioned the Area Agency on Aging. I do not know how it works throughout the rest of the State of Virginia or in your State, but I know, where I live, they are tremendous in telling people all of the services that are available to them for care, for other help for caregivers. It is services for the elderly. You do not have to be a caregiver.

But I think I would ask them, one, to look into the care that is available. You have got to match what you need with what is offered. I will be perfectly honest with you. I think, in many cases in long-term care, we substitute "glitz" for care.

I think you have got to look behind the door, look behind the fresh-cut flowers in the lobby, and the beautiful chandelier that is there to find out, are they really being cared for there. That is a concern that I have for caregivers everywhere.

I know the ones that I have run into that have moved their people to where Pearl is, or from there to somewhere else, they are scared to death that their loved one is not going to be cared for. I was. I was convinced that no one could care for Pearl the way I did. It kind of hurt a little bit, to tell you the truth, when I found that they were doing a lot better job than I ever did.

But I would advise them to start as I did. When you find out you are going to be a caregiver in the home, to start early, as they advised me to do in the support group, and look at everything that is available, look at what you can afford.

You said that I could afford to do this. The reason I could afford to do some of the things I am doing now, is because Pearl and I had saved throughout our late pre-retirement after the kids got out of college, just for doing the things we were going to do after I retired. I had that money salted away. That, plus Social Security, plus my pension, which does not have COLA, from Bell Atlantic like the wonderful government employees have, so I am able to get by. I am one of the very fortunate ones. My heart goes out to the people who cannot. I do not know whether I have answered your question.

The CHAIRMAN. I think so.

I want to go on to another question for you. That would be the fact that it is my understanding that you have been contacted regarding long-term care insurance.

What advice would you offer another family member today who is shopping for long-term care insurance? What kind of information would a prospective purchaser need? In other words, what do you think is most important to consider when you are evaluating long-term care policies?

Mr. KAYS. I am certainly not an expert in that area, because it was not available. I get calls, though, right to this day asking me, telling me, that they are interested in selling me long-term care insurance.

I tell them that they are a bigger fool than they think they are. When I tell them that my wife is in acute assisted living with Alzheimer's and that I had quadruple bypass, they either hang up immediately or excuse themselves politely.

I think it is very important to, one, look at what you can afford. Two, and Gail and this gentlemen, all of them here, everyone up here is more of an expert than I am. But how long are you going to need it? You never know.

Mine would be running out about now if I had long-term care insurance, because after 4 years, roughly, Pearl's expenses are running me, out-of-pocket, about $25,000 a year. Long-term care insurance would not pay all of that, but it would certainly help. I think you have got to look at the costs, look at what is available, and kind of lick your finger and put it up, I guess. I am not an expert.

The CHAIRMAN. Now, Ms. Hunt, your organization has studied the impact of caring for elderly disabled individuals who have long-term care insurance, comparing that with someone who lacks long-term care insurance. For those individuals who are long-term care coverage, the caregivers may experience less stress and fewer disruptions in the workplace.

Would you elaborate on the findings of this study?

Ms. HUNT. Yes. This is a study that is just going to be coming out in the next week or so, actually, that we did with MetLife and a nonprofit organization called Life Plans in Massachusetts. They had access to some data from ASPE on long-term care beneficiaries. They used the data from that, plus data from a combined long-term care insurers pool.

We looked at people who were working caregivers of those with long-term care insurance versus working caregivers of those who did not have long-term care insurance.

The study results showed that those people who are working caregivers of people with long-term care insurance are twice as likely to stay in the workplace. We do not know exactly why, because this was a secondary analysis of data, but we were able to see that they stayed twice as long in the workplace.

Plus, it looks as if the working caregivers which we studied do not really diminish the amount of time that they spend with the older person.

If the older person has long-term care insurance and can afford to buy some services, the caregiver puts more time into "quality time", if you want to call it that, with the older person rather than actually doing the bathing, dressing, feeding tasks.

The CHAIRMAN. Thank you very much.

Now I will turn to Senator Lincoln to see if she has any questions she wants to ask.

Senator LINCOLN. Thank you, Mr. Chairman.

We appreciate Mr. Kays bringing his story to us. One of the things that I would like to highlight, is that, as we look at the issue of the aging and the caregivers, they are predominantly women in most instances. I am hoping that the women of this Nation will recognize that.

The aging population that we have and the needs we are going to have in the future are very much a women's issue, whether it is Social Security and the fact that women live longer, they earn less, and it is based on earnings, and they are in and out of the workforce, so that those issues are important to us. But also, as caregivers.

One of the reasons I tooted the Chairman's horn earlier was that I am an original co-sponsor of the National Family Caregivers Act from last year, which did pass. We were very proud of his leadership on that.

We are hoping that this program will enable communities to provide support to family caregivers. Since the majority of those family caregivers are women, it is interesting to me, if you have any perspective, of how that is different to support women as caregivers in the community. Again, I see it in my own family with my mother.

But looking at the kinds of support services and networks that are in place to help female caregivers, is there any difference in terms of maybe some of the studies you have seen from the long-term care insurance and other mechanisms with women, if there is any difference there? We know it affects women more just because they are the majority of the caregivers.

When I visited with the physicians from our Aging Center in Arkansas at our medical school, they said it is not a fault, it is just a fact, that two-thirds of the patients that come in are brought in by their wives or their daughters.

So I do not know if there are any differences, if there have been any studies or any focus, on the difference that it might have because of the fact that the majority of caregivers are women.

Ms. HUNT. Well, just to follow up a little bit on that. While it is true that when you look at broad-based caregiving studies, it usually breaks out 72 percent women to 28 percent men.

When you look at working caregivers, though, it comes closer to 55 percent women and 45 percent men. So, caregiving is moving in the direction in the workplace of having more men be involved.

Actually, we are seeing somewhat more interest in the workplace in having support to caregivers because it is no longer viewed as a women's issue. It cannot be marginalized. It is actually affecting the mid-level executive who may be viewed as very important to the company.

Senator LINCOLN. Absolutely.

Ms. HUNT. But we do know that there are differences in the activities and, when it comes down to it, women are much more likely to be doing the personal care, the bathing, dressing, feeding activi-

ties. Men are more likely to be doing the IADLs, managing the finances, maybe doing the transportation, and some of those things.

Long-term care insurance really does not cover the IADL tasks, it covers more the ADL activities. At some level you could almost see that long-term care insurance might help provide financial support for some of those activities that the women would have been doing, the more intensive personal care.

Ms. ALECXIH. In terms of targeting caregiver supports, one of the areas that is very important is more the cultural competence and the cultural differences that people bring to caregiving, the approach they take to caregiving, and their feelings and attitudes about it. Because the majority of them are women, the difference that is going to make, the distinction between the different groups, has more to do with culture than gender.

Mr. LUTZKY. One of the keys in designing programs is to have the flexibility that is going to adapt to the individual circumstances. I can think of a situation where there was one caregiver, and she was probably about 100 pounds. She was taking care of her husband, who needed assistance with transferring, and he probably weighed about 200 pounds.

In trying to keep that person in the community, you need to have a program that would be covering home modifications, maybe a lift, and designing services overall so that they are tailored to the individual situations.

Mr. KAYS. I would like to second what he just said. I run a support group for the Alzheimer's and it is predominantly lady caregivers. I think it is much easier for a man to be a caregiver than it is a woman, for the very reason that he just stated. Pearl is 5′1″, weighed 125. I had no problem getting her up, bathing her, and everything.

But you would not be surprised to know that these women, their husband will get down in the bathtub, and they cannot get him up. I do not care what time it is, they have got to call 911 and have them come and get him up. Or they will get down off a couch and they cannot get up off the floor to go to bed. Once they are up they can walk. The ladies are too frail. Some of them are 85 years old. But men do not have that problem, as a rule. I did not have any trouble with that.

Senator LINCOLN. We see that as a fear in our own home, because not only are they fearful that they cannot take care of the individual, but they also then become afraid at some point that they are going to fall and break their hip, and then where are they?

Mr. KAYS. Exactly.

Senator LINCOLN. Because then their immediate caregiver is absolutely gone.

Mr. KAYS. I think Gail had a study years ago that she did that showed that people who are caregivers are far more likely to have health problems, did you not, Gail?

Ms. HUNT. There have been a lot of studies on that topic.

Mr. KAYS. Yes. That showed they are far more likely to have health problems.

Senator LINCOLN. Ms. Hunt, just in closing, you had mentioned in your testimony that, when surveyed, most caregivers did not

even know what types of services that they would like to have made available to them. Mr. Kays mentioned that knowing what is out there is so important.

Do you think there is a role for the Family Caregivers Act to play there, and how do we make that information available to people? Is there a way to get it out? Is there something more that we could be doing?

Ms. HUNT. The National Family Caregiver Support Program is supposed to focus on information and referral for caregivers. But one of the biggest difficulties is outreach to caregivers.

In other words, if they are coming in to the Area Agency, as Bill did, they can ask for and get information. The problem is, a lot of caregivers do not self-identify. So you can run an ad that says here is a caregiver support group, but they do not understand, this is for me.

Senator LINCOLN. They are the caregiver. Yes.

Ms. HUNT. So they are not coming in to the Area Agency. Even where there are corporate eldercare programs, they do not understand the corporate program is for them. So what is needed, is a real outreach program to reach to caregivers and say, this is for you, and this is what these services can do for you.

That is what a lot of caregivers also say: yes, I have heard of adult day care, but I do not need it. They do not understand what adult day care, as one example, can do. So it is really an outreach issue as well as having the resources available.

Senator LINCOLN. Thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you for your interest in this, Senator Lincoln.

I have got just a couple of more questions. I want to start with Ms. Alecxih. We have this problem of 30 to 50 percent of the people that buy long-term care insurance letting the policies lapse. You dealt with State regulation, the amount of resources that go into it, the number of States that use model State regulations to regulate it. I presume all of these available resources have something to do with State regulation.

To what extent is State variation and regulation an obstacle to increasing the sales of long-term care policies?

Ms. ALECXIH. Basically, it requires companies that want to offer long-term care insurance across the country to deal with 51 different sets of rules. A lot of them are similar. Ninety percent of the rules are similar. But then the additional variations from State to State means that they have to tailor their products to each of those States.

The big insurance companies have departments that deal with that and do all right. Where it is more of an obstacle, is actually on the employer side. If a large employer wants to offer long-term care insurance to its employees and has employees across the country, or the company it is contracting with has to deal with it in that respect, that can be a little bit of a barrier to offering it more broadly.

The CHAIRMAN. Mr. Lutzky, you made a statement I agree with about people strongly desiring to receive services at home in the community. Most everybody in this room has heard me say that I

have never met one person in my life who said, I am just dying to get into a nursing home.

In your testimony, you talk about the demand States are facing for these community-based services. What types of things set apart programs that you call "best practices?" I believe you mentioned, Texas, Minnesota, Wisconsin. Is it quality or efficiency in regard to spending that makes a State a model State, in your judgment?

Mr. LUTZKY. It is two components. It is, one, how you target the services, so who you are bringing into the system. The other, is once you have people receiving the services, how you are delivering the care.

So a lot of States, when they set up their waiver program, will say that they will 1,000 slots, and then those slots are filled, then you have to go onto a waiting list. What that does, is that acts as a screen and it screens out anybody who is in Mr. Kays' group, who cannot wait.

So when the only people that you have that are receiving the services are then the individuals who otherwise would have remained in the community, it is of benefit to them and it is reducing some of their stress.

But from the State perspective it is not saving us any money and this is just becoming an add-on cost. The flip side of it, when you get them into the community, controlling the costs and ensuring quality, it becomes a much more difficult endeavor. We have looked at managed care.

What I have seen from managed care in the States that have moved ahead with it, it can be a very positive thing. We are seeing in some of these States that managed care organizations are doing something that is very innovative for managed care, in that they are actually managing the care.

So, in a sense, what you are having is a transfer of the decision. Right now we said a person can receive up to six hours of personal care a day and no other services.

So what you will have, is somebody will come into the waiver. The home care company will make sure that everybody is receiving six hours of care a day, whether or not they actually need that.

When we go into managed care and provide capitated payments, we provide the freedom and the flexibility so that they can design the services to meet the individuals' needs in the most cost-effective way.

The CHAIRMAN. You may have touched on this just a little bit in part of what you just answered. Let me say, before I ask the question, I have been looking, both as a member of this committee, and other members of this committee who also served on the Aging Committee over the last few years, for some sort of better measurement of quality of care in nursing homes. You mentioned several States that use outcome-based measures of quality.

I would like to have you describe these, and particularly how you would tie measurements to reimbursement.

Mr. LUTZKY. Most States are considering this, and we are seeing a lot of progress made in this direction. With the Wisconsin Family Care Program, they have an outcome-based measure of quality that is based on the work on the Council in Support of Quality for People with Disabilities.

A number of States on the side of serving people with mental retardation and developmental disabilities have what they call the Core Indicators Project that are focusing more on outcome-based measures.

They are looking at health and safety measures, but they are also looking at what is called person-centered delivery of care. So to the extent that the individual or the family feels that the care they are receiving is meeting their needs, using that as the most important measure of the care.

When you tie that to reimbursement, that is the standard. If a provider is meeting that standard, then they would be getting a higher reimbursement rate, or maybe a bonus payment, than somebody who is failing to meet that standard.

The CHAIRMAN. Thank you.

Ms. Alecxih, Senator Mikulski and I got passed last year a program so that, through the Federal Benefit Program, the Federal Government can offer long-term care insurance.

We wanted to do that for the Federal Government to set an example, but also because it is something that we want people to actually do for long-term risk management.

What could you share with us regarding the types of plans that we should expect to see offered by the Federal Government, and what sort of features do you expect will appear in the Federal policies?

Ms. ALECXIH. The Office of Personnel Management is looking to be a leader and an innovator in terms of the long-term care policy it is going to offer. I think, in a lot of ways, it will look like the typical offerings, which include assisted living, nursing facility, and home- and community-based care, and have sort of a pool of money to use across all those services as opposed to say, all right, this much is for this service, and this much is for this service.

But they are also looking to try to include people—potentially include people. This is a huge challenge for them—who already have disabilities, and their potential for possibly getting involved in a policy, either focusing it on a very high catastrophic coverage policy so they will not go into claims immediately and it only gets used when it is absolutely necessary, or some other mechanism. It is a huge challenge to be able to do that.

They are also looking to provide some sort of non-forfeiture benefit, which gives people some benefit if they do stop paying premiums. They are looking at different models for doing that that will provide a benefit, but will also not increase the premiums dramatically so that it is not competitive.

The CHAIRMAN. My last question is to Ms. Hunt. In regard to consumer information being a big difference in regard to long-term care policies, in regard to one's keeping current and avoiding a lapse of coverage, what can you tell us about the experience of family caregivers in shopping for long-term care plans? Is there particular information that is most critical to family caregivers who might be wanting to buy long-term care policies?

Ms. HUNT. Of course, the issue that has been brought up here before is, if it is the family caregiver looking for long-term care insurance for the older person, it may be too late because the person cannot be underwritten.

The CHAIRMAN. And probably in every instance it would be too late. Nobody is going to sell you a policy, are they, if you are already in that situation?

Ms. HUNT. If you are already in that situation. Right. So what you are really looking for, is to reach the baby boomer, the younger person.

There is a study that the American Council of Life Insurers, ACLI, is coming out with that shows that caregiving itself is a big factor in baby boomers deciding to buy long-term care insurance, because they recognize that, boy, this caregiving costs me a lot, or it cost my parents a lot, and I do not want the same thing to happen to me. So, that is a factor for them in purchasing.

But, as I understand it, the single biggest issue when you are looking for long-term care insurance is that you have got to pick a company that will still be in business 20 or 30 years from now. You have got to try to be able to predict, which is, of course, difficult. You have to pick a really reliable company so that they are still around when you are going to need this.

Then it is, as everybody here has said, very complex. There are lots of alternatives in terms of the home care benefit versus the nursing home benefit. Do I get a whole pool of money to draw on? What about the inflation protection? But that inflation protection is, again, a big issue for family caregivers, or anybody thinking about purchasing long-term care insurance.

The other thing I wanted to mention is that about half of the long-term care insurance companies now have a benefit for family caregivers.

It may be just the value of a couple of days of the older person's home care benefits, so it may just be a couple of hundred dollars, but half of the insurance companies offer either training money for the caregiver or they offer respite money for the caregiver.

So, that is something that people should keep in mind, when they are looking for the policy, to think about for their children when their children are going to be taking care of them.

The CHAIRMAN. Now, if an employer offers this as part of a benefit package, I suppose that very definitely helps overcome a problem that an individual shopper might have. Would that be a fair statement?

Ms. HUNT. Yes. The employer can ask for certain of these benefits to be built into that group policy.

The CHAIRMAN. Yes. But do we not assume that an employer is going to probably be more discriminating in what might be offered than an individual?

Ms. HUNT. We would hope so. We would hope that they have benefits managers who are looking into that.

Ms. ALECXIH. Either the benefits manager, or they will go to a benefits consultant, more often than not. That means that the employer has done the screening of the products and has chosen one that they consider reliable. That does make the choice easier.

The CHAIRMAN. Senator Lincoln, do you have a closing comment, or anything?

Senator LINCOLN. I am glad that we ended up on that note, because that was my final question, was to talk about the fact that we certainly hope that we are going to have a tax credit to provide

for long-term care insurance. With that, we are going to be providing a tax credit for a very new product.

Hopefully, we will look ahead to see what pitfalls might be there and how we do work through the processes of making sure that people have the information they need to make educated decisions, and get a product that they are aware of, what the premiums are today, but they are going to know what the premiums are going to be 10 years from now. Is it a company that is reliable and is going to be there for them?

Also, the guidelines that they need in purchasing a long-term care policy so that we can recognize what the pitfalls are, and certainly the areas of concern that people should have in looking at this new product that we really, really want to encourage, because I do think it can be very beneficial in the years to come in dealing with the problems and the crisis we may have with our aging community.

You have answered a good bit of that. I do not know if you have any other concerns or pitfalls you might add to that list of what we do with this new product or what we might look for in this new product.

Ms. ALECXIH. I think keeping the consumer protection aspect in mind, and the way that it gets enforced through all 50 States, and how that might vary, is important.

Senator LINCOLN. Yes. It is going to vary.

Thank you, Mr. Chairman.

The CHAIRMAN. Well, we have got an abundant amount of quality information on this subject from all of you. We thank each of you for your individual contributions to what is the product of a very effective panel.

We thank you very much and wish you well, particularly you, Mr. Kays, for sharing your personal experience with us, bringing the real world to Capitol Hill here. Thank you very much.

The hearing is adjourned.

[Whereupon, at 11:49 a.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

PREPARED STATEMENT OF LISA MARIA B. ALECXIH

Private long-term care insurance provides one of the few available mechanisms for the elderly to protect themselves against the catastrophic costs of long-term care. Although long-term care insurance currently pays for only a small portion of the total cost of long-term care, it could become more important in the future. Federal and state governments have an interest in this market to help potentially reduce their own expenditures for long-term care and to ensure that consumers receive adequate protection from products they purchase.

In my testimony, I provide an examination of the current long-term care insurance market. I describe the evolution of the market, provide an in-depth look at current products and choices, discuss underwriting and premiums, examine long-term care insurance regulations, outline consumers' ability to make informed decisions; and assess the adequacy of protection for purchasers against the costs of long-term care and the ability of products to meet consumer needs. I conclude by offering conditions that must be met in order to expand the role of long term care insurance and potential directions that the federal government might pursue.[1]

I. BACKGROUND

Long-term care insurance incorporates aspects of health, disability, and life insurance into a unique, relatively new form of insurance. Like health insurance, it offers coverage for health-related needs typically on a fee-for-service basis. Like disability insurance, policies cover a wide array of services that are necessitated by a long-term disabling functional or cognitive impairment; in addition, some policies provide monthly cash payments. Long-term care insurance, like life insurance, depends on prefunding a benefit typically needed many years in the future. The hybrid nature of the product has implications for regulation, purchasing decisions by consumers, the likelihood consumers will have coverage for services they desire, and pricing of the product.

Insurers began offering long-term care insurance widely in the mid-1980s. By 1998, 5.8 million policies had been sold. Current policyholders are dominated by purchasers of individual policies. However, recent growth in new sales has increasingly come from employer-sponsored products. The federal long term care insurance offering is expected to double the number of employer-sponsored policyholders by the middle of the decade.

Current long-term care insurance policies typically include nursing home, assisted living facility and home and community-based care coverage. The purchaser generally can select a daily amount of coverage up to which the policy will pay benefits if the policyholder receives services from a certified provider and meets the insurer's disability eligibility criteria. Purchasers also have the option of automatically increasing the level of coverage over time or buying increased coverage at specified intervals (inflation protection). In some cases, purchasers also have the option to purchase nonforfeiture benefits that return some of the insured's investment in his or her policy if he or she stops paying premiums (lapses). Typical features purchased

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[1] This testimony borrows heavily from the executive summary of a report I co-authored, "Key Issues for Long-Term Care Insurance: Ensuring Quality Products, increasing Access to Coverage, and Enabling Consumer Choice," prepared for the Office of Research and Demonstrations, Health Care Financing Administration, February 1996. More recent information has been incorporated as appropriate.

have changed over time with many more purchasers opting for more complete coverage (see **Exhibit 1**).

Exhibit 1:
Characteristics Of Individual Long-Term Care Insurance Policies Purchased In 1990, 1994 and 2000

Policy Characteristic	1990	1994	2000
Policy Type			
Nursing home only	63%	33%	14%
Nursing home and home care	37%	61%	77%
Home care only	---	6%	9%
Daily Benefit Amount for Nursing Home Care	$72	$85	$109
Daily Benefit Amount for Home Care	$36	$76	$106
Nursing Home Benefit Duration[a]	5.6 years	5.1 years	5.6 years
Individuals Choosing Inflation Protection	40%	33%	40%
Annual Premium	$1,071	$1,505	$1,677

[a] Lifetime policies were assumed to provide benefits for 10 years in calculating average benefit duration.

Note: Based on an analysis of 14,400 individual long-term care insurance policies sold in 1990 and 6,446 sold in 1994, and 5,407 sold in 2000.

Source: Health Insurance Association of America, ***Who Buys Long-Term Care Insurance in 2000? A Decade of Study of Buyers and Nonbuyers*** prepared by LifePlans Inc., 2000.

Over the past five years, most insurance companies have switched to offering a single pool of money rather than separate pools that can only be used for certain services (i.e. nursing home or home- and community-based care). This single pool maximizes the flexibility of service-based benefits because an insured can apply the money to services and facilities she or he needs and desires, as long as it is for a covered service. The benefit duration under this model is dependent on how long it takes the insured to spend his or her pool of money rather than a certain specified time period. For example, a policy with separate pools of money with four years of coverage for nursing home care at $100/day and home care at $50/day would allow the insured to receive up to $100 a day in a nursing facility or $50 a day of home care for only four years. On the other hand, the same policy with a single pool of money policy would offer $219,000 that could be used for either type of care. Thus, the policy could be stretched out to cover 12 years of home care coverage if an average of $50 a day were spent or it could cover six years of nursing home care if the facility cost $100 a day.

II. THE BUSINESS OF LONG TERM CARE INSURANCE

Three key issues that could determine the success of long-term care insurance include how adequately companies: 1) screen poor risks (underwriting), 2) set premiums, and 3) manage claims. Underwriting is the process through which insurance companies determine if someone applying for a policy should be issued a policy. Companies underwrite policies to avoid adverse selection by using written health questions, medical record review, interviews, and assessments. The depth of the assessment done on an applicant generally increases with age. Insurers generally have a more difficult time screening for mild to moderate cognitive impairment than physical impairment and severe cognitive impairment.

The premiums that insurers charge influence whether consumers will purchase the policies and whether the product is profitable for the company. Premium levels vary significantly depending upon the level of benefits, age of purchaser, and risk factors, such as smoking (as well as claims expectations, interest rates, and profit margins). Most long-term care insurance policies are sold with level premiums, i.e., premiums are set to remain the same over time as long as the assumptions used to develop the premiums are borne out. Premiums can range from $274 annually for a four-year policy with no inflation protection that covered nursing home, assisted living and home care and was issued at age 40 to $7,022 per year for a policy with similar benefits, but that includes inflation protection and benefits if the purchaser stops paying premiums (nonforfeiture) issued at age 79 (see **Exhibit 2**).

Exhibit 2
Average Annual Premiums for Leading Long Term Care Insurance Sellers in 1997

Age	Base	With 5% Compounded Inflation (IP)	With a Nonforfeiture Benefit (NFB)	With Inflation Protection and Nonforfeiture
40	$274	$595	$357	$770
50	$385	$888	$485	$1,110
65	$1,007	$1,850	$1,232	$2,305
79	$4,100	$5,880	$4,779	$7,022

Source: Coronel, Susan A., ***Long-Term Care Insurance in 1997-1998***, Health Insurance Association of America, 2000.

Insurers ability to manage filed claims also determines the profitability of the product. Insurers have to balance two costs: 1) the costs associated with determining if someone should receive benefits; and 2) the costs associated with providing benefits to people who may not need or be eligible for them. Insurers will probably want to avoid regularly denying benefits without a thorough in-person review because of the negative word-of-mouth and lawsuits this practice would likely generate. The insurer which can find the most efficient balance between paying for in-depth assessments and paying for inappropriate benefits will have an advantage in the market because of the ability to offer lower premiums.

III. REGULATION

Similar to other insurance products, states regulate and monitor the long-term care insurance market to ensure that companies have sufficient reserves to pay claims in the future (solvency) and that policy provisions and marketing practices are fair (consumer protection). The National Association of Insurance Commissioners (NAIC) recommends specific regulatory provisions related to all forms of insurance for state adoption.

State adoption of NAIC provisions for long-term care insurance has been inconsistent. All states and the District of Columbia have instituted, or in the case of DC initiated the process of instituting, long term care insurance regulations. However, members of Congress and others have criticized states for failing to institute the most recent provisions of the NAIC long-term care model act and regulation.

While the NAIC model has strongly influenced states' long-term care insurance regulations, a significant number of the provisions have not been adopted by many or most states. The NAIC long-term care regulations have changed frequently since they were introduced in 1986 and adherence to the NAIC models by states is voluntary. More states have adopted NAIC provisions related to benefit requirements and limits on policy restrictions than those related to marketing and business practices. Some noncompliance is attributable to lag time between NAIC adoption of a provision and state adoption due to the nature of legislative cycles. So many differing regulations increases the burden on insurance companies that operate nationally and can be particularly problematic for large employers considering the product.

In addition, while not a regulation, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 defined qualified plans for the purpose of tax deductibility, including an eligibility trigger floor to control the tax revenue loss associated with this provision and refers to 1993 NAIC model regulations related to consumer protection. Consequently, although HIPAA's benefit triggers are more restrictive than those that the NAIC recommends for long-term care insurance policies, almost all insurers have modified their benefit eligibility requirements to reflect HIPAA's requirements. While HIPPA brought tax deductibility for long term care insurance, it also has burdened insurance companies with inflexible criteria that cannot adapt easily to the continuing innovation of the product.

State insurance departments' available resources and expertise to regulate the long-term care insurance market vary considerably. States generally have ample ability to review whether long-term care insurance policies meet regulatory requirements regarding product features and presentation of materials in outlines of coverage. On the other hand, a lack of resources and the nature of the sales transaction makes it difficult for states to oversee marketing practices. The combination of limited resources and staff expertise in state insurance departments and limited claims experience data in the industry results in states having restricted ability to assess initial premium rate filings and rate increase requests. A recent review of state insurance department capacity and regulations related to rate review found that many states do not use actuaries to review rate submissions and most states do not request the breadth of information necessary to conduct a thorough review of initial

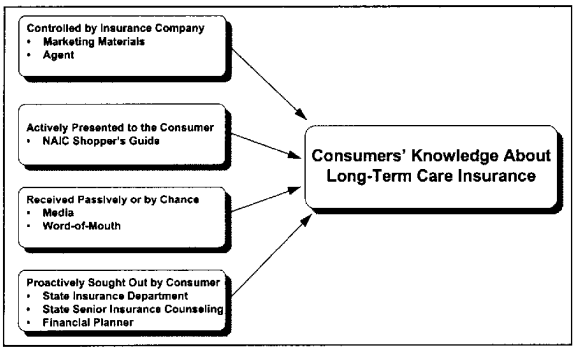
long term care insurance premiums and rate increase requests. Substantial increases in premiums charged by some companies in recent years have raised concern about the stability of long term care insurance premiums and the adequacy of regulatory review.

IV. CONSUMER AWARENESS

Consumers can make informed choices only if they have an understanding of the nature of the risk associated with needing long-term care and the potential for protection from that risk offered by insurance. Consumers must first decide whether purchasing a product is appropriate given their personal circumstances. Many consumer groups and regulators argue that long-term care insurance is not appropriate for certain people and should not be sold to them, particularly those who would quickly qualify for Medicaid if they were to require long-term care services. However, industry representatives contend that the population for whom long-term care insurance is appropriate is unclear and that while some general suitability guidelines may help consumers make an informed choice, anyone should be able to purchase long-term care insurance if they choose to do so. Purchasers of long term care insurance are on average in their late 60s, married, highly educated relative to the general population and have substantial income and assets.[2]

Once a decision on the suitability of purchase has been made, consumers are faced with difficult and confusing choices related to product features. The ability of consumers to compare policies and make informed choices is hampered by: 1) numerous policy options and features; 2) the complexity of the product; 3) the rapid changes occurring in products; and 4) a lack of easy-to-obtain, unbiased sources of information. Currently, insurance agents serve as the primary mechanism for translating arcane language and providing advice on which policy to buy and options to choose (see **Exhibit 3**). Consumer groups question whether agents always have the best interest of the purchaser in mind because they earn commissions.

Exhibit 3:
Sources of Information About Long Term Care Insurance



Source: Lutzky, Steven and Lisa Maria B. Alecxih, "Enabling Informed Consumer Choice in the Long-Term Care Insurance Market," ***Journal of Aging and Social Policy***, vol. 10, no. 3 (1999): pp.27-44.

The regulation of long-term care insurance often requires tradeoffs between protecting consumers and allowing them to make choices. Consumer groups express concern that long-term care insurance is too complicated for the typical consumer too understand and efforts should be directed at making policies easier to compare, such as standardizing definitions and eligibility triggers for benefits. These groups also advocate that certain provisions, such as inflation protection, be included in all long-term care policies. Industry representatives contend that the consumer should be permitted as much freedom as possible in tailoring policies to his or her own circumstances. While most parties generally support improved consumer information and agent education, only selected consumer groups support standardizing policy choices at the national level in a fashion similar to Medicare supplemental insurance.

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[2]Health Insurance Association of America, **Who Buys Long-Term Care Insurance in 2000? A Decade of Study of Buyers and Nonbuyers** prepared by LifePlans Inc., 2000.

V. ADEQUACY OF LONG-TERM CARE INSURANCE PROTECTION

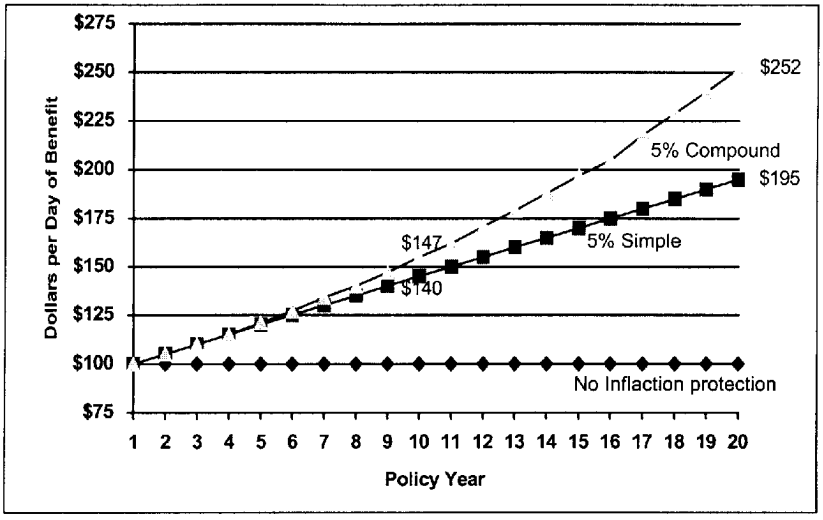
In order for a policy to offer adequate protection against the cost of long-term care four conditions must be met: (1) the person must pay premiums and retain the policy (not lapse); (2) the policy must offer enough benefits to cover a reasonable portion of the costs of long-term care when the person needs it; (3) the person must qualify for benefits under the insurer's criteria when she or he is in need of care; and (4) the long-term care services the person needs must be covered by the policy.

While current long-term care insurance policies appear to offer significantly better coverage than their predecessors, there is still reason to be concerned about the adequacy of the protection this form of insurance offers. Many people will not have protection against the costs of long-term care because they will not have active policies when they need benefits. The limited data available suggests that 30 to 50 percent of all individual purchasers of long-term care insurance lapse within five years. Unfortunately, current data does not allow us to fully understand why people lapse and whether these lapses result mostly from mortality and people upgrading their policies, or whether they reflect people paying premiums for a time and dropping their policies. There are a number of ways that regulatory mechanisms may reduce lapse rates, including consumer education, agent training, limits on commissions, suitability standards, and mandating nonforfeiture benefits. However, some of these mechanisms limit consumers ability to choose which features they want and also can increase price.

To assure adequate protection from the financial risk associated with long-term care, a person must purchase a benefit that provides enough coverage for a long enough period of time to prevent erosion of assets. This level of coverage needs to account for increases in the cost of long-term care. "Adequate coverage" differs depending upon the individual's aversion to risk and willingness to self-insure. While some people look for complete protection against all the costs of long-term care, others would rather keep premiums low by only insuring against catastrophic costs (i.e., an extended stay in a nursing home).

Among those who keep their policies until they need benefits, some may experience substantial out-of-pocket payments because: 1) purchased benefit amounts are lower than typical nursing home costs; and 2) over one-seventh of policyholders who go into a nursing home could be in an institution longer than the duration of their policy. Those who do not purchase inflation protection could have significantly greater out-of-pocket expenses (see **Exhibit 4**).

Exhibit 4:
Comparison of Benefits Offered by Long-Term Care Insurance Policies With No, Simple and Compound Inflation Protection



The benefit triggers a company uses and how it assesses whether an individual meets its criteria will strongly influence whether or when a person receives benefits.

Companies using functional impairment triggers base them almost exclusively on impairment in activities of daily living (ADLs) and cognitive impairment and nearly all policies sold today comply with the HIPAA criteria to be a "qualified" plan. To be qualified, long-term care insurance benefits are only "triggered" when a person needs substantial assistance in performing at least two of six activities of daily living and the assistance is expected to last at least ninety days, or requires substantial supervision resulting from a severe cognitive impairment.[3]

VI. THE FEDERAL OFFERING OF LONG TERM CARE INSURANCE

Employer-based sales can reduce premiums by: 1) marketing to younger purchasers who have lower premiums; 2) reducing administrative costs through reduced marketing (especially no or extremely limited agent commissions); and 3) reducing the potential for adverse selection if sufficient sales are generated. By October of next year, the Office of Personnel Management (OPM) will offer the long term care insurance to approximately 20 million active and retired federal employees, U.S. Postal employees and uniformed services personnel, and their qualified relatives (e.g., spouses, parent and dependents). OPM expects between three and five percent of the potentially eligible to enroll, or 600,000 to one million individuals.

The federal offering will be the largest employer-sponsored offering by over tenfold. Congressional inclusion of long term care insurance in the federal benefit package may encourage other employers to offer the benefit. Like most employer-sponsored products, employees and others will be responsible for the full premium. It is expected that the federal experience may become a standard for other employer-sponsored offerings. OPM is attempting to balance the need to offer a competitive well-designed and adequately priced product with the desire to be inclusive of individuals with existing disabilities and explore innovative benefit structures.

VII. CONCLUSIONS

In order for long-term care insurance to finance a substantial portion of services in the future, the following conditions need to be met:

- Consumers must realize that they need to protect themselves against the costs associated with long-term care.
- Consumers need to purchase long-term care insurance early enough that they can prefund their care.
- Consumers need to purchase long-term care insurance policies that account for the increased costs of care between when the policy is purchased/and when benefits are needed.
- Consumers must purchase policies that match their needs for protection.
- Premiums cannot increase sharply.
- Insurers should consider the use of benefit triggers for community-based services that are more responsive to the need for care than finite triggers based on having impairment in a particular number of ADLs.
- Policyholders need to be able to adapt their policies to account for changes in their circumstances and the service delivery system.

The federal government has four general directions it can pursue if it wishes to increase the proportion of care for which long-term care insurance pays:

1. The government could do nothing and allow market forces and existing NAIC/state regulation to resolve the obstacles to sales and adequate coverage.
2. The government could intervene to enable more informed consumer choice.
3. The government could intervene to try to encourage the sale of long-term care insurance products.
4. Finally, the government could intervene to try to ensure that products are of high quality.

The particular course chosen will depend upon the philosophy of the decision makers and the value placed on expanding the number of people covered by long-term care insurance relative to the quality of coverage.

The federal government could improve knowledge and information available about long-term care insurance by:

- Providing unbiased, neutral information. HCFA has recently embarked on a Congressionally mandated information campaign about long term care.
- Providing information that actively promotes the purchase of long-term care insurance.

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[3] See 26 U.S.C. §7702B(c)(2)(A)(iii). The law also authorizes a third trigger for a level of disability comparable to the inability to perform two of six activities of daily living. See id. §7702B(c)(2)(A)(ii). However, this standard has been extremely difficult to develop and apply.

- Requiring agents to have a thorough knowledge of the product through licensing and continuing education.

The federal government could improve states' ability to regulate the long-term care insurance market by:

- Increasing states' ability to oversee the long-term care insurance market (e.g., by supplying them with funds to hire an actuary).
- Developing better mechanisms for monitoring rates and marketing practices (e.g., by establishing an acceptable range of rates for products).

The federal government could provide incentives for the purchase of long-term care insurance by:

- **Providing tax breaks to consumers and employers who purchase long-term care insurance**—Tax incentives would have the effect of lowering the price consumers face for policies. Tax incentives could: 1) reduce the imbalance in tax treatment relative to acute care benefits; 2) possibly increase sales through the employer market; and 3) theoretically reduce Medicaid expenditures. In addition, tax incentives could increase sales by sending a signal that long-term care is the individual's responsibility. However, sales may not increase substantially because consumers who would benefit from tax breaks would likely have purchased a policy without the incentive. Moreover, the revenue loss from these tax deductions would likely exceed any Medicaid savings because tax incentives benefit those with moderate to high income and those likely to need Medicaid generally cannot afford long term care insurance.
- **Developing and expanding public-private partnerships designed to provide easier access to Medicaid benefits for consumers who purchase long-term care insurance**—The most extensive current initiative is the Robert Wood Johnson (RWJ) Foundation's Public/Private Partnership for Long-Term Care Insurance. These programs allow individuals who buy certified long-term care insurance policies to become Medicaid eligible while keeping more of their assets than normally allowed. Four states currently run these programs and one more is developing a program. While the RWJ Partnership polices have had little direct effect on increasing long-term care insurance sales, they may have had an indirect effect of increasing the public's awareness of the need to protect against the costs associated with long-term care and improving the quality of policies.
- **Tightening Medicaid eligibility requirements**—More people may be induced to buy long-term care insurance if they view Medicaid as less of an option for paying their long-term care costs. However, making eligibility criteria more stringent may expose more people to poverty and tightening Medicaid estate planning requirements appears to have had little, if any, impact on the sale of long-term care insurance.

The federal government could provide standards and regulations for long-term care insurance by:

- Offering a seal of approval for policies that have certain features. The federal seal of approval could be made more attractive by tying it to tax incentives.
- Developing standard definitions and benefit triggers to be used in all policies.
- Requiring the inclusion of certain features (e.g. nonforfeiture, inflation protection) in all policies.
- Standardizing policies and allowing only a limited number of types to be offered, similar to the Medicare supplemental insurance market.

In conclusion, long-term care insurance appears to be headed towards providing high quality coverage to a limited, but potentially growing, number of people who can afford the premiums and are knowledgeable enough to purchase a good product. Another group of individuals will buy products that provide only limited coverage that may not defray large portions of the costs of long-term care. Even with full government support, private long-term care insurance is not likely to provide coverage to most people needing long-term care. However, government intervention may be able to significantly enable informed consumer choice, ensure the purchase of high quality products, and increase the number of people purchasing products.

PREPARED STATEMENT OF GAIL GIBSON HUNT

Mr. Chairman and members of the committee:

Thank you for the opportunity to speak to you today. My name is Gail Gibson Hunt, the Executive Director of the National Alliance for Caregiving, a nonprofit coalition of 25 national organizations that have come together around the issues of family caregiving. The Alliance conducts research, develops national programs to

support family caregivers and the professionals who work with them, and works to increase public awareness of caregiver needs and concerns.

THE DEMOGRAPHICS OF FAMILY CAREGIVING

Dimensions of the Issue

According to the 1997 national caregiver survey by the National Alliance for Caregiving and AARP, 22.4 million US households—nearly one-quarter—contain someone 18 or older who is caring for a family member, friend or neighbor who is 50 or older (the definition we used for caregiver).

What is the national profile of the family caregiver of an older person: a 46-year-old baby boomer woman who works full-time and cares for her 77-year-old mother who has a chronic illness and lives nearby. The caregiver spends an average of 18 hours per week caring for her mother and, on average, will spend four-and-a-half years doing so. The MetLife Juggling Act study showed that people's expectations of how long they would be responsible for someone significantly underestimated how long they actually spent. For example, those who thought that they might only have to be caregivers for six months or so, say after a relative's hospitalization and convalescence, found themselves caregiving for a year or more. Those who expected to do these tasks for a year or two ended up doing them for four or more years Also keep in mind that nearly one-third of caregivers take care of two or more people over a "caregiving career."

The average annual income of the caregiver is roughly equal to Americans as a whole: $35,000. Forty-one percent also have children under 18 living at home.

What formal, paid services do caregivers use most for their relative or friend:

	Percent
Personal and nursing care	38
Home modifications	28
Meals-on-wheels	16
Assistance with housework	16

When asked what services they would like to have had available to help with caregiving, caregivers in the national survey responded 1) they "don't know" what would have helped (38%) or "nothing" (18.5%); and 2) they would like "free time/time for oneself" (17%). These responses indicate a lack of knowledge of what existing and available services can do for them (that is, they recognize services by name but do not know how the services can help), together with the clear need for some time off.

In addition, when asked in another survey what information they want most, caregivers ask for information on how to deal with stress, how to find and evaluate good quality home care, and how to balance the demands of work and caregiving. Caregivers also cited the need for practical, hands-on training in their everyday tasks—bathing, transferring from bed to chair, nutrition, etc.

Caregiving and Money

In 1998, the United Hospital Fund conducted an analysis that estimated the value of caregiving to society at $196 billion per year—which is more than the value of in-home care and nursing home care combined. Without family caregivers, the long-term care system would bankrupt the country—especially as the Baby Boomers age.

As for caregivers themselves, they spend on average $171 per month out-of-pocket for groceries, medications, home modifications, etc. The major expenses: food, transportation, medications, utilities, medical care and in-home care for the care recipient. This conservative amount is roughly equivalent to an IRA that the caregiver might otherwise be able to save for his or her retirement. The Juggling Act study of working caregivers calculated that, over a "lifetime" of intense caregiving, this out-of-pocket amount could average nearly $20,000. Yet it is important to keep in mind that only a small percentage of caregivers (between 7–20%, depending upon the study) complain that caregiving represents a financial hardship.

Interestingly, in another study, half of caregivers report feeling financially unprepared for their own long term care. Caregivers more than most people are aware of the tremendous financial drain that long-term care can have on a family.

Caregiving and Work

Three-quarters of caregivers work full or part-time, and 54% of those who work are making work-related adjustments—an important factor because of the implications for productivity. Those workplace accommodations break out as follows:

	Percent
Go in late, leave early, time off during work	49
Leave of absence	11

	Percent
Dropped back to part-time, less demanding job	7
Lost job benefits	4
Turned down promotion	3
Chose early retirement	4
Give up work entirely	6

In the MetLife Study of the cost of caregiving to US employers, the estimate of annual cost in terms of lost productivity is between $11.4 to $29 billion per year. The lower figure counts caregivers who work full-time, live nearby their relative and perform personal care tasks (e.g., bathing , dressing, feeding, etc.) The $29 billion per year includes caregivers who work part-time, do long-distance caregiving, and who also perform less intensive Instrumental Activities of Daily Living (e.g., managing finances, providing transportation to doctor's appointments, shopping for groceries).

The chances of a caregiver's having to make the types of workplace accommodations listed above increase if the following risk factors are in place: the caregiver helps with two or more personal care activities, resides together with the care recipient, is the primary caregiver, or if the care recipient has Alzheimer's.

Beyond the cost to employers, the total cost to working caregivers over their caregiving and work career was documented in the Juggling Act study at nearly $660,000. This figure is comprised of:

	Dollars
Negative impact on Social Security	25,494
Pension lost	67,202
Wages lost	566,443
Total Wealth Lost	659,139

Caregiving and Health

There are many well-documented studies of the impact of caregiving on the caregiver's health, especially where the caregiver is older and frailer to begin with or where the care recipient has Alzheimer's. In broad-based surveys of caregiving, such as the national caregiver survey, only about 15% of caregivers say they've actually experienced physical or mental health problems as a result of caregiving. About one-quarter of caregivers say that they find caregiving as emotionally stressful, although that percentage goes up considerably as factors such as co-residence, amount of time spent caregiving, and Alzheimer's caregiving increase.

Almost three-quarters of working caregivers doing the more intense, personal care say that it has somewhat or a lot of negative impact on their health. Of these caregivers, half cited making additional visits to their physician as a result, which can translate into higher health care costs for themselves and their employer. In addition, 40% of working caregivers doing the more intense personal care tasks believe that their ability to work productively and to continue to work was affected by their caregiving-related health problems.

PREPARED STATEMENT OF BILL KAYS

Thank you Chairman Grassley and members of the Committee:

It is a true honor to have the opportunity to address you today. I was quite surprised when I received the invitation to testify. However, I have to say that the greatest surprise I have ever had was when I was told ten years ago that my beautiful 60 year old wife, Pearl, had Alzheimer's disease. Her diagnosis came just one year after I had retired from Bell Atlantic with great expectations of travel and all the other wonderful plans we had postponed and saved for our entire married life. It was now too late for any of those plans.

When Pearl was diagnosed, I didn't know how to spell Alzheimer's but I quickly learned that there was no cure, effective treatment or prevention for it. I was devastated.

I cared for Pearl at home alone for six years because I didn't want to interfere with the lives of my children and their careers. I joined an Alzheimer's support group, thank goodness, and they told me that I should start looking for someplace to put Pearl because it was never going to get any better. I put her in day care so that she could get the benefit of a therapeutic program, and so I could have some respite and could start looking at different places and facilities. The day care cost me about $1,000 a month. At the time, it seemed like a huge expense. But I didn't know how lucky I was to have that option.

Senators, when I started visiting homes where Pearl could be cared for properly, that's when the real shock came. When I found that it would cost between $4,000

to $6,000 per month to keep Pearl in a long term care home, I nearly fainted. You see, Pearl needed help with everything at that point—bathing, feeding, dressing and toileting. She would wander away if you took your eyes off her. The title of the Alzheimer's book, "The 36-Hour Day," couldn't be more accurate. A caregiver's day seems that long.

I had to do something. I was running out of time and choices because Pearl's needs were increasing. After a lengthy search, I finally found a place. It was 57 miles away from our home but it was perfect for Pearl. It is called Royal Haven, Inc. and it is in Front Royal, Virginia. The cost was much more reasonable than anything in the Northern Virginia area and the care matched exactly what Pearl needed.

Pearl went to live at Royal Haven four years ago and it was without a doubt the most difficult decision I have ever made. Three months after she moved there I had a heart attack and quadruple bypass surgery. My doctor told me that the heart attack was caused by all of the stress I endured as a caregiver.

Senators, I am one of the lucky ones. Pearl and I had saved and planned and put off a lot of expenses until my retirement. It is true that we never got to spend it as we had hoped but now we are just barely able to afford her care. Medicare doesn't cover the cost of the home and we're above the Medicaid level. We have no long term care insurance and my pension doesn't have a cost of living (COLA) adjustment each year like many retirees. My out-of-pocket expenses are running over $25,000 per year, not counting the cost of gas to go visit her twice a week.

I often think about the folks who are less fortunate than I am. I have met many who have had to spend themselves into poverty in order to qualify for Medicaid. My heart goes out to them.

Senators, as you know, the situation is getting worse. The fastest growing population is the group over 65 and they are the ones who will need help. I just read in the *Fauquier Democrat* up in Warrenton where Pearl and I grew up together that according to the 2000 Census, the total population of the county went up by 13 percent but the over 65 population went up by 40 percent. I realize that I am preaching to the converted but as the baby boomers reach their golden years the problem is going to skyrocket.

I would like to thank Chairman Grassley, Senator Graham and others for their proposal for a $3,000 caregiver tax credit. It would be a tremendous help but it will not begin to cover the cost of care for Pearl and me and millions like us. It is certainly true that we all have to take some responsibility for our care. And the proposed tax incentive for long term care insurance will help some people make better plans for the future.

But the problem cannot be fixed by long term care insurance alone. When Pearl and I were planning for our retirement, long term care insurance really wasn't available. Lord knows, I wish it had been. But even if I had bought a policy, we would have exhausted the benefits by now because of the length of Pearl's illness. Every once in awhile I'll get a telephone call at home from someone who wants to sell me a long term care insurance policy. When I tell them that I am 69 years old, that I have a heart condition and that my wife has Alzheimer's disease and is in a nursing home, the callers quickly hang up.

Senators, I ask that you and your colleagues walk in our shoes for just a short distance. I pray that you will give favorable consideration to the proposed tax credit. But we are going to have to do a lot more to make sure that a family that is unlucky enough to get hit with something like Alzheimer's disease is not financially devastated. We have to develop a better combination of public and private insurance that will fairly share the risk of long term care and will meet everyone's needs in a way that families and the nation can afford.

Before I close, I want to remind you that long term care is about more than just helping families pay for care. It is about assuring the quality of that care. And the biggest single factor that determines quality is staffing. Pearl is getting wonderful care at Royal Haven because the staff is great, and they have been there a long time. But I know from people in my support group, and from what I read in the papers, that this is not always the case.

Taking care of a person is some of the hardest and most important work we ask people to do. We need to recognize them for that work, pay them enough to support their own families, give them a manageable work load, and make sure they have the training it takes to understand how to care for a person with dementia.

Senator Grassley, on behalf of Pearl and every other person who needs long term care, thank you for all that you are doing to improve staffing and quality. Thank you, for your efforts to help ease the financial burden of long term care. And thank

you for holding this hearing to remind your colleagues and the country of this urgent national problem.

PREPARED STATEMENT OF STEVEN LUTZKY

My name is Steven Lutzky and I am the Chief of the Office on Disabilities and Aging within the Medical Assistance Administration in the DC Department of Health. My office oversees programs serving older adults, younger adults with physical disabilities, individuals with mental retardation and developmental disabilities, and individual with HIV/AIDS. Prior to joining the DC government, I reviewed model long-term care programs for clients including the Department of Health and Human Services. I also facilitated strategic planning in the area of long-term care for states and private sector organizations.

How states design their delivery systems plays the central role in shaping long-term care in the United States because the majority of people needing paid long-term care services rely on states to fund the services they need. For example, state Medicaid programs funded care for approximately one million of the 1.5 million nursing facility residents in 1999.[1] States have recognized this responsibility and have been taking advantage of increasing flexibility given by the federal government to try to develop cost-effective care delivery systems that better serve our citizens.

States have had the twin concerns of controlling costs, while providing services that meet our citizens' needs. In the past, these concerns have often been at odds. States have resisted expanding services designed to keep people in the community, such as personal care, adult day care, and assisted living, because they feared that these services would be so desirable that demand and costs would escalate dramatically. To quell these concerns, states placed limits on the number of people who could receive these services, the amount they could receive, and tried to keep reimbursement as low as possible.

However, states that have lead the way in expanding access to home and community-based services (HCBS), such as Oregon and Washington, have not experienced run away costs. In fact, at least one study suggests that expanding HCBS may produce modest overall savings.[2]

In the District of Columbia, we are adapting best practices we have observed in model states to design a cost-effective system that will not only enhance the lives of some of our most vulnerable citizens, but could help us improve the fabric of our community. These model states have designed their programs to support individuals and families rather than replacing them. I would like to briefly describe the key lessons that we have learned.

MAXIMIZING THE LIKELIHOOD THAT HCBS WILL SERVE INDIVIDUALS WHO WOULD OTHERWISE BE IN AN INSTITUTION

To be cost-effective, a system must maximize the likelihood that HCBS will serve individuals who would otherwise be in an institution. First, the program must ensure that accessing HCBS is as easy as accessing an institution. By the time families and individuals get to the point that they seek out assistance, they are often in a caregiving crisis that must be resolved quickly. Waiting lists that take years and authorization processes that take months act to force institutionalization on individuals who cannot wait for assistance. The District is addressing this issue by following the lead of other HCBS Medicaid waiver programs that do not have wait lists and have sped up their eligibility determination process.

Second, individuals must be directed to services that can provide alternatives to institutions. In the District, we are following the lead of states like Wisconsin by building a Resource Center that will empower consumers to make informed choices about long-term care. The Resource Center will receive mandatory referrals from all major pathways to institutionalization (e.g., applicants to nursing facilities, home health agencies, hospitals, etc.). The Resource Center then offers individual counseling about options for receiving long-term care and will quickly determine eligibility for publicly-funded programs. The Resource Center can save money by (1) diverting individuals not eligible for Medicaid to less expensive settings (e.g., from nursing facility to assisted living or their own home) thereby delaying their spend-

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[1] AARP (2000). *Across the States 2000: Profiles of Long-Term Care Systems*. Washington, DC: AARP.

[2] Alecxih, L.M.B., Lutzky, S., and Corea, J. (1996). *Estimated Cost Savings From the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States*. Washington, D.C.: American Association of Retired Persons, Public Policy Institute.

ing down to Medicaid eligibility and (2) placing individuals eligible for Medicaid in the most cost-effective setting appropriate to their needs.

ENSURING THAT HCBS IS COST-EFFECTIVE

Once the District increases access to HCBS, it must design reimbursement and create infrastructure so that services are provided in a cost-effective manner and quality is carefully monitored. Other states experience suggests that to achieve this goal, the District must increase both flexibility and the ability to carefully monitor costs and quality. The District is working to achieve this goal by: (1) incorporating managed care principles; (2) broadening the range of HCBS services to add more flexible and potentially cost-saving services; (3) implementing information technology that will facilitate the delivery of care and monitoring cost and quality; and (4) adopting outcome-based measures of quality.

Incorporating managed care principles. Current financing for HCBS in most states contains very crude cost-control mechanisms that create the incentive to maximize covered services regardless of whether they best meet the needs of an individual. Managed care payment mechanisms, such as capitated payments or other incentives for providing care cost-effectively, can act to move the decisions about how care is made from the state closer to the actual delivery of care. The goal of adopting managed care mechanisms is to shift the decision of how best to use limited resources from a distant state representative to care managers and the individual and his or her family. The District is carefully watching the experience of demonstrations, such as Texas Star+Plus, Minnesota Senior Health Options, and the Wisconsin Partnership and Family Care programs to determine which reimbursement structure makes sense for the District. Issues to be decided include which services will be included, to what extent risk will be shared among providers and the District, and which community organizations in the District will assume risk.

Broadening the range of HCBS services to add more flexible and potentially cost-saving services. The increased flexibility offered by managed care payment arrangements must be accompanied by a corresponding increase in the flexibility of services that are offered. In the District, we are working to broaden HCBS available by creating financing for new services, such as consumer-directed attendant care and assisted living facilities. The District currently only offers personal care offered through an agency. This type of care, while appropriate for some, may be costly because of the agencies' administrative costs and other requirements, such as mandating that a visit must be a minimum of four hours. The District is looking to follow the lead of other states, such as Washington, and offer direct payments to individuals. For example, an individual with paraplegia may require assistance for a brief period of time in the morning, noon, afternoon and before bedtime. The District may have to pay for up to sixteen hours of care to induce an agency with a four-hour mandatory minimum to provide services. Under an attendant care program, the District could pay a neighbor who has been trained to provide care for only four hours and with lower administrative costs.

Residential alternatives to nursing facilities, such as assisted living facilities have been key to other states' efforts to reduce the use of nursing facilities. States like Oregon and Washington have demonstrated that these services can improve quality of life, while controlling costs.

Implementing information technology that will facilitate the delivery of care and monitoring cost and quality. The District recognizes that offering capitated payments and increasing flexibility also increases opportunity for providers to limit or provide low quality services. Therefore, we are building infrastructure necessary to more carefully monitor costs and quality. The District has included funds in its 2002 budget to develop a long-term care information technology system. Newly available internet-based technology can help improve the quality of care, as well as the ability to monitor and control costs and meet necessary federal reporting requirements. This system will be vital to providing case managers with the flexibility to provide services in cost-effective ways, while providing the District with the ability to continually monitor cost and quality. Providers in Texas, Arizona, and Connecticut are currently using these systems.

Adopting outcome-based measures of quality. The District is also planning on adopting outcome-based measures of quality. Monitoring quality in HCBS requires vastly different tools than those used for institutional providers. Licensing mechanisms that the District currently uses add significantly to the cost of care and often impair quality of life. Under the redesigned system, the District would join other states that assess outcome-based measures of quality. The District hopes to

improve the ability of this effort to affect quality by tying these outcomes directly to reimbursement.

I would like to take the remaining time that I have to first thank Congress and the federal government for the freedom and support necessary to develop these new programs; 1915(c) HCBS waivers, enhanced matches and other provisions have played a crucial role in transforming long-term care delivery systems. These programs have allowed individuals who felt helpless to feel in control over their destiny. They have made individuals and their families stronger.

I have been very encouraged by what I have seen thus far from the Bush Administration. The District plans on taking advantage of the opportunities offered under the President's New Freedom Initiative. Secretary Thompson of the Department of Health and Human Services understands what states are trying to achieve. In fact, many of the aspects of the District's proposed redesign are based on programs initiated under then Governor Thompson's watch in Wisconsin.

I would like to briefly mention some barriers that must be overcome in the years ahead. First, states need more latitude in blending Medicare dollars with Medicaid dollars. Many individuals in the populations we serve are eligible for both programs, and it is difficult to create financial incentives for coordination if we can only influence one funding stream. Second, we need the Health Care Financing Administration (HCFA) to view the states as partners. If a state is doing something innovative or there are concerns regarding quality, consider having HCFA detail someone to work with the state rather relying on the often endless process of requests for additional information. Third, consider mechanisms that will allow us to broaden the population we serve. Current requirements for HCBS waivers make it difficult to intervene earlier and prevent individuals with predisposing conditions from progressing to more severe and costly disabilities.

Thank you very much for allowing me to have the opportunity to testify.

PREPARED STATEMENT OF CAROL O'SHAUGHNESSY

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, and the role of families and federal programs in providing care.

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 insurance policies, a limited but growing market, also use ADL limitations to trigger payment of benefits.

Long-term care services include a continuum of health and social services, ranging from care in nursing homes (which averages over $40,000 per year) to care at home through home health and homemaker services, and services in the community, such as adult day care. Long-term care may also be provided 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 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

[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-

Continued

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.

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.

About one quarter of adults of all ages who receive care at home and through 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, about half of adults of all ages who receive assistance in the community 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 person age 85 and older receive long-term care assistance, either in community settings or in nursing homes, compared to only 12% 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**)

Future Demand. 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. Estimates show that the number of elderly persons alone who need long-term care assistance could grow by 24% over the next 20 years, and by 75% over the next 40 years. (**Chart 2**)

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 may also grow due to the recent Supreme Court decision in *Olmstead v. L.C.* and advocacy efforts of younger persons with disabilities.[2]

Over the last decade, national research on the long-term care population has documented a rather marked increase in the disability levels of persons who receive help. Increases in disability levels have been noted among those who receive assistance at home and through community services, but especially among nursing home residents. Over 80% of nursing home residents have severe impairments, needing assistance with three or more activities of daily living. These trends have implications for caring for very disabled family members at home, as well as for demands on the home care and nursing home workforce.

THE ROLE OF FEDERAL PROGRAMS AND FAMILIES

National Spending. 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 3**)

Of total national spending on long-term care, Medicaid and out-of-pocket spending represented 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 represented about 10% of the total. (**Chart 4**)

Role of Families and Informal Supports. Despite substantial public spending for long-term care, families provide the majority of long-term care services. About 37 million caregivers provide informal, or unpaid care to family members of all ages. Typically, this care is provided by adult children to elderly parents and by spouses to one another.

Term Care, Institute on Medicine, by William D. Spector, et.al., 1998. These surveys contain the most recent national data on long-term care.

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.

[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.

The role of families and other informal caregivers is considerable. Almost 60% of the functionally impaired elderly, and nearly three-quarters of adults under age 65, receiving care rely *exclusively* on informal, unpaid assistance. (**Chart 5** displays caregiver patterns for persons 65 and older.) 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.[3] Some estimates have placed the economic value of caregiving even higher.[4]

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 long-term care services. None focus exclusively on long-term care. Eligibility requirements, services authorized, and administrative structures vary among the programs, making coordination difficult. (**Chart 6**)

- *Medicaid* provides coverage for nursing home care and 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.
- *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 full-time 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 federal 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; and various targeted state grant programs such as *Public Health Service* demonstration grants to develop model services programs for persons with Alzheimer's disease. The *Department of Veterans Affairs (DVA)* provides a wide range of long-term care to the Nation's veterans, including nursing home, domiciliary, home health care, and assistance to caregivers.

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.

The Heavy Reliance on Medicaid. While only a small proportion of those receiving long-term care services reside in nursing homes, public spending for nursing home care, primarily through Medicaid, is disproportionately high. Of total Medicaid spending on long-term care in FY1998 ($61.9 billion), almost three-quarters was for nursing home care and care in intermediate care facilities for the mentally retarded; about one-quarter was for home- and community-based care. (**Chart 7**)

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[3] 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.

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

Although nursing home care still dominates Medicaid spending, a shift toward home and community-based care has occurred over the last decade primarily as a result of states' initiatives to provide these services under waiver authority granted by the Department of Health and Human Services under Section 1915(c) of the Medicaid statute. 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 nursing home care.[5] Also, nursing home spending has decreased as a share of total long-term care spending and of total Medicaid spending over the same period.[6]

Many states consider their Medicaid home and community-based waiver programs as key components in developing long-term care systems. Despite its rapid growth, however, many analysts consider these 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.

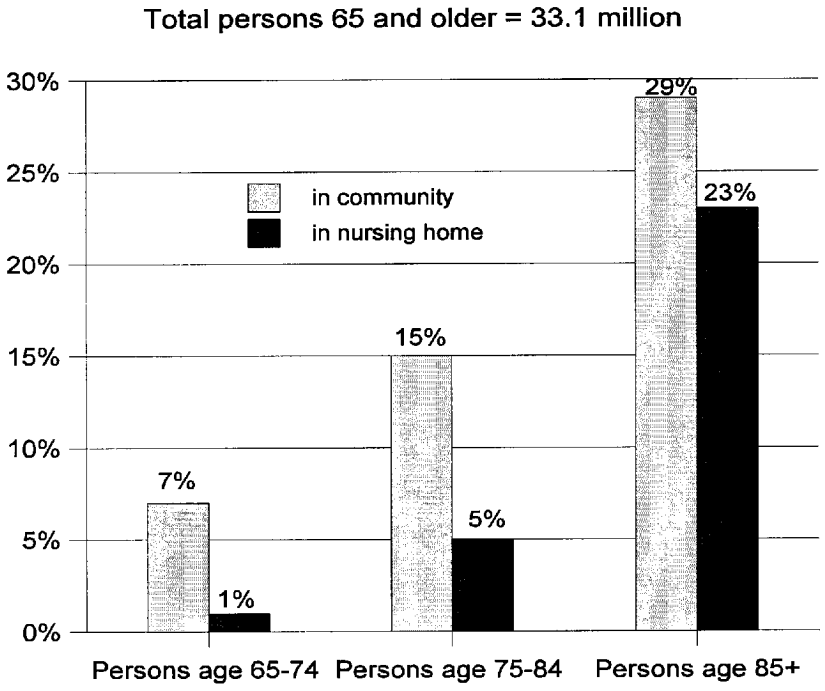
FUTURE DIRECTIONS

Congress has chosen an incremental approach to changing the federal role in long-term care. Proposals have included both incremental and large scale approaches. Among the proposals advanced are tax credits for persons with long-term care needs, incentives for private financing through tax deductions for the costs of long-term care insurance, an additional personal exemption for caregivers, and combinations of these. Other broad approaches have included proposals for large scale grants for home and community-based care, social insurance coverage for long-term care costs, as well as expansion of current home and community-based services to cover the entire population in need. A significant challenge for policymakers is to reconcile the concerns about the costs of these proposals as well as the relative roles of the public and private sectors.

[5] Spending for home and community-based care increased by more than 280% from $4.1 billion in FY1990 to $15.7 billion in FY1998, while spending for nursing home and ICF/MR care increased by 70%, from $26.0 billion to $44.3 billion.

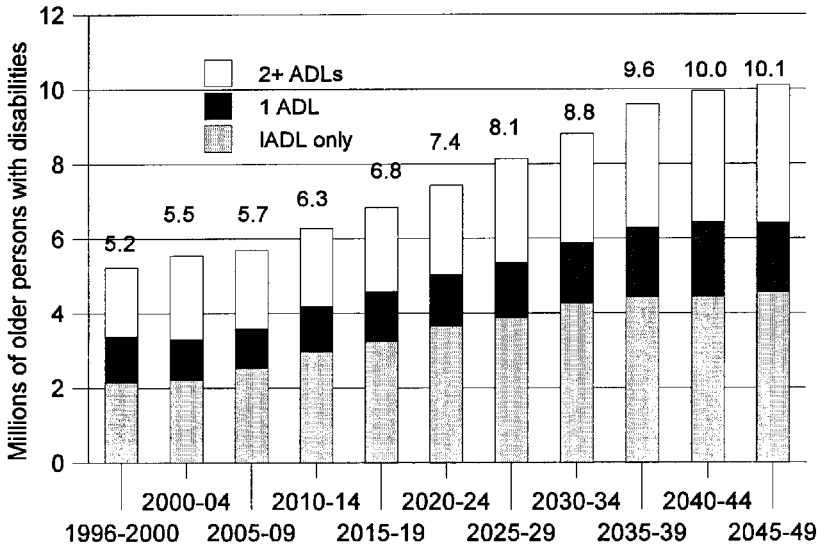
[6] Medicaid nursing home spending declined from 61% to 56% of Medicaid long-term care spending from 1990 to 1998. As a percent of total Medicaid spending it declined from 86% to 71%.

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.

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

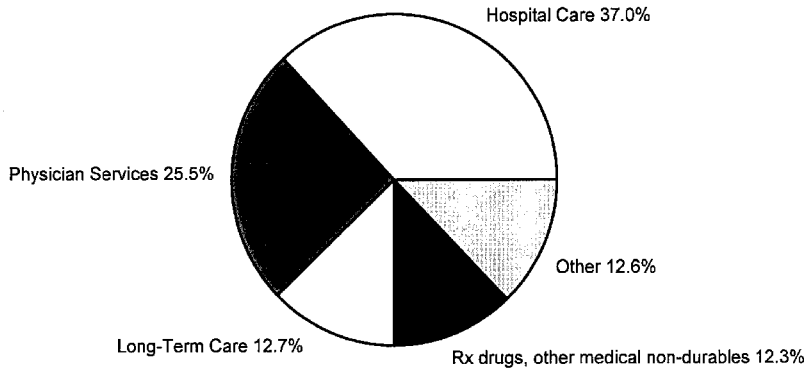


Source: *The Long-Term Care Financing Model.* Prepared by the Levin Group, Inc. for DHHS, 2000. The projected number of older persons with disabilities represents the average for each time period.

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

Chart 3. Long-Term Care Spending as a Share of Total Personal Health Care Spending for All Ages, 1999

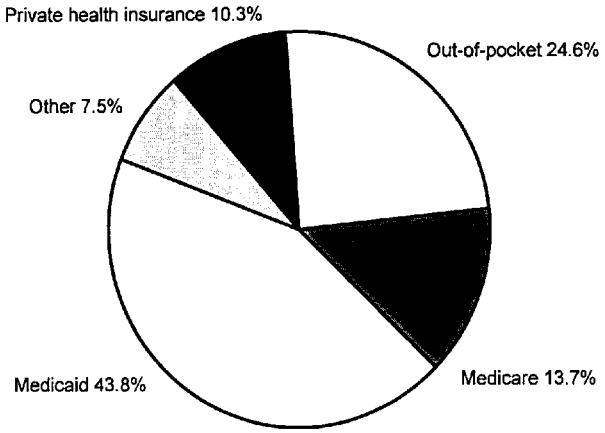
Total personal health care spending = $1.06 trillion



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

Chart 4. Sources of Long-Term Care Funding, 1999

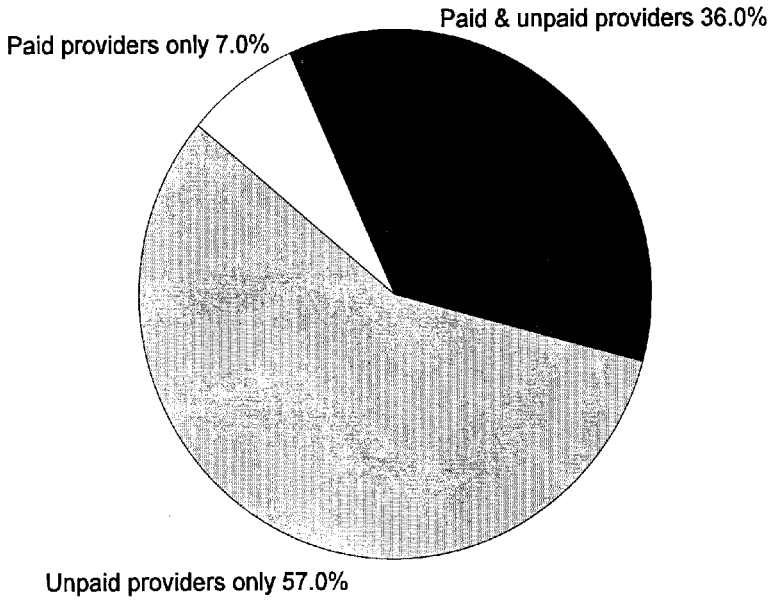
Total long-term care spending = $133.8 billion



Source: Health Care Financing Administration, Office of the Actuary, National Health Statistics Group.
Note: Percentages do not sum to 100% due to rounding. Medicaid includes expenditures for nursing homes, ICFs-MR, home health, and home and community-based waiver services.

Chart 5. Percent of Persons Age 65 and Older Receiving Long-Term Care Assistance in the Community, 1994

Persons age 65+ receiving assistance in the community = 3.9 million



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.

Chart 6. 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

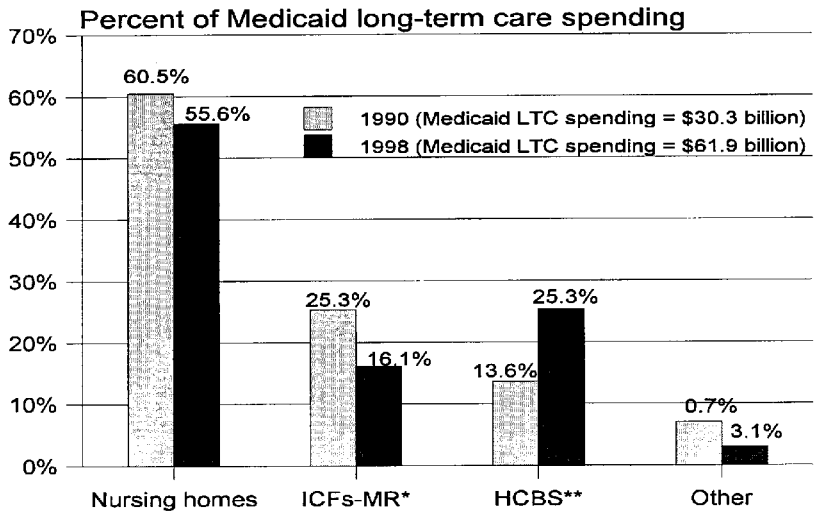
Supplemental Security Income (SSI) State Supplemental Program
- *Eligibility*: Children and adults who are blind, disabled, and/or age 65 and older who meet state income and asset tests
- *Services*: Cash payments may be used by beneficiaries for home and community care
- *Administration*: State

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 income other factors
- *Services*: A range of institutional, residential, and supportive services
- *Administration*: Federal

Chart 7. Medicaid Spending for Long-Term Care, 1990 and 1998



Source: Urban Institute, based on data from HCFA-64 reports.
Note: Percentages do not sum to 100% due to rounding.
*Intermediate care facilities for the mentally retarded.
**Home and Community-Based Services.

Note: *See also,* "Long-Term Care Chart Book: Persons Served, Payors, and Spending," study prepared by The Urban Institute in collaboration with the Congressional Research Service (CRS), May 5, 2000.

PREPARED STATEMENT OF HON. JOHN D. ROCKEFELLER IV

Mr. Chairman, thank you for calling this hearing. It's a wonderful opportunity for all of us to reignite the torch on the issue of long-term care. It's been a decade since the Bipartisan Commission on Comprehensive Health Care, known as the Pepper Commission, sent its "Call to Action" to Congress. Since that time, incremental changes have been made to encourage both creative new programs and private coverage.

Still, many of those in need of long-term care and their caregivers are facing tremendous challenges in receiving and paying for needed services. People are forced to deplete their life savings on the private cost of long-term care before they can be eligible for Medicaid-financed long-term care. Because the elderly exhaust their personal resources, in many cases they are financially unable to return home even when their physical conditions allow it.

We also know with great certainty that providing long-term care to a large group of baby boomers will be our greatest challenge in the immediate future. We clearly have a national imperative, and in my own State the need is even more pressing. West Virginia is projected to have the second highest proportion of elderly by 2025. And right now for the second year in a row, residents in my State were the country's oldest. While the West Virginia Medicaid waiver program provides needed non-nursing home services to more than 4,000 individuals each year, the unmet need is tremendously high.

There are few issues that are as challenging as providing a solution for the long-term care problem. I learned this lesson from Chairing the Pepper Commission. The recommendations of the Commission received significant bipartisan support, but died in Congress.

The underlying tenet of the recommendations was that all people with severe disabilities—no matter their age—should receive either home care or nursing home

care from the Medicare program. Yes, cost-sharing was a part of the proposal, as were limitations on nursing home care, but a goal of the recommendations was to provide a measure of estate protection. This sounds strikingly similar to recent proposals to abolish the estate tax.

I note that Citizens for Long-Term Care—led by a former Member of this Committee and the Pepper Commission, Senator David Durenberger—has recently released a set of principles agreed upon by many providers, caregivers, and insurers. Some of the basic concepts of the Pepper Commission are embodied in the report, and I look forward to working on new solutions with this organization.

While the issue of long-term care coverage frequently seems insurmountable, we've already made great progress for those veterans who receive care from the Department of Veterans Affairs. In VA, the demand for long-term care is even more pressing, as about 35 percent of the veteran population is 65 years or older. Following legislation I helped pass in 1999, all veterans enrolled with the VA health care system can now expect a standard benefit package which includes comprehensive noninstitutional long-term care services. Coverage for nursing home care is provided for our most seriously disabled veterans. New long-term care copayments for services exceeding 21 days in any year were implemented as a way to offset the costs. We took an important step forward for our veterans, and I am hopeful that it signals a new concern for providing long-term care for all elderly Americans.

There are few issues that are as challenging as providing a solution for meeting the long-term care needs of our society. We face a tremendous challenge to address this issue and address it in a way that really makes a difference for those who need long-term care.

Will Congress muster the will to do something to solve the problem? With the budget surplus in mind, now is exactly the time to look at how we can address long-term care reforms. However, a massive tax cut targeted to the wealthiest Americans precludes any meaningful chance of making progress on long-term care.

PREAPRED STATEMENT OF WILLIAM J. SCANLON

Chairman Grassley, Ranking Member Baucus, and Members of the Committee:

I am pleased to be here today as you discuss the challenges we as a society face in financing long-term care needs. These challenges are formidable already, as an estimated 9 million persons age 18 or older receive long-term care assistance, either at home or in institutions such as nursing homes. While family members provide much care, paying for purchased services presents a significant financial burden for many individuals and for public health care programs. For those needing nursing home or other extensive continuous care, the costs can be substantial. On average, nursing home care currently costs $55,000 annually, with many nursing home residents paying much of that out of their own pockets.

Providing and financing long-term care will become even more challenging in just over a decade when the 76 million baby boomers begin to turn 65. Over the next 30 years, the number of elderly individuals is expected to double. Moreover, with baby boomers expected to live longer and greater numbers reaching age 85 and older, this generation is expected to have a dramatic effect on the number of people needing long-term care services, as the prevalence of disabilities and dependencies increases with age. To help alleviate the pressures on public programs and families in meeting the needs of these persons, some advocate a growing role for private long-term care insurance. Several recent congressional initiatives aim to increase the use of private insurance in financing long-term care needs. These initiatives include establishing a program to make group long-term care insurance available to federal employees, members of the uniformed services, and civilian and military retirees; and proposals to provide additional tax subsidies to individuals purchasing long-term care insurance.

In view of these issues, you asked us to provide the Committee information on long-term care insurance to assist you in considering what role it may play in meeting future long-term care needs. Accordingly, my remarks today, which are based on our previous work and other published and ongoing research,[1] focus on (1) the increased demand an aging baby boom generation will likely create for long-term care; (2) an overview of current spending for long-term care, including recent changes in Medicaid and Medicare financing of long-term care; and (3) the potential role of private long-term care insurance in helping finance this care, including who

[1] A list of related GAO products follows this statement.

is likely to buy this insurance, its affordability, and the critical need for consumer protections.

While my focus will be on financing the projected increase in the need for long-term care for the elderly, long-term care needs of younger persons should not be overlooked. Disability and dependency have no age boundaries, and the long-term care needs of the nonelderly and the burden of satisfying them can be profound. How to better meet these needs and distribute the burden deserves our attention. However, the potential for private long-term care insurance to assist those whose disabilities or dependencies begin at younger ages may be very limited.

In summary, the confluence of the aging baby boom generation, longer life expectancies, and evolving options for providing and financing long-term care services will require substantial public and private investment in long-term care and the development of sufficient capacity to serve this growing population. Spending for long-term care, including post-acute and chronic care in nursing homes and home and community-base care, was about $134 billion in 1999. Medicaid and Medicare paid for nearly 58 percent of these services in 1999, contributing about $59 billion and $18 billion, respectively. Medicaid funds primarily go to nursing homes and other institutional settings of long-term care, but home and community-based services receive a growing share. Medicare primarily covers acute-care services and thus plays a lesser role in financing nursing home care-by paying only for short-term stays following a hospitalization. While the Medicare home health benefit had grown to play a significant role in covering long-term care, the new BBA-mandated payment system may reduce the provision of such services. Medicaid, which is a jointly funded federal-state program, poses a large burden on states' budgets, creating pressure on their capacity to absorb additional costs associated with the growing need for long-term care services over the coming decades.

Private long-term care insurance is viewed as a possible way to reduce catastrophic financial risk for the elderly needing long-term care and to relieve some of the financing burden now shouldered by public long-term care programs. Yet private insurance, including both traditional health insurance and long-term care insurance, represents only about 10 percent of long-term care spending—about $14 billion in 1999. Less than 10 percent of the elderly and an even lower percentage of the near-elderly have bought long-term care insurance, although the number of individuals purchasing long-term care insurance increased during the 1990s. Questions remain about the affordability of policies and the value of the coverage relative to the premiums charged, and while many states have adopted standards for long-term care policies, it is uncertain whether these fully assure consumer confidence in the reliability of long-term care insurance. If long-term care insurance is to have a more significant role in addressing the baby boom generation's upcoming chronic health care needs, the policies offered must be viewed by consumers as reliable, affordable products with benefits and limitations that are easy to understand.

BACKGROUND

Long-term care includes many types of services needed when a person has a physical or mental disability. Individuals needing long-term care may have difficulty performing some activities of daily living (ADL) without assistance, such as bathing, dressing, toileting, eating, and moving from one location to another. They may have mental impairments, such as Alzheimer's disease, that necessitate supervision to avoid harm to themselves or others or require assistance with tasks such as taking medications. Although a chronic physical or mental disability may occur at any age, the older an individual becomes, the more likely a disabling condition will develop or worsen. Nearly one-seventh of the nation's current elderly population—an estimated 5.2 million—have a limitation in either ADLs; instrumental activities of daily living (IADL) such as preparing food, doing housekeeping, and handling finances; or both. More than one-third of these people have limitations in two or more ADLs.

Long-term care encompasses a wide array of care settings and services, not only institutional care provided by nursing homes for individuals with more extensive care needs but also home and community-based care. Nearly 80 percent of the elderly requiring assistance with ADLs or IADLs live at home or in community-based settings, while more than 20 percent live in nursing homes or other institutions. The majority of long-term care is provided by unpaid family caregivers to elderly individuals living either in their own homes or with their families. However, a growing minority of the elderly receives paid assistance from various sources. For example, state Medicaid programs have increased significantly the number of beneficiaries receiving in-home or community services. In addition, alternatives to nursing home care, such as assisted-living arrangements, are developing that have long-term care services available.

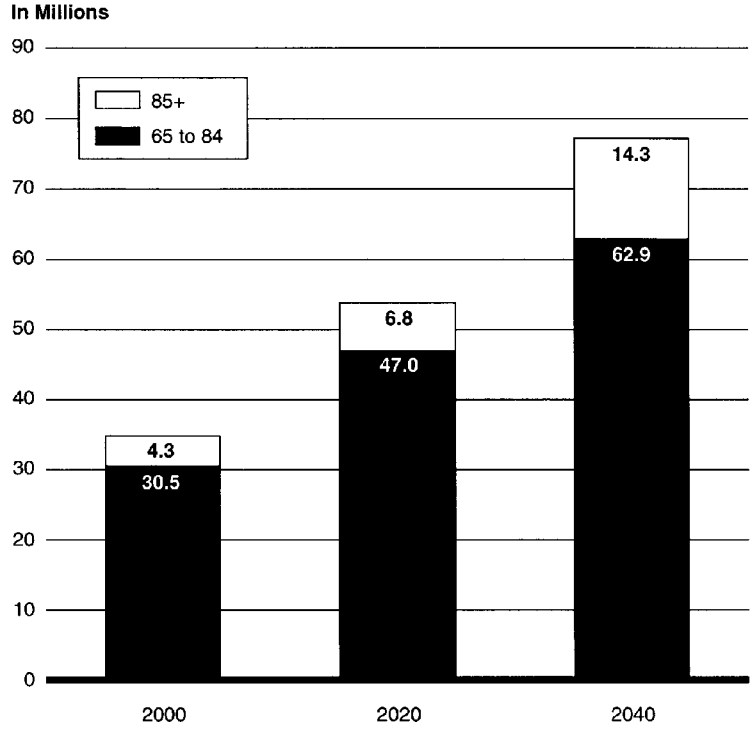
Long-term care needs are an especially significant concern for women. Women represent 7 of 10 unpaid caregivers, three-quarters of nursing home residents 65 years and older, and two-thirds of home health care users. Given their longer life expectancies and the fact that married women usually outlive their spouses, many women face a greater risk of needing long-term care by a paid caregiver.

THE BABY BOOM GENERATION WILL GREATLY EXPAND DEMAND FOR LONG-TERM CARE

The baby boom generation, about 76 million people born between 1946 and 1964, will contribute significantly to the growth in the number of elderly individuals who need long-term care and in the amount of resources required to pay for it. The oldest baby boomers are now in their fifties. In 2011, the first of the baby boomers born in 1946 will turn 65 years old and become eligible for Medicare. The Medicaid program, which pays for many health care services for low-income elderly, including nursing home care, will also begin to be affected. Baby boomers are likely to have a disproportionate effect on the demand for long-term care because more are expected to live to advanced ages, when need is most prevalent. The first baby boomers reach age 85 in 2030.

In 2000, individuals aged 65 or older made up 12.7 percent of our nation's total population. By 2020, that percentage will increase by nearly one-third to 16.5 percent—one in six Americans—and will represent nearly 20 million more seniors than there are today. By 2040, the number of seniors aged 85 years and older will more than triple to 14 million (see fig. 1).

Figure 1: Estimated Number of Elderly Individuals in 2000, 2020, and 2040



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

Projecting the number of baby boomers who will need long-term care services is complicated by several factors. While experts agree that the growing elderly population will increase the number of disabled elderly needing long-term care over the

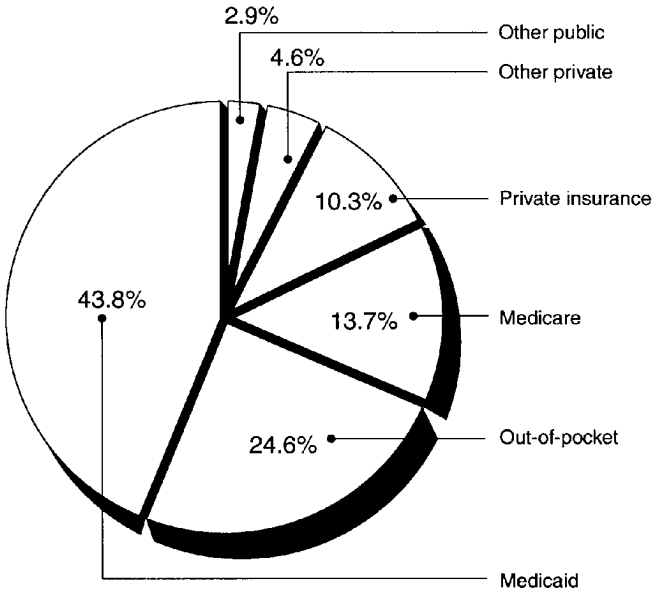
next several decades, no consensus exists on the size of that increase. Projections of the number of disabled elderly who will need care range between 2 and 4 times the current number. Researchers also disagree about the effects of better health care and healthier lifestyles on the baby boomers' need for long-term care. Some contend that medical advances have increased life expectancy but have not changed the age of onset of illness and that therefore the need for long-term care may have increased. Others contend that better treatment and prevention could decrease the time period at the end of life when long-term care is needed.

Baby boomers may also have a disproportionate effect on the demand for paid services. Many baby boomers will have fewer options besides paid long-term care providers because a smaller proportion of this generation may have a spouse or adult children to provide unpaid caregiving. This likelihood stems from the geographic dispersion of families and the large percentage of women who work outside the home, which may reduce the number of unpaid caregivers available to elderly baby boomers.

PUBLIC PROGRAMS AND OUT-OF-POCKET SPENDING PREDOMINANTLY FINANCE LONG-TERM CARE SERVICES

In 1999, spending for nursing home and home health care was about $134 billion. Individuals needing care and their families paid for almost 25 percent of these expenditures out-of-pocket, public programs (predominantly Medicaid and Medicare) funded 61 percent, private insurance (including long-term care insurance as well as services paid by traditional health insurance) accounted for about 10 percent, and other private sources paid the remaining 5 percent (see fig. 2). These amounts, however, do not include the many hidden costs of long-term care. For example, they do not include wages lost when an unpaid family caregiver takes time off from work to provide assistance. An estimated 60 percent of the disabled elderly living in communities rely exclusively on their families and other unpaid sources for their care.

Figure 2: Percentage of Expenditures for Nursing Home and Home Health are, by Source of Payment, 1999



Note: Also includes Medicaid expenditures for home and community-based services, which are considered as part of "other personal health care" in the Health Care Financing Administration's (HCFA) national health care accounts.

Source: Department of Health and Human Services, HCFA, Office of the Actuary, National Health Statistics Group, Personal Health Care Expenditures, 2001.

Medicaid

Medicaid, a joint federal-state health financing program for low-income individuals, continues to be the largest public funding source for long-term care. Within broad federal guidelines, states design and administer Medicaid programs that include coverage for certain mandatory services, such as skilled nursing facility care, and other optional coverage, including home and community-based services. Long-term care services under Medicaid are not limited to adults—about 1 million children with special needs also receive long-term care services from Medicaid. Although most Medicaid long-term care expenditures are for nursing home care, in the last two decades the proportion of expenditures for home and community-based care has increased. By fiscal year 1998, the number of Medicaid recipients receiving home health or home and community-based services was similar to the number of Medicaid recipients receiving nursing facility services. How much service Medicaid provides varies among states, and Medicaid financing can be vulnerable to shifts in state revenues.

State Medicaid programs have, by default, become the major form of insurance for long-term care. About two-thirds of nursing home residents in 1998 relied on Medicaid to help pay for their care, but Medicaid provides insurance only after individuals have become nearly impoverished by "spending down" their assets. Medicaid eligibility for many elderly persons results from having become poor as the result of depleting assets to pay for nursing home care, which costs an average of $55,000 per year.[2] In most states, nursing home residents without a spouse must have less than $2,000 in countable assets to become eligible for Medicaid coverage. An overall increase in wealth among the elderly means that a smaller proportion of elderly individuals will initially qualify for Medicaid—and others will need to become impoverished before they qualify.

States historically limited coverage of in-home services under Medicaid because of concern about the potential cost of covering services for the large number of disabled who were being cared for by their families. However, as part of the Omnibus Budget Reconciliation Act of 1981, the Congress established the home and community-based service waiver program. The waiver program gave states the option of applying for Medicaid waivers to fund home and community-based services for people, including the nonelderly, who met Medicaid eligibility requirements for nursing home care. These waivers also allowed states to restrict the number and costs of eligible individuals served under Medicaid in home and community-based settings. All states now have home and community-based waivers, and more than 200 waiver programs served more than 450,000 individuals nationwide in fiscal year 1998. Medicaid expenditures for home and community-based waivers increased an average of 29 percent per year from 1988 to 1999, reaching over $10 billion in 1999. The extent of services provided varies considerably among the states. Medicaid per capita expenditures for home care in 1999 ranged from a low of about $8 in Mississippi to a high of nearly $230 in New York.[3]

Medicaid is a significant share of state budgets—comprising 20 percent on average. Dependence on state budgets makes Medicaid financing vulnerable to states' fiscal health. States generally must maintain balanced budgets without deficits, and their revenues often decline in periods of low or negative economic growth. A recent fiscal survey of states showed that about one-half of states are expecting declines in revenue growth for 2001 to 2002, and a few states are reducing current-year appropriations and making other adjustments to maintain balanced budgets.[4] At the same time, one-half of the states estimate that Medicaid spending will exceed their current projections. With declining revenue and increasing Medicaid expenditures, maintaining balanced budgets in states may require constraining Medicaid expenditures, including the large share represented by long-term care services.

Medicare

While Medicare primarily covers acute care, in the early 1990s it also became a de facto payer for some long-term care services.[5] However, as spending for both skilled nursing facility services and home health care became the fastest growing components of Medicare, the Congress in the Balanced Budget Act of 1997 (BBA)

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[2] MetLife Mature Market Institute survey, 2000. This survey also found that nursing home costs vary widely by geographic region, from nearly $33,000 per year in Hibbing, Minnesota, to more than $100,000 per year in the Borough of Manhattan in New York City.

[3] The range excludes Arizona, which is unique in having a capitated long-term care system.

[4] National Association of State Budget Officers, National Governor's Association, *The Fiscal Survey of States: December 2000* (Washington, D.C.).

[5] Medicare predominantly covers the elderly, but more than 5 million of the 39 million Medicare beneficiaries are nonelderly disabled individuals eligible for Medicare because they have received Social Security or Railroad Retirement Board disability benefits for at least 2 years.

introduced new payment systems for nursing facilities and home health providers to control this spending.

In contrast to Medicaid, which paid nearly half of total nursing home and other institutional care expenditures in 2000, Medicare plays a relatively small role, paying only about 12 percent of total nursing home and other institutional care expenditures. Medicare primarily covers acute-health-care costs and therefore limits its nursing home coverage to short-term, post-acute stays of up to 100 days per spell of illness following hospitalization. Medicare nursing home spending increased from $1.7 billion in 1990 to $10.4 billion in 1998 and declined to $9.6 billion in 1999.

Since 1989, Medicare became a significant funding source of home care, financing $8.7 billion in care in 1999—or more than one-fourth of the home care purchased for the elderly. Court decisions and legislative changes in coverage essentially transformed the Medicare home health benefit from one focused on patients needing acute, short-term care after hospitalization to one that primarily served chronic, long-term care patients. By 1994, only about one-fourth of home health visits covered by Medicare occurred within 60 days following a hospitalization. As a result, Medicare, on a de facto basis, financed an increasing amount of long-term care through its home health care benefit. Both the number of beneficiaries receiving home health care and the number of visits per user more than doubled from 1989 to 1996. From 1990 to 1997, the average annual growth rate for Medicare home health care spending was 25.2 percent—more than 3 times the growth rate for Medicare spending as a whole. This increase in the use of these services cannot be explained by any increase in the incidence of illness among Medicare beneficiaries.

In response to concerns about the growth in spending for Medicare services, including skilled nursing facility and home health services, the BBA included provisions to slow Medicare spending growth. The BBA required prospective payment systems (PPS) to be implemented for Medicare services provided through home health care agencies and skilled nursing facilities, replacing retrospective, cost-based reimbursement systems that did not provide adequate incentives to control costs. The skilled nursing facility PPS began to be implemented in July 1998 and will be completely phased in this year.

For home health, rather than immediately introducing a PPS, an interim home health care payment system was implemented in October 1997, pending development of a case-mix adjusted prospective payment system. Between 1997 and 1998, Medicare home health spending fell by nearly 15 percent, while home health visits dropped sharply by 40 percent, and this decline continued in 1999.[6] The new home health PPS, implemented in October 2000, is expected to be a more appropriate payment tool than the interim payment system because it is designed to more closely align payments with patient needs.[7] PPS rates are based on a higher number of home health visits per user than those currently being provided. As a result, the PPS can support a large expansion of services. However, PPS incentives are intended to reward efficiency and control use of services. Because criteria for what constitutes appropriate home health care do not exist, it may be difficult for Medicare to ensure that patients receive all necessary services. How home health agencies respond to the PPS and its incentives could have major implications for the amount of future Medicare funding for home health care, the services provided, and whether Medicare remains a significant payer of long-term care.

Private Long-Term Care Insurance Is Small but Growing

Many baby boomers will have more financial resources in retirement than their parents and may therefore be better able to absorb some long-term care costs. However, long-term care will represent a catastrophic cost for a relatively small portion of families. Private insurance can provide protection for such catastrophes because it spreads the risk among larger numbers of persons. Private long-term care insurance has been viewed as a means of both reducing potential catastrophic financial losses for the elderly and relieving some of the financing burden now shouldered by public long-term care programs. Some observers also believe private long-term care insurance could give individuals a greater choice of services to satisfy their long-term care needs. However, less than 10 percent of elderly individuals and even fewer near-elderly individuals (those aged 55 to 64) have purchased long-term care insurance. The National Association of Insurance Commissioners' (NAIC) most recent data show that approximately 4.1 million persons were insured through long-

[6] See *Medicare Home Health Care: Prospective Payment System Could Reverse Recent Declines in Spending* (GAO/HEHS–00–176, Sept. 8, 2000).

[7] See *Medicare Refinements Should Continue to Improve Appropriateness of Provider Payments* (GAO/T–HEHS–00–160, July 19, 2000).

term care policies in 1998, compared with 1.7 million persons in 1992.[8] In contrast, about two-thirds of the elderly—about 23 million individuals—have private Medicare supplemental (Medigap) insurance policies for non-Medicare-covered expenses such as copayments, deductibles, and prescription drugs.

Barriers to purchasing long-term care policies still exist, including misunderstandings among consumers about the roles of public programs, personal resources, and private insurance in financing long-term care. Private long-term care insurance is still a little known product, but insurance providers are seeking to build a larger market. Many baby boomers continue to believe they will never need such coverage. A recent survey of the elderly and near elderly found that only about 40 percent believed that they or their families would be responsible for paying for their long-term care. Some mistakenly believed that public programs, including Medicaid and Medicare, or their own health care insurance would provide comprehensive coverage for the services they need. This low perceived need for protection decreases demand for long-term care insurance. People also may be concerned about whether they can afford such insurance now or in the future when their premiums may increase and their retirement incomes may have decreased.

Some employers offer employees a voluntary group policy option for long-term care insurance, but this market remains small and includes predominantly large employers. Usually employers do not pay for any of the costs of these policies, but group policies have lower administrative costs than individually purchased policies, which can result in lower premiums. One study estimated that 6 to 9 percent of eligible employees took advantage of employer-provided group long-term care insurance where it was available.[9] Last year, the Congress passed legislation to offer unsubsidized, optional group long-term care insurance to federal employees and retirees beginning by fiscal year 2003. This initiative will likely establish the largest group offering of long-term care insurance and could significantly expand this market.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) extended tax deductibility of some premiums and tax exemptions for certain benefits to qualified long-term care insurance policies that must satisfy certain consumer protection standards and other requirements.[10] The consumer protection standards are deemed satisfied if a policy complies with NAIC's Long-Term Care Model Act and Regulation as of 1993. As of July 1998, the Health Insurance Association of America (HIAA) reported that all 50 states (which have primary responsibility for regulating insurance policies) required policies to adhere to at least three of these NAIC long-term care insurance standards. These three standards require policies to (1) not make prior hospitalization a condition for coverage, (2) have an outline of the coverage the policy provides, and (3) be guaranteed to be renewable and noncancelable except for nonpayment of premiums. In addition, all but one state adheres to the NAIC definition of long-term care insurance (policies that provide coverage for at least 12 months for necessary services provided in settings other than acute-care hospital units), and all but two states adhere to the preexisting conditions standard. Overall, HIAA identified 14 NAIC provisions specified for long-term care policies to be tax-qualified under HIPAA that had been adopted by at least 35 states as of July 1998.

Affordability of Long-Term Care Insurance Concerns Many Elderly Individuals

Many elderly and near-elderly individuals question the affordability and the value of long-term care insurance relative to the premiums charged. Long-term care insurance costs vary depending on the policyholder's age at the time of purchase, optional benefits and terms selected, and the insurer. Premiums for a 65-year-old are typically about $1,000 per year and can be much higher for more generous coverage or for older buyers. The affordability of long-term care insurance determines to a great

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[8] The accuracy of these policy numbers is dependent upon the accuracy of the information filed by the insurers themselves with the NAIC.

[9] Steven Lutzky and others, *Preliminary Data From a Survey of Employers Offering Group Long-Term Care Insurance to Their Employees: Interim Report* (June 1999).

[10] A qualified long-term care insurance plan is defined as a contract that covers only long-term care services; does not pay for services covered under Medicare; is guaranteed to be renewable; does not provide for a cash surrender value or other money that can be paid, assigned, pledged as collateral for a loan, or borrowed; applies all refunds of premiums and all policyholder dividends or similar amounts as a reduction in future premiums or to increase future benefits; and meets certain consumer protection standards. Also, payments received from a qualified plan are considered medical expenses and are excluded from gross income for determining income taxes. Per diem policies that pay on the basis of disability rather than reimbursing for services used are subject to a cap of $180 per day per person in 1998. Out-of-pocket expenses for long-term care are allowed as itemized deductions along with other medical expenses if they exceed 7.5 percent of adjusted gross income.

extent its market and is a key factor in individuals' decisions to purchase and retain a long-term care insurance policy. Although assessing whether individuals can afford a policy is subjective, some studies estimate that long-term care insurance is affordable for only 10 to 20 percent of the elderly. Affordability is even more of an issue for married couples, who must each purchase individual coverage. While some insurers offer discounts to married couples when both purchase long-term care coverage, elderly couples are still likely to pay at least several thousand dollars annually for long-term care coverage. Those who consider and decide against purchasing long-term care insurance say they are skeptical about whether private policies will give adequate coverage. Those who do find long-term care insurance affordable when purchased may later decide it is not if their financial circumstances change or the premiums increase. An industry group estimates that 55 to 65 percent of all long-term care insurance policies sold as of June 1998 remain in force.

Insurers state that it is prudent to buy long-term care insurance earlier rather than later in life because premiums are based largely on an individual's age when the policy is purchased. A policy purchased when a person is in his or her 40s or 50s has much lower premiums than a policy purchased later; however, the younger person pays the premiums over a longer period. If a person waits until age 79 to buy, the premiums are typically about 2-1/2 times higher than if the same policy had been purchased when he or she was 65, and about 6 to 10 times higher than if the policy had been purchased at age 50.

Unfamiliarity with the concept and uncertainty of the value of long-term care insurance may deter some people from purchasing a policy. A relatively low premium at age 45 may nonetheless seem high for a risk that may not be realized for 40 years. Concerns about the cost of premiums relative to the value of policies may be a factor deterring purchases, especially when premiums for a similar policy for the same individual can vary widely. For example, a 65-year-old in Wisconsin can pay $857 to $2,061 per year for a long-term care insurance policy depending on the carrier, even if the terms are similar.[11]

Consumer Protection Vital, Especially If Private Insurance Plays a Larger Role in Financing Long-Term Care

Consumers deserve complete and accurate information about any insurance product that they purchase, and sales of long-term care policies are not likely to increase significantly unless consumers are given adequate and understandable information to assess them. If long-term care insurance is to help address the baby boom generation's future long-term care needs, individuals must understand what they are buying and what future changes, if any, they may face in their policy's coverage or premiums. While NAIC's model standards have helped address prior deficiencies in the terms of long-term care policies,[12] it is uncertain whether these have been sufficient to assure consumers that long-term care products are reliable and the terms of the products are easily understood and will be fulfilled. Recently, NAIC further amended its models in response to concerns about dramatic premium increases that some long-term care policyholders experienced.

In August 2000, NAIC amended its Long-Term Care Insurance Model Act and Regulation to strengthen consumer disclosure and encourage insurers to set initial rates at levels unlikely to require further increases. In part, this was intended to address problems such as those highlighted by a recently settled class action lawsuit involving long-term care policyholders in North Dakota who had dramatic premium increases—some by more than 700 percent—even though they believed that their premiums would not increase as long as they held their policies. In states that adopt the new NAIC model amendments, insurers will have to provide written information to prospective purchasers explaining

- that a policy's premium may increase in the future,
- why premium increases may occur,
- what options a policyholder has in the event of an increase, and
- the 10-year rate history for their policies.

In states that adopt the model, consumers will also have to specifically acknowledge that they understand their policy's premiums may increase, and insurers must

[11] Annual premiums for individual basic long-term care insurance policies marketed in Wisconsin as of October 1999, with a $100 per-day nursing home benefit, $50 per-day home health benefit, lifetime benefits, a 90- or 100-day elimination period, and no optional benefits.

[12] In 1993, we reported on a number of problems in the long-term care insurance market, including those related to disclosure standards, inflation protection options, clear and uniform definitions of services, eligibility criteria, grievance procedures, nonforfeiture of benefits, options for upgrading coverage, and sales commission structures that potentially created incentives for marketing abuses. See *Health Care Reform: Supplemental and Long-Term Care Insurance* (GAO/T–HRD–94–58, Nov. 9, 1993).

explain any contingent benefit available to policyholders who let their policies lapse because of a substantial rate increase. Additionally, NAIC adopted amendments to better ensure that long-term care insurers price their policy premiums to be sufficient over the lifetime of the policy, so as to minimize the need for future premium increases. As a further consumer protection, these amendments require insurers to reimburse policyholders when any rate increase is found to be unnecessary and allow state insurance commissioners to ban an insurer from the long-term care market if the insurer has a pattern of offering initial policy purchasers inadequate premium rates. For the new NAIC model provisions to become effective, states must choose to adopt them as part of their statutes or regulations. An NAIC official reported that some states have begun considering legislation or regulations reflecting the revised NAIC models but that states will vary in whether and how quickly they adopt particular portions.

CONCLUDING OBSERVATIONS

The aging of the baby boomers will greatly increase the nation's elderly population in the next 3 decades and thus increase the population who need long-term care services. The need for these services will become more critical after 2030, when this population reaches age 85 and older, which is the age group with the greatest need for long-term care. Recent legislation authorizing a new federal employees' long-term care insurance offering and proposals that would establish new tax subsidies for the purchase of private long-term care insurance aim to increase the role private insurance plays in financing long-term care. Increased confidence in long-term care insurance and the availability of affordable, reliable products are also crucial components of private insurance if it is expected to play a larger role in financing future generations' long-term care needs.

Chairman Grassley and Ranking Member Baucus, this concludes my prepared statement. I will be happy to answer any questions that you or Members of the Committee have at this time.

RELATED GAO PRODUCTS

Long-Term Care Insurance: Better Information Critical to Prospective Purchasers (GAO/HEHS–00–196, Sept. 13, 2000).

Medicare Home Health Care: Prospective Payment System Could Reverse Recent Declines in Spending (GAO/HEHS–00–176, Sept. 8, 2000).

Medicare and Medicaid: Implementing State Demonstrations for Dual Eligibles Has Proven Challenging (GAO/HEHS–00–94, Aug. 18, 2000).

Medicare: Refinements Should Continue to Improve Appropriateness of Provider Payments (GAO/T–HEHS–00–160, July 19, 2000).

Low-Income Medicare Beneficiaries: Further Outreach and Administration Could Increase Enrollment (GAO/HEHS–99–61, Apr. 9, 1999).

Long-Term Care: Baby Boom Generation Presents Financing Challenges (GAO/T–HEHS–98–107, Mar. 9, 1998).

Health-Care Reform: Supplemental and Long-Term Care Insurance (GAO/T–HRD–94–58, Nov. 9, 1993).

COMMUNICATIONS

STATEMENT OF THE AMERICAN COUNCIL OF LIFE INSURERS

The American Council of Life Insurers (ACLI) is a Washington, D.C.-based national trade association representing more than 400 member companies that offer life insurance, annuities, pensions, long-term care insurance, disability income insurance and other retirement and financial protection products. ACLI member companies have 87 percent of the long-term care insurance in force in the United States.

We are delighted that this Committee is addressing long-term care insurance through the hearing process and through legislation. Chairman Grassley and several members of this Committee have taken the lead in highlighting the significant role that private long-term care insurance protection plays in retirement security.

One of the greatest risks to asset loss in retirement is unanticipated long-term care expenses. Currently, it costs almost $16,000 annually for daily visits by a home health care aide and an average cost of over $55,000 per year for nursing home care. Within the next 30 years, these expenses are projected to reach $68,000 per year for a home health care aide to $241,000 for a year of care in a nursing home. These costs can quickly erode a hard-earned retirement nest egg. Moreover, we know this Committee is acutely aware that Medicaid will never be able to foot the bill for the millions of baby boomers who will need long-term care services in the not-so-distant future.

Again, Chairman Grassley and several members of this Committee have supported the need to encourage the purchase of private long-term care insurance in order to meet the nation's long-term care needs without crippling taxpayers and already strained government programs.

Today Chairman Grassley and other members of this Committee reintroduce legislation originally introduced in the last Congress, the "Long-Term Care and Retirement Security Act of 2001". Representatives Nancy Johnson and Karen Thurman have introduced companion legislation in the House designated as H.R. 831. The measure provides individuals with an above-the-line federal income tax deduction for the premiums they pay to purchase long-term care insurance. The long-term care policies subject to the deduction are covered by broad consumer protections. In addition, the measure would permit long-term care insurance policies to be offered under employer-sponsored cafeteria plans and flexible spending accounts. Finally the bill includes a tax credit to individuals with long-term care needs or their caregivers of up to $3000.

Tax incentives to encourage the purchase of long-term care insurance will encourage Americans to prepare for their future retirements and, to be protected against the financial devastation of paying for long-term care. Moreover, providing this important tax incentive means that Americans who take advantage of long-term care protection will not be a burden on the Medicaid system and will not have to spend-down their retirement assets to pay for long-term care before becoming eligible for Medicaid. Instead, they will have the choice of a variety of services if they are unable to perform a specific number of activities of daily living or are cognitively impaired. Today's long-term care insurance policies cover a wide range of services to help people live at home, participate in community life, as well as receive skilled care in a nursing home. Policies may also include respite care, medical equipment coverage, care coordination services, payment for family care givers, or coverage for home modification. These options can enable people who are chronically ill to live in the community and to retain their independence.

While the financial benefits to individual policyholders are obvious, the benefits to government—and future taxpayers—of wider purchase of private long-term care insurance are substantial as illustrated by an ACLI study *Can Aging Baby Boomers Avoid the Nursing Home?* Medicaid's annual nursing home expenditures are projected to skyrocket from today's $29 billion to $134 billion by 2030—an increase of

360 percent. ACLI's research indicates that by paying policyholder's nursing home costs—and by keeping policyholders out of nursing homes by paying for home- and community-based services, private long-term care insurance could reduce Medicaid's institutional care expenditures by $40 billion a year, or about 30 percent.

In addition, the ACLI study found that wider purchase of long-term care insurance could increase general tax revenues by $8 billion per year, because of the number of family caregivers who would remain at work. Today, 31 percent of caregivers quit work to care for an older person; nearly two-thirds have to cut back their work schedules; more than a quarter take leaves of absence, and 10 percent turn down promotions because of their caregiving responsibilities. It costs the typical working caregiver about $109 per day in lost wages and health benefits to provide full-time care at home—which is almost as much as the cost of nursing home care.

The life insurance industry and the National Association of Insurance Commissioners (NAIC) are committed to maintaining and justifying consumer confidence in this increasingly important protection product. We believe that, working together, the industry and its regulators have come up with a model regulation that affords maximum protection to long-term care insurance purchasers both in terms of consumer protection and rate stability.

CONSUMER PROTECTIONS

It can now be said that private long-term care insurance is clearly an idea whose time has come. The product is considered a valuable and meaningful tool for planning a financially secure retirement. It is also a product that is fully regulated with a substantial NAIC Model Act and Regulation which is used as an effective guidepost for states to follow and adopt. All states, including the District of Columbia, have some version of the Model enacted into their state laws and regulations. Further, the NAIC Long-Term Care Insurance Models have been revised, updated and strengthened many times since the initial Models were adopted in 1986.

The passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which set certain requirements for long-term care insurance policies in order for them to be eligible for favorable tax treatment as federally qualified long-term care insurance policies, provided the initial spring board needed to encourage purchase of this product. It is important to recognize that HIPAA allows only a portion of the premiums to apply toward the 7.5 percent base for medical expense deductions currently allowed in the federal tax code.

The federal government's message through passage of this law was that individuals have to begin to take responsibility for their own retirement future and that message is now being heard throughout both the public and private sector. We firmly believe the passage of currently proposed federal legislation for an above-the-line deduction, and allowing cafeteria plans and flexible spending accounts to include long-term care insurance will help to continue to expand and build on that important message. The ACLI and its member companies are also very proud and supportive of the major strides that have been made with long-term care insurance with respect to the strong consumer protections now in place. Over the past 15 years, the NAIC, working with consumer groups and the insurance industry, has made certain that much needed consumer protections are included in the NAIC Long-Term Care Insurance Model Act and Regulation. All long-term care policies must meet the consumer protections standards set by the state in which they are sold, and any policy purchased today that qualifies for the HIPAA federal tax incentives must meet numerous NAIC consumer protections and other standards required by this federal law.

ACLI supports the current NAIC Long-Term Care Insurance Models in total and their adoption in the states. A few examples of the consumer protections that currently exist in the model are:

(1) The offer of a nonforfeiture benefit—a policy provision that provides a paid-up benefit equal to the premiums if the policy is canceled or lapses;

(2) A contingent benefit upon lapse—a provision that requires if premiums increase to a certain level (based on a table of increases) the insured is offered (a) a reduction in the benefits provided by the contract so that premium costs remain the same, (b) a conversion of the policy to a paid-up status with a shorter benefit period, or (c) to keep the policy and pay the increase;

(3) the delivery of Long-Term Care Insurance Shopper's Guide—must be given to consumers by agents and insurers to help consumers understand long-term care insurance and decide which, if any, policy to purchase.

This guide is designed to educate consumers on how to purchase, how the policy works, and the cost and other shopping tips;

(4) An offer of inflation protection—a policy benefit provision that provides for increases in benefit levels to help pay for expected increases in the costs of long-term care services;
(5) A prohibition on limiting or excluding coverage for Alzheimer's or certain other illnesses;
(6) A prohibition on cancellation of the policy due to advancing age or deteriorating health;
(7) A prohibition on increasing premiums due to advancing age;
(8) A continuation or conversion required for individuals covered under group policies;
(9) A designated individual, other than the insured, to receive notice of policy termination due to nonpayment of a premium, and the reinstatement of the policy if there is proof of cognitive impairment or loss of functional capacity;
(10) A prohibition against post-claims underwriting;
(11) A prohibition on requiring a prior hospital stay in order to qualify for benefits;
(12) Minimum standards for home health and community care benefits; and,
(13) A 30 day free-look period.

RATE STABILITY

The NAIC has recently completed its work and has adopted a new and important consumer protection provision to address concerns over premium rate increases for long-term care insurance. The goal of this new provision is to increase the likelihood that premium rates offered by long-term care insurance companies will be adequate over the life of the policy, that rate increases will be less likely, that only justified increases will occur, and that necessary increases will be smaller and less frequent.

The following is a list of key items included in the new NAIC provisions on rate stability:

1. Initial loss ratio requirements eliminated.

The current 60 percent loss ratio requirements on initial rate filings is eliminated. This enables companies to set more conservative initial premiums.

2. Limits are established on expense allowances on increases.

All rate increases are subject to an 85 percent (70 percent for exceptional increases) loss ratio on the increase and 58 percent on the initial premium. The 58 percent allows for a more conservative initial premium and the 85 percent severely limits amounts available for commissions and profit. It provides a powerful incentive for companies to charge an adequate initial premium.

3. Unnecessary rate increases reimbursed to the policyholder.

For each rate increase, the insurer must file its subsequent experience with the commissioner and if the increase appears excessive, the commissioner may require the company to increase benefits at no further cost to the policyholder or to reduce the premiums. This makes certain that premium increases that turn out to be unnecessary are returned to policyholders.

4. Review of administration and claim practices authorized.

If the majority of policyholders subject to the increase are eligible for contingent benefit upon lapse, the company must file a plan, subject to commissioner approval, for improved administration or claims processing or demonstrate that appropriate processing is in effect. This is intended to eliminate lax administration and claims handling practices as a cause of continued rate increases. This will force companies to review claims more closely and to prevent them from paying inappropriate claims, which contribute to the need to increase premiums.

5. Option to escape rate spirals by converting to currently sold insurance provided.

Any time after the first rate increase, for other than an exceptional rate increase, if the majority of policyholders subject to the increase are eligible for contingent benefit upon lapse, and if the commissioner determines that a rising rate spiral exists, as demonstrated by a significant number of policyholders dropping their insurance, the commissioner may require the company to offer to replace existing coverage with a comparable product currently being sold without underwriting. This is a type of pooling. It provides policyholders trapped in a rising rate spiral the opportunity to switch from the troubled policy to a more stable, current policy without the insured being subject to any underwriting.

6. State Insurance Commissioner authorized to ban companies from the market place.

If the Commissioner determines that a company has persistently filed inadequate initial premium rates, the State Insurance Commissioner may ban the company from marketing long-term care insurance in that for up to five years. This penalty will essentially put the company out of this business in the state. It is intended as a last resort for the Insurance Commissioner when all else fails.

7. Actuarial certifications required.

For all rate filings, the company is required to provide an actuarial certification that no rate increases are anticipated. Actuaries signing such certifications are subject to existing standards of professional actuarial practice. This puts the burden on the company, rather than the state, to secure actuarial certification.

8. Disclosure of rate increase histories required.

Companies must provide consumers with a rate increase history. This is intended to inform consumers of past company practices and to deter companies from increasing premiums.

This new measure, once adopted by states, will provide consumers the necessary peace of mind that the premium rate increase that they would pay in the event of a rate increase, will be smaller, less frequent and more manageable. ACLI supports the NAIC's overall effort and believes consumers should be protected from unreasonable and unexpected rate increases.

ACLI acknowledges that there have been situations where rate increases have occurred and that some states did not have the proper tools to regulate and evaluate the rates. It is important to stress though that the majority of the market has not experienced rate increases on this product line. The industry has stepped up to the plate on this issue and has joined with state regulators, and consumer groups, working countless hours over the past three years to adequately and appropriately address this matter—and trying to accomplish all of this without harming future market innovation and growth.

We recognize that the fear of rate increases has been a concern for some. It is important to remember that long-term care insurance is a guaranteed renewable product which means insurers are permitted under the contract to revise the premiums, but only if the rates are changed for the entire class of policyholders. Again, the majority of long-term care insurers have not raised the premium rates, but where rates have been increased, many of those increases have not been to an extent that should cause alarm to all consumers or regulators.

It is important to note, too, that in recent years the average termination or lapse rate for long-term care insurance by policyholders has declined. A long-term care policy lapses if the policyholder does not pay the premium by the end of a specified time, or if the policyholder replaces it with a newer product. ACLI's analysis shows that in the individual market, two percent of policyholders voluntarily lapsed or replaced their policies in 1997 versus six percent in 1992. Group terminations fell to seven percent in 1997 from eight and one-half percent in 1995. To minimize lapse rates, companies typically offer new policyholders time to examine the policy, and the full premium is returned if the buyer decides within a specified period not to keep the policy. Since many buyers are older, many long-term care policies allow the policyholder to designate a third party for the insurer to notify when premiums are not paid. Insurers frequently reinstate coverage if the policy lapses because the policyholder has a cognitive impairment.

Though the issue of concern on premium rate increases is centered around a limited segment of the market, the insurance industry believes it had to address the concerns head on and believes we have accomplished that goal working with the NAIC. The next step is for the states to move forward and adopt the new provisions. In many cases states will have to repeal their current legislative or regulatory requirements and replace them with the new NAIC rate stability provisions. Some states will have to have new statutory authority to monitor, implement and enforce these unique new provisions and this will take enabling legislation by the state to allow the state insurance departments to move forward on them. ACLI is committed to working with the states to accomplish that goal.

A SMART AND KNOWLEDGEABLE CONSUMER

Another important part of purchasing long-term care insurance is to be a smart and knowledgeable consumer. Consumers must think through their purchase and understand what it is they are buying.

ACLI encourages consumers, when considering a major purchase of long-term care insurance, to:

(1) look for insurance companies that are reputable, consumer oriented, financially sound and licensed in their particular state,

(2) obtain the name, address and telephone number of the agent and insurance company,

(3) take time when making a purchase, ask for and read the outline of coverage of several policies,

(4) understand what the policy covers and ask questions to be clear about what the policy is not intended to cover,

(5) understand when the policy becomes effective, what triggers benefits and if it is tax deductible at the state and/or federal level,

(6) answer questions on medical history and health truthfully on the application, and

(7) contact the State Insurance Department or the State Health Insurance Assistance Program with questions on long-term care insurance and the insurance company with specific questions about the policy.

In conclusion, we believe that protection and coverage for long-term care is critical to the economic security and peace of mind of all American families. Private long-term care insurance is an important part of the solution for tomorrow's uncertain future. As Americans enter the 21st century, living longer than ever before, their lives can be made more secure knowing that long-term care insurance can provide choices, help assure quality care, and protect their hard-earned savings and assets when they need assistance in the future. We also believe that the costs to Medicaid—and therefore to tomorrow's taxpayers—will be extraordinary as the baby boom generation ages into retirement, unless middle-income workers are encouraged to purchase private insurance now to provide for their own eventual long-term care needs. ACLI believes it is essential that Americans be given an above-the line deduction for this product that is so vital for their retirement security.

Again, the ACLI looks forward to working with this Committee to help Americans protect themselves against the risk of long term care needs.

STATEMENT OF THE HEATH INSURANCE ASSOCIATION OF AMERICA

The Health Insurance Association of America (HIAA) commends Senator Charles Grassley (R–IA), the Chairman of the Senate Finance Committee, and his fellow Committee Members for holding this hearing to address the crucial issue of long-term care (LTC). Concerns about access to the right kind of long-term care services, paying for those services, and the quality of those services will touch most American families in the years ahead. Unless Congress begins now to take steps to address a looming crisis, an aging "Baby Boom" generation will overwhelm our nation's patchwork long-term care system and leave millions of Americans unprepared for the heavy financial and emotional burdens of long-term care.

Today, Chairman Grassley and Senator Bob Graham (D–FL) introduced legislation that would take major steps to help American families afford long-term care. This legislation, the "Long-Term Care and Retirement Security Act of 2001," would establish a 100% above-the-line federal income tax deduction for LTC insurance premiums. The bill would also phase-in a tax credit of up to $3,000 for taxpayers already in need of long-term care services—or for their caregivers. As we did last year, HIAA is pleased to join with AARP in support of this legislation. HIAA will work hard this year with Senators Grassley and Graham—and also with the sponsors of the House companion measure, Representatives Nancy Johnson (R–CT) and Karen Thurman (D–FL)—for the enactment of this legislation.

HIAA has long been an advocate for stronger federal tax incentives for private LTC insurance coverage, because:

- Long-term care is the largest unfunded liability facing Americans today, and despite the tremendous need for long-term care protection, most Americans remain unprepared to meet their future long-term care needs.
- In 2020, one of six Americans will be age 65 or older—20 million more seniors than today. Americans 85 and older (the group most likely to require long-term care) will double to 7 million by 2020 and double again to 14 million by 2040, according to the Bureau of the Census.
- Without substantial assistance, the full cost of long-term care is out of reach of most families. The average cost of a one-year nursing home stay is nearly $50,000—and growing. Helping people pay for these services directly and helping them purchase quality insurance products should be part of our nation's answer to long-term care need.

- There is a growing and crucial role for private insurance to provide a better means of financing long-term care for the vast majority of Americans who can afford to protect themselves. Continued growth of the market will protect millions of Americans against the financial risk of long-term care need, enhance their long-term care choices, and help reduce reliance on scarce public dollars.
- The long-term care (LTC) insurance tax clarifications in The Health Insurance Portability and Accountability Act (HIPAA) of 1996, while helpful, were not enough. HIPAA's LTC insurance tax benefits for premiums apply primarily to employer-sponsored coverage. However, 80 percent of LTC insurance is individual coverage. Under current tax law, an individual purchasing a LTC insurance policy who is not self-employed can deduct premiums only if he or she itemizes deductions and only to the extent medical expenses exceed 7.5 percent of adjusted gross income. This provision applies to very few Americans—only about 4.5 percent of taxpayers report medical expenses as itemized deductions.
- Stronger federal tax incentives for LTC insurance would reduce the cost of long-term care coverage, increase its appeal, and strengthen public confidence in the product. A March 2000 study commissioned by HIAA estimates that a 100 percent above-the-line tax deduction for LTC insurance would reduce premium costs, on average, by 19 percent and increase private long-term care coverage by up to 24 percent above current growth. Further, this important tax incentive would generate more than enough future savings in Medicaid spending on long-term care to offset the cost of the tax deduction. (See *Tax Deductibility of Long-Term Care Insurance Premiums: Implications for Market Growth and Public LTC Expenditures*, attached.)
- When asked what the single most important action government can take to help with long-term care, Americans most often choose stronger tax incentives for the purchase of private LTC insurance coverage. (Please see the HIAA publication *Who Buys Long-Term Care Insurance in 2000?*, attached.)
- In addition to the peace of mind gained from knowing that there will be sufficient resources to pay for care if needed, private LTC insurance offers significant improvements in quality of life for policyholders and their families. Private coverage often delays or prevents institutionalization, provides easier access to home care and/or assisted living, and eases the financial, physical and emotional burdens on families providing continuing care.

The Long-Term Care and Retirement Security Act also would strengthen LTC insurance consumer protections. HIAA has an extensive history of supporting public policies aimed at maximizing the benefits that private LTC insurance coverage can bring to consumers, caregivers, and government treasuries—including the development and implementation of long-term care insurance consumer protections.

- HIAA supports all the mandatory provisions of the 2000 National Association of Insurance Commissioners (NAIC) Long-Term Care Model Act and Regulation. HIAA also supports the adoption of the 2000 Model by the states. We believe the 2000 Model will go a long way toward addressing the LTC insurance rate stability concerns of our industry, regulators, consumers, and the Congress.
- In conjunction with the establishment of an above-the-line federal income tax deduction for LTC insurance premiums, HIAA supports updating the long-term care insurance consumer protection provisions of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 by reference to the appropriate components of the 2000 NAIC Model.
- It is imperative, however, that the incorporation of components of the 2000 NAIC Model preserve the appropriate and distinct role of the states in the regulation of insurance.

HIAA is the nation's most prominent trade association representing the private health care system. Its 294 members provide health, long-term care, dental, disability, and supplemental coverage to more than 123 million Americans. It is the nation's premier provider of self-study courses on health insurance and managed care.

Attachment.

Preface

In September 1999, the Health Insurance Association of America (HIAA), a leader in the study of long-term care (LTC) insurance and public policy, commissioned researchers Marc A. Cohen, Ph.D. of LifePlans, Inc. and Maurice Weinrobe, Ph.D. professor of economics at Clark University, to undertake an examination of the impact of tax policies on LTC insurance coverage. More specifically, HIAA was interested in finding out the extent to which further tax enhancements for private LTC insurance would help Americans deal with the financing of their present and future long-term care needs.

The researchers projected the impact on LTC insurance coverage of a 100 percent above-the-line tax deduction for LTC policies. The study also estimated what the deductibility of LTC insurance premiums would cost in tax revenues foregone. Finally, the study gauged the savings in public expenditures that such a deduction might yield. It concludes that a 100 percent above-the-line federal tax deduction for LTC insurance premiums would significantly increase LTC insurance coverage and that the resulting savings in Medicaid spending would more than pay for the foregone tax revenues.

The study was augmented in March 2000, adding a new section describing the impact of tax deductibility on Medicaid spending in the 10 states with the largest senior populations.

TAX DEDUCTIBILITY OF LONG-TERM CARE (LTC) INSURANCE PREMIUMS: IMPLICATIONS FOR MARKET GROWTH AND PUBLIC LONG-TERM CARE EXPENDITURES

As baby boomers begin to enter their retirement years, and as lifespans continue to increase, America faces the challenge of providing long-term care to millions more of its citizens. Indeed, by 2030, 70 million elderly Americans (more than twice today's population of seniors) are likely to have some long-term care needs. Paying for these needs is (or should be) near the top of both our personal and public policy agendas.

Medicare does not provide coverage for long-term care. Medicaid covers only those who have depleted most of their assets and have very low incomes. Moreover, long-term care services are costly today and are likely to be more costly in the future. Given competing demands on public dollars, government programs alone are not likely to meet the nation's growing long-term care needs. LTC insurance can play a key role in filling the gap. Private policies offer a flexible and affordable way to cover the costs of the myriad of services that an older person may need, from nursing homes to adult day care to home-delivered meals.

Long-term care is the largest unfunded liability facing Americans today. Despite the tremendous need for long-term care protection, few people plan for their long-term care needs. As Congress struggles to preserve Social Security and Medicare, there is a developing consensus that action should be taken to encourage Americans to plan for their future long-term care needs. One method is to help make private policies more affordable. Federal tax policy can play a key role in this effort by lowering the effective cost of coverage and by signaling to consumers that it is in their clear interest to take personal responsibility for protecting themselves against potential long-term care costs.

A FIRST STEP: THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT

In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA). HIPAA clarified that for federal income tax purposes, LTC insurance is to be treated essentially the same as major medical insurance. More specifically HIPAA provided that:

- benefits from private LTC coverage, generally, are not taxable;
- employers can deduct the costs of establishing an LTC insurance plan for employees and contributions toward premiums;
- employer contributions to LTC premiums are excluded from the taxable income of employees; and,
- LTC insurance premiums (and out-of-pocket costs for LTC services) can be applied toward meeting the 7.5 percent threshold in the federal tax code for medical expense deductions. (Limits, based on the policyholder's age, are still placed on the total premium amount that can be applied toward the 7.5 percent threshold.)

HIPAA clearly raised awareness of the value of private long-term care insurance. However, in practical terms, the law's financial benefits accrue almost entirely to those who enjoy LTC coverage through the workplace (less than 20 percent of the LTC market).

Under HIPAA, an individual purchaser can only deduct premiums if he or she itemizes deductions and only to the extent that medical expenses exceed 7.5 percent of adjusted gross income. Internal Revenue Service (IRS) data show that only 4.5 percent of all filers use the medical-dental deduction. Accordingly, only an estimated 6 percent of LTC policy purchasers can take advantage of the deduction.

BENEFITS OF 100 PERCENT TAX DEDUCTION FOR LTC POLICIES

A 100 percent above-the-line deduction would affect millions of Americans because the full amount of the premium from a purchased LTC policy would be deductible

from income, whether or not an individual itemizes deductions or has medical expenses above the 7.5 percent threshold. As discussed below, market expansions would also reduce reliance on public expenditures, especially in the Medicaid program.

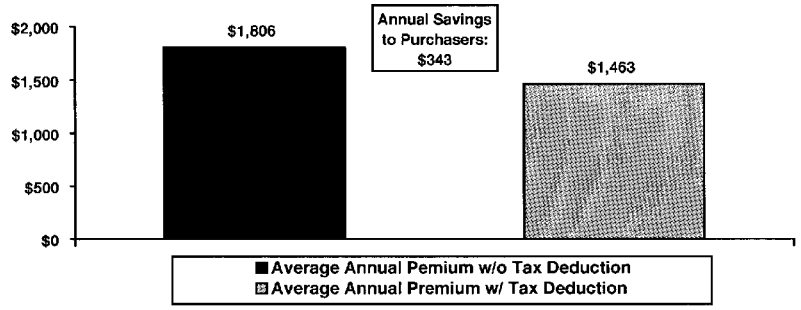
All current and future purchasers who file income taxes would benefit from a 100 percent above-the-line deduction because it means that consumers will be able to reduce their taxable income, resulting in lower taxes. Thus, the proposed deduction would effectively reduce the cost of premiums. Finally, proponents argue that an above-the-line tax deduction is easy to administer; is easy for consumers to understand; potentially benefits a large segment of the population; and is an effective means of encouraging the public to insure against potential LTC expenses.

Reductions in Cost of LTC Coverage

An above-the-line 100 percent federal tax deduction for LTC insurance premiums would effectively reduce the net premium costs for policies. For example, if a taxpayer is taxed at the 28 percent marginal rate, a deduction of $1,000 reduces taxes by $280, and an above-the-line deduction for LTC insurance premiums would be equivalent to a reduction in premium at that same rate.

The average annual premium for the purchase of an LTC policy in 1995 (the last year for which precise data are available) was $1,806. At that time, the average annual income of a LTC insurance purchaser was about $ $37,000, taxable at the marginal rate of 19 percent. For this individual, a 100 percent above-the-line tax deduction on LTC insurance premiums would have resulted in a 19 percent decrease in the cost of LTC coverage—a savings of $343 per year. (This also can be thought of as the average cost of the tax expenditure.) Thus, individuals who availed themselves of the deduction would, effectively, pay a reduced net premium of about $1,460.

Figure 1:
An above-the-line tax deduction for LTC Insurance reduces cost of coverage



Source: LifePlans, Inc., 1999.

Significant Increase in LTC Coverage

The intent and effect of an above-the-line deduction for LTC insurance premiums are to reduce the net cost of LTC insurance premiums. The extent to which this induces individuals to buy insurance depends largely on how sensitive they are to price changes for this type of insurance. Prior studies suggest that price is a major consideration in the purchase of LTC insurance. (HIAA's 1995 study of LTC purchasers shows that the most common reason for not purchasing LTC insurance is its cost.)

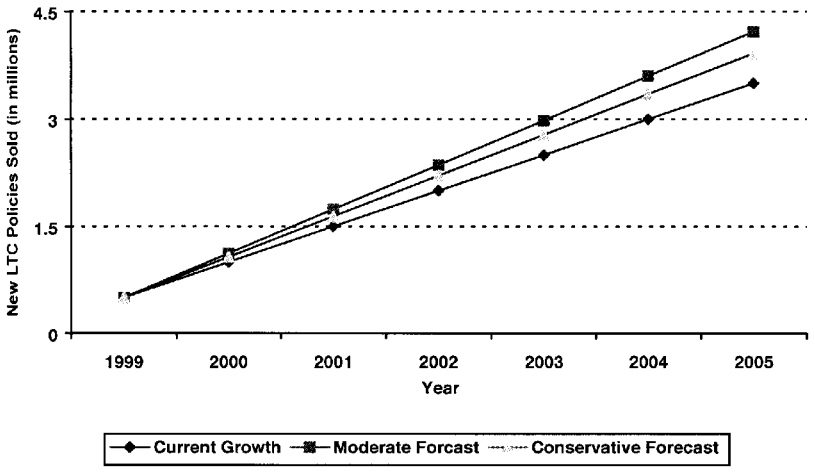
Changes in the demand for a good or service in response to a change in its net cost is described by that good's "price elasticity of demand." For example, if insurance premiums increase by 10 percent and the quantity of policies demanded declines by 15 percent, the elasticity of demand is—1.5: for every 1 percent increase in price, the quantity demanded declines by 1.5 percent.

Each year, starting with 1991 and ending with 1996, about 500,000 new LTC insurance policies were sold. By 1996, about 5 million policies had been sold (HIAA, 1998). If this trend continues, absent any change in the tax status of the insurance,

by 2005 the annual growth rate in the market will be about 6 percent, and total polices sold will rise to about 9.5 million.

An above-the-line tax deduction would bring about a net decrease in LTC insurance premiums, which should encourage growth in the market. Applying price elasticity of demand estimates for LTC insurance of between -0.75 (conservative forecast) and -1.25 (moderate forecast), an average price decline of 19 percent would lead to a 14 to 24 percent increase in the number of insurance policies purchased. This represents an estimated increase in annual sales-above and beyond current growth-of between 70,000 and 120,000 policies. Taken in conjunction with current growth rates, between 2000–2005, in the presence of a 100 percent above-the-line tax deduction, up to 4.2 million new policies will have been sold. Total sales since the industry began selling policies would rise to roughly 10 million.

Figure 2
An above-the-line tax deduction would spur additional growth in LTC coverage



Source: LifePlans, Inc., 1999.

In addition, a change of this sort in federal tax policy would raise awareness of the risks and costs of long-term care. It would focus attention on the baby boomers' looming retirement. It would highlight the widespread availability of long-term care coverage and point the direction of government long-term care policy for the foreseeable future. Although this signaling effect is difficult to quantify, it is an important policy consideration. The growing awareness, affluence, and investment sophistication of retirees will all significantly affect attitudes and behaviors toward LTC insurance. If recent experience with the federal tax deduction for IRA contributions is any guide to the likely impact of an LTC insurance tax deduction the impact could be substantial. Growth in insurance purchases could easily exceed the 14 to 24 percent estimates on market growth due just to the effect of full deductibility on net premium cost.

MEDICAID SAVINGS WOULD OFFSET THE COST OF FULL DEDUCTIBILITY FOR LTC INSURANCE

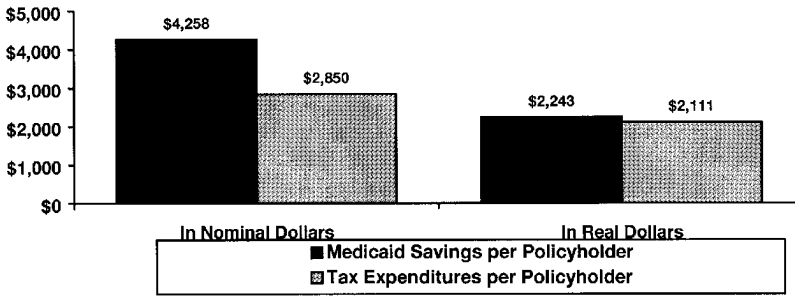
Private LTC coverage enables middle- to lower-income policyholders to access long-term care services without having to rely on Medicaid. In 1995, 68 percent of new private LTC purchasers had incomes below $35,000; these same purchasers had average assets valued at $63,000 (HIAA/LifePlans, 1995). Without the protection of long-term care insurance, 13 percent of these individuals would be likely to "spend down" to Medicaid eligibility levels if they ever needed long-term care. Their private

LTC coverage, however, would help them avoid Medicaid, thereby saving public expenditures.

To calculate annual Medicaid savings per policyholder, we estimated how much Medicaid would have to spend on policyholders under two scenarios: (1) in the presence of LTC insurance, and (2) in the absence of LTC insurance. We found that on average, for every insured policyholder, Medicaid saves $6,148. We then multiplied this figure by a projection of the number of LTC policies sold annually after enactment of full deductibility: 570,000 (under a conservative scenario) and 620,000 (a still moderate estimate). This calculation yielded annual Medicaid savings of $3.5 billion to $3.8 billion. The aggregate annual tax expenditure cost of the tax deduction is projected at between $3.1 and $3.5 billion over the five-year period following enactment.

These comparisons are in "nominal" dollars (a simple comparison of total savings to total revenue foregone). However, there would be a significant lag between the beginning of tax benefits and the eventual generation of Medicaid savings. While tax expenditures are counted from the year of purchase of the LTC policy, Medicaid savings for each policyholder are realized on average 12 years after the purchase. It is therefore appropriate to make comparisons of Medicaid savings and tax expenditure costs in "real" dollars. To compare the total per-policyholder tax expenditure with projected Medicaid savings, future savings must be discounted (using a 6 percent annual discount rate) relative to current expenditures to reflect the time value of money.

Figure 3:
Medicaid savings would offset the cost of an LTC above-the-line deduction



Source: LifePlans, Inc., 1999.

In nominal terms, the projected cost per policyholder of the tax deduction is $2,850, and the Medicaid savings are $4,258. In real terms, these figures are $2,111 and $2,243, respectively. Thus, for every federal dollar of tax expenditure, Medicaid saves $1.06. Future Medicaid savings are likely be even greater because full tax deductibility for LTC insurance premiums will also have the educational and signaling effects described above.

STATE TREASURIES WOULD SHARE IN THE FISCAL BENEFITS OF STRONGER FEDERAL LTC TAX INCENTIVES

The preceding analysis estimates the total Medicaid savings realized through accelerated growth in LTC coverage from 2000 through 2005 in the presence of a 100 percent above-the-line federal income tax deduction for LTC insurance premiums. Because state governments share the cost of Medicaid nursing home expenditures with the federal government, a portion of the Medicaid savings ultimately realized through more widespread LTC insurance coverage would also accrue to the states. While states may allow their own LTC insurance tax deductions or credits (20 states now do so), even states without such tax policies would benefit financially from federal tax deductibility of LTC insurance premiums by virtue of savings to the Medicaid programs.

State Medicaid savings would vary according to how much additional LTC coverage results from the deduction; the relative cost of Medicaid nursing home care; and the state/federal matching rate under the Medicaid program. To illustrate the

fiscal benefits to states of full federal tax deductibility for LTC insurance, HIAA commissioned further research focusing on the 10 states with the largest senior populations. Figure 4, below, summarizes this analysis.

Figure 4
An Above-the-line federal tax deduction for LTC insurance would result in Medicaid savings for the states

	New LTC Policies Purchased (2000-2005)	State Share of Medicaid Savings per Policyholder	Lapse-Adjusted Real Medicaid Savings Per Policyholder (State Share)
California	43,000-47,000	$3,651	$1,935
Florida	59,000-65,000	$2,067	$1,096
Illinois	40,000-43,000	$2,819	$1,494
Michigan	21,000-23,600	$2,238	$1,186
New Jersey	11,000-12,200	$4,954	$2,626
New York	16,000-17,000	$4,447	$2,357
North Carolina	10,600-11,500	$1,796	$952
Ohio	29,600-32,200	$2,707	$1,435
Pennsylvania	41,000-45,000	$3,126	$1,657
Texas	31,000-33,500	$2,006	$1,063

Source: LifePlans, Inc.

These state Medicaid savings estimates assume that full federal deductibility would induce a 24% increase in LTC policy purchases. The final column of the table shows the state share of Medicaid savings discounted for the time value of money and adjusted for the expected rate of policy lapse. For these 10 states, the "real" Medicaid savings per policyholder ranges from $952 in North Carolina to $2,626 in New Jersey.

Twenty states (including California, New York, North Carolina, and Ohio) currently provide some kind of state tax incentive of their own for the purchase of LTC insurance. Other states (including Illinois, Michigan, New Jersey, and Pennsylvania) are considering LTC insurance tax measures. State income tax rates are lower than the federal rates, and state tax incentives tend to be more modest than the proposed federal tax deduction. Even so, state tax incentives could work in tandem with federal tax incentives to help make LTC insurance premiums even more affordable, increase LTC insurance coverage, and reduce long-term care expenditures.

IMPROVED QUALITY OF LIFE FOR MILLIONS OF POLICYHOLDERS

Beyond the quantitative advantages of providing enhanced tax incentives for the purchase of private LTC coverage, there would also be significant qualitative benefits to policyholders, claimants, and their families. In addition to the peace of mind of knowing that there will be sufficient resources to pay for long-term care if needed, private LTC coverage can bring significant improvements in quality of life. Recent studies of policyholders, claimants, and informal caregivers suggest that the presence of LTC insurance can:

- delay or prevent institutionalization;
- enable easier access home care and/or assisted living;
- afford a greater choice of long-term care services and providers;
- ease the financial, physical, and emotional burdens on families providing care in the home; and
- preserve assets for heirs.

CONCLUSIONS

A 100 percent above-the-line federal tax deduction for LTC insurance premiums would reduce net premium costs, increase LTC coverage, and bring about Medicaid savings. The tax expenditure, in both nominal and real terms, would be offset by future reductions in Medicaid expenditures. Medicaid savings would accrue both to

the states and the federal government. Thus, as individuals are encouraged to assume greater personal responsibility for meeting their future long-term care needs by purchasing private insurance, the fiscal pressures on the federal government and state governments will decline. This will help assure that the private sector piece of the long-term care financing puzzle will play an ever-growing and critical role in helping to address this important social policy issue.

NATIONAL COUNCIL ON DISABILITY (NCD)

April 18, 2001

Hon. CHARLES GRASSLEY,
Chairman, Senate Finance Committee,
U.S. Senate,
Washington, DC.

Dear Mr. Chairman: On behalf of the National Council on Disability (NCD), I want to thank you for your leadership in issues related to care-giving and health care reform and for the March 27, 2001 hearing on these issues. Your work to ensure an equitable system of health care in this nation is essential for many of our nation's citizens, particularly people with disabilities who need either short or long-term care.

NCD is an independent federal agency mandated to make recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. In keeping with our mission to advise the President and Congress on public policy that affects people with disabilities, NCD has taken an interest in the ability of Americans with disabilities to fully participate in and equally benefit from a comprehensive health care bill, including one that address patients' rights. I want to inform you of our activities and to offer our expertise to you and your staff as you move forward with your work on this all-important issue.

NCD has prepared the attached statement to enter into the Committee record of testimony. It outlines ten key principles on equitable health care and background information from our studies and reports over the past eight years, as evidence of consumers' and advocates' support for the enactment of comprehensive and enforceable legislation that also protects patients' rights. We hope that the information will be useful to you and your colleagues on the Senate Finance Committee. Further, we would offer the expertise of the members of NCD and would welcome the opportunity to meet with you and your staff at some time in the near future to further explore ways that our leadership can be of assistance to you as you move forward with legislative inquiry and proposals that impact all Americans, including people with disabilities.

Sincerely,

MARCA BRISTO, *Chairperson*

Enclosures.

Patients' Rights Principles

Scope: A patients' bill of rights should cover all 161 million Americans with private insurance.

Access to Specialists: All patients, especially patients with disabilities and chronic conditions, should have timely access to specialty physicians, providers, and facilities.

Point-of-Service Option: Health plans that only cover services if they are obtained through a closed network of providers should be required to offer enrollees a "point-of-service option" at the time of enrollment which includes reasonable cost sharing.

Continuity of Care for Patients with Ongoing, Chronic Conditions: In order to minimize disruption in service, consumers should have the right to an appropriate transitional period (such as 90 days) from the date of a provider's termination from a network plan, with limited exceptions. This transitional period should be further extended to include enrollees with terminal illnesses, pregnancies, or those who are receiving institutional or inpatient care at the time of the change in providers.

Timely and Accurate Comparative Information: All patients, particularly persons with disabilities, should have access to accurate, easily understandable information to assist them in making informed decisions about their health plans, professionals, and facilities.

Right to Participate in Treatment Decisions and to Refuse Treatment: Patients should be fully informed about treatment options, told about risks and benefits, and participate to the maximum extent possible in decisions that impact their mental and physical health care. Patients should have the right to refuse treatment.

Elimination of "Gag Clauses": Physicians and other health care professionals must not be restricted from advising a patient on his or her health care options, regardless of whether the patients' health plan covers such treatment or the treatment is expensive. Financial incentives designed to limit communication between the patient and provider should also be prohibited.

Access to Clinical Trials: Patients with disabilities and chronic illnesses should have access to the full range, and all phases of, federally approved clinical trials. Any routine patient costs incurred for items and services furnished in connection with participation in a clinical trial should be covered by the health plan.

Strong Grievance Procedures: All consumers, including persons with disabilities, should have access to a fair, unbiased, and timely internal appeals process as well as an independent external appeals mechanism to address health plan grievances and to help govern decisions about medically necessary treatments. Health plan liability provisions should strike a balance between holding plans accountable for the medical decisions they make and not creating significant increases in insurance premiums.

Emergency Room Protections: Patients should have a right to visit the closest emergency room in an emergency situation, according to the "prudent layperson" standard, without prior plan authorization.

Drug Formularies: Health plans should be required to disclose to providers and beneficiaries formulary restrictions and provide exceptions when a non-formulary drug alternative is medically indicated. In addition, plans should include physicians and pharmacists in the development of drug formularies.

Introduction

The National Council on Disability ("NCD") is an independent federal agency that advises the President and Congress on issues affecting 54 million Americans with mental and physical disabilities. NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, inclusion, and integration into all aspects of society.

NCD has been engaged in the issue of improving access to and the quality of health care for people with disabilities for many years. NCD has prepared several reports in the past that address these important issues. These reports include:

- Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services. March 4, 1993. This report identifies the major issues of access to health insurance and health-related services for people with disabilities.
- Making Health Care Reform Work for Americans with Disabilities. July 26, 1994. This report summarizes the identified health care priorities of over 130 witnesses and hundreds of participants in five "town meetings" held by NCD during March and April of 1994.
- Achieving Independence: The Challenge for the 21st Century. July 26, 1996. Achieving Independence is the follow-up report to NCD's 1986 report Toward Independence. It offers an assessment of the nation's progress in achieving equal opportunity and empowerment for people with disabilities in the last decade.
- From Privilege to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves. January 20, 2000. In this report, NCD develops ten core recommendations for improving the care of people with psychiatric disabilities.
- National Disability Policy: A Progress Report. May 15, 2000. This report is a series of public policy recommendations designed to advance the inclusion, empowerment, and independence of people with disabilities.

As part of its health care agenda, NCD has long supported the enactment of a comprehensive and enforceable patients' bill of rights. As far back as 1996, NCD argued that "all managed care plans, including those that service only privately insured persons, should be required to meet federal standards to ensure access to specialty care, adequate grievance and appeals procedures and equitable utilization review criteria." Achieving Independence (July 1996). People with disabilities and chronic illnesses are often high users of health care services and devices and, as such, are a litmus test for assessing the effectiveness of patient rights legislation.

In other words, if a patient's bill of rights protects people with disabilities, it is bound to adequately protect the rights of all health care consumers.

NCD has identified the aspects of a patients' bill of rights that are most important to people with disabilities and chronic illnesses. NCD does not endorse any specific legislation. Rather, NCD supports any approach that meets the principles that are identified and described in this document. It is our hope that members of Congress and their staff, other federal and state policymakers, and people with disabilities view this position paper as a valuable tool as Congress continues to debate this important issue.

NCD Managed Care Reform Principles

Scope of Application of the Law: People with disabilities and chronic conditions have historically faced major hurdles in obtaining and maintaining private health insurance. However, NCD's 1993 report Perspectives on Access to Health Insurance and Health-Related Services, found that while private health insurance is difficult to obtain and keep for many in the disability community, particularly in the individual insurance market, it is still the major source of coverage for people with disabilities.

A patients' bill of rights, therefore, should cover all 161 million individuals with private health insurance in order to ensure that its protections apply to all people with disabilities. Application of the patients' bill of rights to all privately insured persons will have the added benefit of establishing a uniform set of protections on which all privately insured Americans can rely, regardless of their employer or the state laws in which they reside. This includes the 48 million Americans who receive group health coverage from their employers who self-insure as well as the additional 113 million Americans whose group or individual health coverage is subject to state law.

Timely Access to Specialty Care

The health care needs of people with disabilities and chronic conditions are best met when the focus is on maintenance of function, rather than on acute or post-episodic care. People with disabilities often require ongoing access to specialist physicians, specialty facilities, and other specialty health care providers to maintain the functional ability required to be independent, participating members of society. In addition, the debilitating impact of many primary and secondary disabilities could be reduced or even avoided if specialty services and supports were available to people with disabilities on a routine basis.

NCD recognized in its 1996 report Achieving Independence: The Challenge for the 21st Century the importance of federal standards to ensure access to specialty care for people with disabilities in managed care health plans. In fact, improving access to specialty care is the highest priority for the disability community in the patients' bill of rights. NCD reiterates its belief that all patients, especially individuals with disabilities, should have timely access to specialized medical services if they need them. Health plans should ensure that the specialist is appropriate to the specific condition of the patient. If an appropriate specialist is not available within a plan's network of providers, the plan should be required to refer the patient to an appropriate specialist outside the provider network for no additional cost to the patient.

Point-of-Service Option

NCD's 1994 report "Making Health Care Reform Work for Americans with Disabilities" detailed the challenge people with disabilities face when seeking appropriate medical care. Many adults with disabilities and parents of children with disabilities have testified that it takes them years to locate medical professionals who are competent in treating a particular disability. Any "closed panel" managed care plan should be required to offer a "point-of-service option" to all enrollees, thereby permitting a person with a disability or chronic condition to access the patient's specialist of choice with reasonable cost sharing. The availability of a point-of-service option is especially important to people with disabilities and chronic illnesses, since the specialized medical care they require is often not available within the existing network of a plan's providers.

Continuity of Care

All health plans should be required to ensure the continuity of care for patients with ongoing, chronic conditions. This can be achieved by permitting an enrollee to continue to visit his or her network of providers for a reasonable period of time after a health plan discontinues operations in a particular geographic region or disrupts its provider network in other ways. In order to minimize the impact of these disruptions, consumers should have a right to an appropriate transitional period (such as 90 days) from the date of a provider's termination from a network plan, except in

cases where a provider is placing patients in harm's way through poor quality care. This transitional period should be further extended for enrollees with terminal illnesses, pregnancies, or those who are receiving institutional or inpatient care, through death, birth and discharge respectively.

Standing Referrals

Finally, consumers with complex or chronic conditions who require frequent specialty care should have the right to "standing referrals" without having to continually return to their primary care physician to secure approval. Standing referrals can be made as part of a treatment plan developed by the specialist, primary care provider and patient, and approved by the health plan. Timely, and in some cases, direct access to specialty care will help foster higher quality, more efficient, and cost-effective health care of people with disabilities and chronic conditions.

Timely and Accurate Comparative Information

In a market-based health care system, reliable and useful information is critical to effective decision-making. NCD strongly believes that all health care consumers, particularly people with disabilities, must have access to accurate, easily understood information to assist them in making informed decisions about their health plans, professionals, and facilities. All consumer-directed information should be available in alternative formats that meet the accessibility and communication needs of people with disabilities so that they are able to fully participate in this decision-making process. Health plans and providers should be required to disclose whether their facilities and operations are in compliance with the Americans with Disabilities Act of 1990.

Health plans and providers should be required to provide certain information upon enrollment and additional information upon request of the plan enrollee. Plans should provide information such as covered benefits and exclusions, lifetime and annual limitations in benefits and cost sharing requirements. Health care providers and facilities should provide information including experience rates in treating specific illnesses or injuries and accreditation status. Health care professionals should provide information including education and board-certification status. Health plans should also be required to disclose to providers and consumers drug formulary restrictions as well as exceptions when a non-formulary drug alternative is medically indicated. In addition, plans should include physicians and pharmacists in the development of drug formularies.

Right to Participate in Treatment Decisions and to Refuse Treatment

NCD believes that all patients should be respected and afforded the opportunity to fully participate in decisions related to their health care or the care of a person under their legal guardianship. Patients should be provided with easily understood information on all appropriate treatment options and should be told about the risks and benefits of each treatment, including mental health services. All patients should also have the right to refuse treatment. Finally, health plans should establish specific policies assisting people with sensory, mental and other disabilities in order to maximize the degree to which they are active participants in the decisions related to their health care, including training health care providers to be aware of how to communicate with people with developmental, psychiatric and sensory disabilities.

Elimination of "Gag Clauses": NCD believes that health plans should be explicitly prohibited from restricting patient-provider communications in any manner. Providers should be allowed to inform patients of all medical options, not just the least expensive, without retribution from the plan. In addition, financial incentives designed to restrict patient-provider communications should be prohibited. Providers should also be permitted to advocate on behalf of their patients, without retribution from the health plan.

Emergency Room Protections

Like all health care consumers, people with disabilities and chronic illnesses are in need of emergency room services on occasion. NCD supports a patients' bill of rights that gives patients the right to visit the closest emergency room in an emergency situation, according to the "prudent layperson" standard. In other words, if a "prudent layperson" without medical training believes that he or she is experiencing an emergency medical condition and visits an emergency room, the health plan should be required to pay for this care. Prior authorization for emergency room care under the prudent layperson standard should be prohibited and the patient should pay no more for an out-of-network emergency room visit than if the emergency provider were in the plan's network. Emergency room patient protections should extend to crisis intervention and emergency mental health services provided to people with acute mental illness.

Access to Clinical Trials

The Medicare program recently announced that it would pay for the routine costs associated with a beneficiary's participation in a clinical trial. "Routine" costs include items and services that Medicare would normally pay for, such as room and board during a hospital stay and health care services to treat the side effects and complications of the clinical trial regimen.

NCD believes that this benefit should be extended to all patients who are covered by private insurance. Patients with chronic illnesses must have access to the full range, and all phases of, federally approved clinical trials. Therefore, individuals with life-threatening or serious illnesses for which no standard treatment is available should be allowed to participate in clinical trials. Any routine patient care costs incurred in connection with participation in the clinical trial should be covered by the health plan.

Strong Grievance Procedures

All patients, including people with disabilities, should have access to a fair and timely internal appeals process as well as an independent, unbiased external appeals mechanism to address health plan grievances and to help govern decisions about medically necessary treatments. Health plans should be held responsible for providing patients with timely, understandable notice of decisions to deny, reduce, or terminate treatment and the reasons for these decisions. All information about the grievance process should also be made available in alternative formats so that effective communication with enrollees with disabilities is ensured. NCD also believes that patients should have access to a binding independent external review process after they have exhausted the plan's internal appeals processes, except in cases of urgently needed care.

Health Plan Liability: NCD is aware that the health plan liability issue has confounded Congress for several years and has led to an unacceptable delay in enacting a comprehensive and enforceable patients' bill of rights. On the other hand, as stated in its recent Progress Reports, NCD believes that without adequate remedies, there will be no meaningful patient rights. Health plans should be held accountable for the medical decisions they make, especially when those decisions harm patients or lead to the patient's death. However, the remedies within the patients' bill of rights should instill accountability in the system without leading to sharp spikes in the cost of health insurance, thereby increasing the number of uninsured Americans. Therefore, NCD will support any thoughtful, balanced approach to health plan liability that holds plans accountable for medical decisions without excessively driving up plan costs.

Patient Rights that Require Additional Attention

There are a number of issues that impact the disability community significantly but have not been included in the patient rights debate to date for a variety of reasons. While NCD is very interested in seeing a patients' bill of rights signed into law at the earliest possible opportunity, the following issues are of such great importance to the disability community that NCD will continue to work for their inclusion in the short and long term:

Benefits/Medical Necessity Definition

One of the greatest threats to the quality of health care of people with disabilities is the restrictive trend in the breadth of most health plans' benefit packages. This trend can be seen in two primary ways: The imposition of limitations and exclusions in benefits and the way in which the term "medical necessity" is defined by the health plan. All of the major patients' rights bills completely omit this important issue. NCD believes that any definition of "medical necessity" should include the concept of not only improving, but maintaining the functional capacity of the patient, taking into account consumer choice, consumer lifestyle, and the long-term effectiveness of the intervention, service, or device under consideration.

In addition, Medicare and Medicaid provide for in-home services critical for people with disabilities, such as physical, occupational, and speech/language therapy, as well as home health aides. Such coverage is often absent or inadequate in private health insurance. Also, most private health plans do not provide coverage for assistive technologies, which are crucial in helping people with disabilities return to work, improve their functional abilities, and live more active and independent lives. Finally, private health plans should be no more restrictive of mental health benefits than they are for physical health benefits. Private health plans should include these kinds of benefits for them to be truly responsive to the needs of all people with disabilities.

Privacy and Confidentiality of Medical Records

NCD believes that patients should be able to communicate with their health care providers in confidence and should have the confidentiality of their individually identifiable health care information protected. Patients should have unfettered access to their own medical records and be able to request amendments to their records to correct mistakes.

ADA Application to Health Plans

NCD believes that health plans and providers with rare exception are subject to Title III of the Americans with Disabilities Act ("ADA"), including the requirement to provide reasonable modifications to their policies, practices, and procedures under Title III of the ADA. In addition, private health plans and providers that receive Medicare and Medicaid funds for the treatment of these beneficiaries are required to meet the nondiscrimination provisions of the Rehabilitation Act of 1973, which apply to federal contractors and recipients of federal funds. Full implementation of these laws by health plans and providers could significantly improve access to and quality of health care for people with disabilities and chronic illnesses.