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CHALLENGE OF PROVIDING LONG-TERM HEALTH CARE

HEARING

BEFORE THE

SUBCOMMITTEE ON MEDICARE AND LONG-TERM CARE

OF THE

COMMITTEE ON FINANCE UNITED STATES SENATE

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SECOND SESSION

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CHALLENGE OF PROVIDING LONG-TERM HEALTH CARE

WEDNESDAY, MAY 13, 1992

U.S. SENATE,
SUBCOMMITTEE ON MEDICARE AND LONG-TERM CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 2:04 p.m. in room SD-215, Dirksen Senate Office Building, Hon. John D. Rockefeller IV (chairman of the subcommittee) presiding.

Also present: Senators Mitchell, Daschle, Durenberger, and Grassley.

[The press release announcing the hearing follows:]

[Press Release No. H-24, May 5, 1992]

SUBCOMMITTEE TO EXAMINE LONG-TERM HEALTH CARE; FAMILIES FEAR CARE WON'T BE AVAILABLE, ROCKEFELLER SAYS

WASHINGTON, DC—Senator John D. Rockefeller IV, Chairman of the Senate Finance Subcommittee on Medicare and Long-Term Care, Tuesday announced a hearing on the challenge of providing long-term health care.

The hearing will be at *2 p.m., Wednesday, May 13, 1992* in Room SD-215 of the Dirksen Senate Office Building.

Rockefeller (D., West Virginia) said the hearing will offer an overview of the problems involved with providing long-term care for Americans suffering from disabling illnesses or conditions.

"The time is past due to give every parent—every son and daughter—peace of mind in knowing they will be able to provide long-term care for a loved one, if needed, without fear of financial ruin," Rockefeller said.

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM WEST VIRGINIA, CHAIRMAN OF THE SUBCOMMITTEE

Senator ROCKEFELLER. We will have this hearing come to order, please. If people could take their seats, we will proceed. I want this afternoon to turn our attention back to long-term care. It still waits. It is impatient, the whole subject of it. It waits for both leadership and, more importantly, it waits for action.

The long-term care problem, as we are going to hear this afternoon, is not just about 11 million American adults and children who have the disabilities and illnesses that require long-term care.

It is the struggles, it is the sacrifices, it is the pain, it is the disruption, it is the incredible burdens that fall on those families and those parts of families, and on neighbors and on communities who are doing their very best to provide this kind of care on their own.

This hearing, really, is designed to be an overview of the long-term problem, the big picture. This hearing is not about one particular bill or one particular approach, it is about the problem. And I want this hearing to point us in the direction towards a solution.

On April 9, I joined members of this committee and other Senators in introducing a comprehensive bill to ensure protection for long-term care for all Americans. In a future hearing, obviously, I want very much to explore that bill and other bills, and do so in detail.

But I think we have to put first things first. And you do that, in health care, I think, by this process of hearings, which is not just a process of moving bills forward, but is the process of talking to Americans, and hearing from Americans, and learning from Americans so that we do not do things in a vacuum; so that we will have what people have to tell us first-hand at this hearing what it means to care for people who have chronic and disabling diseases.

I have no doubt that these witnesses will help us understand why the pressure is on those of us in this Congress to, in fact, enact a national long-term care policy and to do it as fast as we possibly can.

Our witnesses will share their struggles with a system that does not recognize and does not address their needs. First, we are going to hear, for example, from Jenifer Simpson, whose 7-year-old son, Joshua, suffers from cerebral palsy. Ms. Simpson will tell us about her difficulties in obtaining respite care and her need for personal assistant services.

Bill Keane will testify to share his families experiences in trying to care for his mother, who suffered from Alzheimer's Disease for over a decade. He will talk about the burdens on family caregivers and a system that fails them at every single point.

Finally, we are going to hear from Bill and Carol Eager, a couple, who, after raising their own family, now must assume a parenting role themselves once again in assisting both of their mothers; one who is bed-ridden and requires long-term care services, the other who is 90 years old.

Our second panel will provide us with an overview of the problem by experts. That is important, too. Everything is not pain and struggle; it has to be, where do we reach for solutions, where can we find a consensus that allows us to move this problem forward.

And we are going to be hearing from experts who have studied this intensively for a very long time and we can ask them to share their thoughts about how they would address the problem, either in general, or specifically. That will be up to them.

The final panel consists of witnesses who represent many of the people who provide the professional services that are involved in long-term care. I am looking forward to what we can learn from each other and what we can learn, particularly, from each of our witnesses.

I am going to leave the eloquence to the honest and heart-rending testimony of our first panel, and the education to the other panels. I think this hearing should challenge everybody in this room, in this country.

We have to renew our commitment, or, more precisely, I think we have to make our commitment to respond to the growing need across this country for long-term care when illness and disability strike.

It is irrational to stand to the side and to just watch the financial, psychological, and human toll of the current situation, but that is what we are doing.

In poll after poll, Americans say they desperately want protection, not just from fear, but from long-term care. And they recognize that government has to step in and play some sort of role in extending that protection. People are not liquid on that subject; they are very clear what they expect of government.

They tell us, in fact, they are willing to pay a reasonable amount, and they have told us that in many ways, in many surveys, for true financial and emotional security. It is time, now, to take a hard, long look again at this problem and reach some conclusions about what we can do and what we must do.

From my own point of view, I pledge to make every single effort. Really, I want to say to continue to pledge to make every single effort to get this consensus and to get some peace of mind for an awful lot of people in this country.

Senator Grassley.

OPENING STATEMENT OF HON. CHARLES E. GRASSLEY, A U.S. SENATOR FROM IOWA

Senator GRASSLEY. Thank you, Mr. Chairman, for holding a hearing on a very difficult issue and one that is not only a human resource issue, but also very much a budget issue as well.

And it happens to be one of the greatest sources of anxiety and fear for older people, that they may have to some day face long-term care. And it could even be the greatest source of anxiety for older people.

They have good reason to fear the need for these services, because very few people can afford the cost of long-term care, even for relatively short periods of time. And if the need for such services last longer, of course, it is almost certain to cause impoverishment, or near impoverishment.

It is also clear that the psychic costs of caregiving are tremendous and can have consequences for physical health also for those who give that care. For instance, the National Institute of Mental Health has sponsored research which has shown, as I understand it, that the immune function is hindered in those who undertake heavy-duty caregiving.

Now, the long-term care issue certainly is not a new one, because the 1971 and 1981 White House Conferences on Aging focused attention on it. The Aging Committees in both Houses have held many hearings in this area over the years.

Years ago, I held two hearings on long-term care policy, and workshops and hearings on Alzheimer's Disease when I was Chairman of the Subcommittee on Aging, starting in 1983.

Several current members of the Finance Committee introduced long-term care legislation many, many years ago. I can think of Senator Bradley, Senator Hatch, Senator Packwood, and, of course, our Chairman, Senator Rockefeller, has had a longstanding commitment to address this issue.

It seems to me that what has held up action on this problem over a very long period of time is the projected cost of any comprehensive long-term care program. Estimates of the near-term costs of comprehensive programs usually show that they are very expensive. Furthermore, the future costs of such programs, particularly after the baby boomers begin to retire around 2010, are usually projected to increase greatly and very rapidly.

Of course, the advocates for long-term care reform are correct when they remind us that the families of those who need long-term care are now paying most of those costs.

Nevertheless, that does not alter the fact that launching a very expensive new Federal program in the context of our current budget deficit would be very difficult.

I have co-sponsored legislation introduced by Senators Packwood and Dole called the Secure Choice Long-Term Care Program. This legislation would create a public/private program which would try to facilitate the purchase of long-term care insurance for the middle income, and would provide a public program for low-income people.

This legislation, although you can say that it is relatively cheap, is still costly at $7 billion.

Unfortunately, the long-term care question seems to have been shunted to one side in the debate on health care system reform, at least to this point.

Of course, some of the reform proposals do contemplate including long-term care programs. Nevertheless, it does seem to me that most of the debate has focused upon the acute health care system.

As we debate the health care reform issue, we should try not to lose sight of the fact that we have to do what we can to improve and humanize long-term care policy. And this hearing is going to help us do that, Mr. Chairman. Thanks again.

[The prepared statement of Senator Grassley appears in the appendix.]

Senator ROCKEFELLER. Thank you, Senator Grassley. As always, you approach things with absolute sincerity and purpose. That is why it is great to serve with you.

Senator Daschle.

Senator DASCHLE. Mr. Chairman, I have no opening statement today.

Senator ROCKEFELLER. Good. Thank you very much, Senator Daschle. Can we have the first panel come forward, then? We will have Bill and Carol Eager, accompanied by Judy Waxman, who is director of government affairs for Families, USA; Bill Keane, member of the national board of trustees, the Alzheimer's Disease and Related Disorders Association; and Jenifer Simpson, who is here as a parent, and on behalf of the Consortium for Citizens with Disabilities.

Jenifer, if it is all right, I would like to start with you.

STATEMENT OF JENIFER SIMPSON, ON BEHALF OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES ASSOCIATION, WASHINGTON, DC

Ms. SIMPSON. Mr. Chairman, members of the subcommittee, I am Jenifer Simpson. I am here today to talk about my experience with getting personal assistance and other long-term support services for my son, Joshua, age 7, who has cerebral palsy.

Joshua is one of some 500,000–700,000 children and adults with cerebral palsy in the United States today. Overall, there is estimated to be 7 to 9 million Americans with varying disabilities of all ages who need some type of long-term support services so they can participate and be fully productive members of this society.

I testify today as a parent, and as a representative of the Consortium for Citizens with Disabilities Task Force, on Personal Assistance Services and the Long-Term Services Medicaid Task Force. The Consortium will submit, within 10 days, written testimony on these issues, as well.

[The prepared statement of the Consortium for Citizens with Disabilities appears in the appendix.]

Ms. SIMPSON. Mr. Chairman, I am grateful to be here today to tell you about the struggle that I, and thousands of other parents, face trying to get access to such vital supports for our sons and daughters with disabilities and chronic illness.

I would like to describe what life could and should be like for families like my own. In many ways, Joshua is a typical and healthy little boy. He likes computers and he likes to play with toy trains. He is sociable, alert, and attends school. He is skipping it here today to be with us.

What makes Josh different from most other kids, though, is his disability, or, rather, our Nation's failure to support my decision and efforts to raise him at home where he belongs.

Cerebral palsy is neither a disease nor an illness. Rather, it is a lifelong disability that can affect a person's ability to express themselves or perform everyday activities independently; things that you and I do almost without thinking.

Such individuals like Joshua most often rely on assistance from others, or from assistive technology devices such as motorized wheelchairs, augmentative communication aids, crutches and the like, to make otherwise impossible things both possible and within reach. This is the dream of freedom in the ADA, the Americans With Disabilities Act, and it is one I want to see made real for Joshua.

Joshua's disability makes it difficult, if not impossible, for him to walk, talk, eat, drink, use the bathroom, get dressed, or do most anything without a lot of help. He gets most of that assistance from me.

But, besides being a full-time single mom, I am also a full-time policy associate with the United Cerebral Palsy Association's office here in Washington, DC.

Increasingly, therefore, I must pay others to meet Joshua's extraordinary personal assistance and other needs when I cannot be there to do it for him myself. And finding the money to pay for that care and those individuals to do the personal assistance, and to train, them is a constant challenge.

I love my son, but caring for him is a big challenge. I feel that I have two jobs: one at the office, and another as a case worker or as a service coordinator for a child with disabilities. I think these dual roles contributed greatly to my marriage falling apart.

You cannot expect a family, even a regular, middle-class family with college-educated parents who have decent jobs, to stay together under the kind of stresses we have endured.

The needs of a child with severe, multiple disabilities are so many and so immediate, that any committed parent will try to meet those needs first. What gets sacrificed is the marriage.

Only once in the 5 years of our marriage could we afford to arrange respite care for 2 days, and that was paid for out of our own pockets.

The government is there to institutionalize a child after his or her family has fallen apart, but is not there to support a family trying to cope. I hear it now costs about $85,000 a year, on average, of the taxpayers' money to keep someone like my son in an institution.

Where is the logic or the justice in this? I think the government should invest in people with disabilities and their families, not in bricks and mortar.

In Joshua's brief life, he has already been covered by a total of seven different health insurance companies. Two jobs changes, a move out of State, and employers buying into new plans are the reason. And each of these policies has pre-existing condition clauses, different benefit packages, and an awful lot of fine print.

In fact, I have a two-drawer file cabinet at my home just for the insurance paper work on Joshua. And what has he gotten out of this? In fact, very little, in terms of long-term support.

There ought to be a law, one that nurtures and supports the efforts of parents who want to do the right thing by their kids with disabilities, and one that enables adults with disabilities, as Joshua will 1 day be, to gain the personal assistance and other supports they require to lead independent lives.

There have been changes to the Medicaid program which support community and family life for people with disabilities. The Medicaid waiver for home and community-based services provides the option for States to fund the kind of services Joshua needs to live at home, and the new Community-Supported Living Arrangements (CSLA) authority under Medicaid gives eight States the opportunity to fund these kinds of services which emphasize the choice of the consumer and which promote real-life activities rather than institutional living.

But both of these programs are limited in terms of eligibility and funding, and neither is available to my son, as he is not eligible for Medicaid, and the District of Columbia, where we live, does not make either option available for someone in Josh's circumstances.

More often than not, therefore, parents like myself are faced with the ultimatum of either going it all on our own, or placing our son or daughter in an institution, for which Medicaid will pay.

What we really need is Federal legislation that assures access to an array of long-term supports and assistance to Americans of all ages. Families need to be afforded choices and support, not forced to react to either/or ultimatums.

A national entitlement program should be created to invest in and fund a comprehensive array of personal assistance services, therapies, assistive technology, training, and other vital community support services to all those who need them.

Eligibility for these services should be provided to the child or the adult with a disability based on an individualized assessment of their real-life needs and capabilities.

Eligibility should not be based on a limited diagnostic category, or on an arbitrary description of limitations, such as the use of activities of daily living, as a sole criteria for determination of need. Instrumental activities of daily living must also be considered, e.g., the need for assistance in shopping, or food preparation. I'm not talking maid service—this is simply disability—or illness-related inabilities.

Many States now have exclusionary eligibility criteria based on categories like cognitive disability, and not on the real and similar needs of people. Furthermore, eligibility should take into account the disability-related expenditures or extraordinary expenses of the individual or the family.

Joshua, for instance, will need many kinds of support as he grows to adulthood. He will continue to need physical therapy, occupational therapy, and speech therapy.

He will probably need assessments and services from speech pathologists, neurologists, and others throughout his life. He will certainly need service coordination assistance when I am no longer around or available to do it for him.

He will also need training and other supports to get and keep a job. He also needs access to assistive technology, such as a computerized communication device, so he can learn to express himself.

Similarly, as an adolescent and adult, he will need assistance in living independently, with things like making meals, shopping, paying bills; what are called instrumental activities of daily living.

Most of these services are not covered by any health insurance plan or social service system that I know of, or for which I, and Joshua himself as a adult, might be eligible.

Moreover, Joshua's greatest need is for personal assistance services to help with bathing, dressing, and other day-to-day activities; what I call feeding him and wiping his bottom.

Right now, as I said, I meet much of this need myself. But what happens to my son if I develop an illness or am forced to take another job to try and make ends meet.

Would Josh have to go into a nursing home? Probably so. The personal anguish of such a decision would devastate me, and I would not be the first parent compelled to make such a choice.

As both a parent of a child with a disability and a taxpayer, this makes no sense to me. If Medicaid monies can be used to support individuals with disabilities and their families at home and the community, all States should be urged, if not required, to take full advantage of these provisions and these options.

Similarly, individuals with disabilities and families should not be forced to become poor in order to qualify or become eligible to receive vital support services.

Access to personal assistance services, all the therapies, technology, training, and other long-term community support services must be viewed as a right, not a privilege, in our Nation. I am trying to care for my child at home where he belongs, and for that I get no help.

Joshua has a right to full participation in the American dream, and that will not happen if he is hidden away, that is, segregated, in some big, brick institution away from the rest of us.

I have been a responsible worker in the American work force since I was 16. I have always paid taxes. There is no equity in a system which compels me to go to incredible lengths to get what he needs and to live under stresses which have caused a family system to break apart.

I am pleading with you now to enact meaningful change as soon as possible so Joshua and the thousands of children with disabilities and chronic health care needs can get the personal assistance services and long-term community support they and their families so desperately need. Joshua and I need it now. We cannot afford to wait any longer. Thank you.

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

Senator ROCKEFELLER. Thank you very much, Ms. Simpson. If the committee is willing to go along with this, I would like to have us talk to you first because Josh is with you. He is very lucky to have a mom that fights for him as hard as you do. Let us make that very clear.

What you basically said is that when it comes to walking, talking, eating, drinking, using the bathroom, getting dressed, and most other daily activities, he needs help.

Ms. SIMPSON. Yes.

Senator ROCKEFELLER. The decision to keep Joshua at home with you is incredibly personal, incredibly important to you and also very difficult. You shared partly what you had to go through in looking at this financially, in human terms, as a mother, et cetera. Can you just tell us a little bit more?

Ms. SIMPSON. I think respite is a real key piece of this. We have never had any respite other than what we paid for, and I think the sheer stress of hardly ever getting a break, either when I was married or even now, was and is one of themost enduring stresses that I must manage.

It is interesting to me that, now I am divorced, I get court-ordered respite in the sense that my spouse now takes care of my son more during child visitation time. That is the respite I get now.

Senator ROCKEFELLER. In our concept of America, when somebody is in trouble, the community, neighbors, everybody comes to help the nuclear family. It appears to me that the nuclear family is scattered across the country a lot much more, now.

In this round-the-clock responsibility that you have—Josh at home, loving mother, fighting mother—to what extent is there, or is there not, a support network out there for you—non-governmental.

Ms. SIMPSON. No; there isn't much. Most of my family lives on the west coast. I have applied many times to programs. In fact, I have been rejected from several programs for different reasons. Sometimes there are eligibility issues around Joshua's disability; sometimes there are issues of eligibility around my income level.

Mostly they do not take into account the extraordinary expenses associated for personal assistance care for Joshua when they calculate need based on financial means tests.

I spend between $7,000 and $10,000 a year on personal assistance services for Joshua, and other out-of-pocket medical expenses.

Senator ROCKEFELLER. And resources, either from an extended family or from a community, or whatever, coming to help you, that just does not happen, or it happens for awhile and then it——

Ms. SIMPSON. I get tired of being in a position of begging, actually. I do not like that.

Senator ROCKEFELLER. Explain to me what you mean.

Ms. SIMPSON. Several times I have coordinated, say, funding for a special chair for Joshua so he can sit upright in the special position with a tray, and applied for the funding through the insurance company. They have turned me down and said, no, that is not something that is covered; you will have to get someone else to pay for that.

One insurance company said to me, why do you not go to the Elks or the Knights of Columbus, they will give you the money for that. So, I proceeded to do that. I also went to my family. And through sort of a smorgasbord of hunting and searching, I was able to pay for this $300 special chair for Joshua.

Actually, it is the coordination of all the things he needs that is also very stressful. Right now, I am running a search for a personal assistant for him. This means I have to run home and interview people during the day.

I am also in a struggle with the school district about the transportation system. They forgot to pick him up from school yesterday. For some reason, the bus did not make it to the school.

All last year I had a running struggle with the school bus system because the elevator did not work on the bus and I finally had to go through a legal due process to have them have an elevator on the bus that worked. Just about any area, it seems, is a struggle. Sometimes it works; sometimes it does not seem to work very well.

I live in the inner city. I encounter the normal, everyday stresses that all families in the inner city deal with: drug deals on the corner, sirens all the time. And those are just on top of all the other stuff, really. Or maybe the disability needs are on top of all that. I am sometimes not sure which one has the priority in terms of survival.

Senator ROCKEFELLER. I am trying to think of how you could handle your day, even as you are working for an organization which is clearly in every way sympathetic and helpful to you, and I am trying to imagine what you would do if you were working for some other organization which did not have that.

Ms. SIMPSON. Until I worked for United Cerebral Palsy, I worked for a private company and had to work out taking time off without pay or use my accrued vacation or sick time in order to accomplish some of these things that Joshua needed.

Senator ROCKEFELLER. The question of personal care services and respite care. I thought I heard you say at the beginning of your testimony that you only had 2 days. Was that a government-supplied 2 days, or personal?

Ms. SIMPSON. No. We paid for that out-of-pocket.

Senator ROCKEFELLER. That was your own.

Ms. SIMPSON. We found someone to come into the home and we went away for a weekend.

Senator ROCKEFELLER. And, tell me, when you went away for that weekend, the business of sort of getting yourself back together, getting some sleep, writing some letters, calling up some friends. What is it that you need the most from us on this to help you?

Ms. SIMPSON. I think there needs to be available a fully accessible, affordable respite service that a parent can trust and have choices about who comes to their home to take care of their child or their individual with a chronic condition.

Senator ROCKEFELLER. Yes.

Ms. SIMPSON. I think it has to be consumer-driven. I mean, you are letting someone into your home whom you have to be able to trust to take care of somebody who sometimes cannot communicate back to you if—there is a whole protection issue here, I think. There has to be safeguards in there for consumers like Joshua and other adult consumers with disabilities.

Senator ROCKEFELLER. Ms. Simpson, our Majority Leader, Senator Mitchell, has joined us. And I know that Dave Durenberger, who has not spoken yet, and our other members understand he is very busy. He chaired all the health committees in the Finance Committee before he became Majority Leader on the floor. He has a passionate interest in all of this.

Mr. Leader, Jenifer's son has severe cerebral palsy. She has been trying to do this as a mother. She keeps him at home. She is up against a system which is not responding to her, and she has been telling us about that.

I wonder if you had either a statement that you wanted to make, or questions, assuming that your time is limited.

OPENING STATEMENT OF HON. GEORGE J. MITCHELL, A U.S. SENATOR FROM MAINE

Senator MITCHELL. Yes. Mr. Chairman, thank you very much for your courtesy. My thanks to Senator Durenberger, Senator Grassley, and Senator Daschle for their courtesy as well. I do have a statement I would like to make.

I do not have any questions for Ms. Simpson. I do want to commend her for having the courage to come here today. I know it is not easy to get into personal details in public, but I think your example will be helpful to the committee and to all of us in understanding and coming to grips with the problem.

I would, Mr. Chairman, if it is permissible, like to make a brief statement and then submit questions for the record for these and other witnesses here today.

Senator ROCKEFELLER. Of course.

[The questions appear in the appendix.]

Senator MITCHELL. Mr. Chairman, I begin by commending you for holding the hearing to focus the subcommittee's attention on this important issue. There is a lot of talk about health care reform this year, and, in the process, we cannot forget the needs of millions of elderly and disabled Americans for long-term care.

Last month, I joined with you, Mr. Chairman, and other Senators, to introduce the Long-Term Care Family Security Act of 1992. The bill is a product of a collaborative effort on the part of a number of members of the House and Senate, all of whom are committed to the development and enactment of a comprehensive long-term care policy.

In 1988, as chairman of this subcommittee, I introduced the first comprehensive long-term care bill in the Senate. Since then, a lot has changed. But, also, a lot has not changed. And the need for meaningful long-term care has not changed. In fact, the need has grown greater.

It is critical and it is becoming more critical as our population ages and persons over 85 become the fastest growing age group in percentage terms in our country. But long-term care is not and should not be regarded as an elderly issue alone. The absence of a long-term care policy affects persons of all ages, as we are hearing right here today.

The need for long-term care affects young adults who become disabled in automobile accidents; it affects the middle-aged children of the elderly who must choose between caring for a parent or putting a child through college; and it can sometimes affect children who are born with serious disabilities which require chronic home care.

I believe we must find a way to develop a rational, affordable long-term care program to meet the needs of those Americans who cannot fully care for themselves.

Any policy must, first, cover persons of all ages. I think it is essential that this be seen clearly for what it is, not just a problem of elderly Americans. It affects Americans of all ages.

Second, it must provide the full range of benefits based on the needs of the individual rather than what is or is not reimbursable. Too many health care decisions today are driven by reimbursement policies. That ought not continue.

Third, it must contain significant cost containment provisions. Fourth, it must include care management and quality assessment. And, finally, I believe it should reserve a role for private long-term care insurance.

The legislation Senator Rockefeller, and I, and others have sponsored includes such provisions and represents a good step forward to reaching consensus on such a national policy. We do not offer it as the ideal policy or the perfect solution, but it is a serious effort to deal with a serious problem.

Some criticize the bill because the benefits are limited. Others criticize it because the benefits are too many. Others say it goes too far and costs too much. But it is the product of our best effort to design a policy that will provide the full range of necessary services while attempting to control the costs of providing such care.

Enactment of this legislation will be difficult. No one should have any illusion about that. This is a very difficult undertaking. It will have to be phased in over time to manage the costs. But, to ignore the problem because it is too difficult or too expensive will not make the problem go away, it will only make the ultimate solution more expensive and more difficult.

Those who will be eligible for this program are the most frail among us: the elderly, the disabled. They need our help to be able to live the most productive lives possible, and almost, without exception, they can lead productive lives.

We have got to work to develop this policy, and we are going to do it. And I look forward to working with my colleagues here, each of whom I know is committed to this goal. And I look forward to reviewing the testimony of the witnesses.

Mr. Chairman, I thank you very much, again, for your courtesy, particularly in permitting me to interrupt the testimony. And I do have a number of questions that I will submit for the record.

Senator ROCKEFELLER. Thank you, Mr. Leader.

Senator Grassley.

Senator GRASSLEY. Mr. Chairman, I do not have any questions of this witness. But, obviously, it is very moving testimony and is going to make a real impact on this issue, coming, as it does, first-hand from someone who has experienced the difficulties of this family situation and this health situation. So, I commend you for appearing, and particularly commend you for the humanitarian approach that you take.

Ms. SIMPSON. Thank you.

Senator ROCKEFELLER. Thank you, Senator. Senator Daschle.

Senator DASCHLE. Thank you, Mr. Chairman. Ms. Simpson, I was interested in your answer to Senator Rockefeller when he asked if there was one thing we could do.

And your answer, probably not surprisingly, was to find a way to offer you some reprieve through what must be a very tortuous week as you consider all of your responsibilities. I think a possible answer might be some form of financial relief.

You had indicated your expenses are $7,000 to $10,000 a year. You also indicate that some of the assistance you get financially is in the form of private health care insurance coverage. Is that correct?

Ms. SIMPSON. They will cover certain reimbursable items at 80 percent of its cost. There are many out-of-pocket items, though. There is always the 20-percent co-payment, the $400 family deductible, and the premium that I am paying. (I pay $40 a month for health insurance; my employer pays the premium balance of about $625 per month for us.)

What I would also like to see is what are called the family support items. In Michigan and Minnesota, for instance, there is a cash grant or voucher program where families that have a child with a disability—and I do not believe it is a means tested program—are given a certain amount—I think $3,000 a year—to spend any way they wish. Sometimes they spend it on diapers. I could certainly use financial assistance with diapers. I spend about $550 a year on diapers.

Other families would spend it, say, on respite, or on the elevator in the van if they buy a car and they need to adapt it, which I will need to do as Joshua gets bigger and needs a bigger wheelchair. Joshua will need many more disability-related things as he ages. And I could use that kind of straightforward assistance.

Senator DASCHLE. What I am trying to do is arrive at an annual cost for caring for Joshua at this cost. You had indicated your out-of-pocket costs of $7,000 to $10,000. That is a very significant contribution. Beyond that, there is a contribution made by the insurance company.

Do you have any way of estimating what the value of that coverage in terms of costs on an annual basis might be? Is it somewhat similar to the commitment you have made? For example, do you pay 50 percent of the costs and does the insurance company pay the other 50 percent?

Ms. SIMPSON. Different insurance companies have paid some acute care costs, e.g., one year there was $8,000 on surgery for his legs. He has had two wheelchairs in 3 years, totalling about $7,000. This year foot braces cost $800. I do know that if Joshua were in an institution it averages around $85,000 a year.

Senator DASCHLE. $85,000?

Ms. SIMPSON. Yes. That is what it costs the taxpayers under the Medicaid program for ICF–MR on average. In Wisconsin, I know it is close to $100,000. I make something like a third of all that, so I do it for considerably less than the institutions could do it.

But, then, on the other hand, Joshua goes without a lot of things, as do many adults who choose to live on their own with disabilities. They are sacrificing things that they would need. Joshua would need a communication device, for instance. Those cost around $8,000. Insurance. I am asking insurance now if they will pick up any of it. They are going to get back to me at some point about that. Sometimes the school system will pay for pieces of what he needs, e.g., physical therapy during school year, but not over the summer. Insurance pays 80 percent of that then.

There is a huge coordination piece here that I find difficult to deal with. I know some of his needs. The adults with disabilities, I know, know their needs. Very often it is trying to work out who is going to pay for it other than themselves is the hard part.

Senator DASCHLE. Which is what you were alluding to earlier, the fact that you have got to beg for some services that you simply cannot afford personally. Is that correct?

Ms. SIMPSON. Yes. Coordinating financial support, providers, suppliers, what's needed, requires a lot of figuring out. There is a great deal that Joshua goes without, for instance. Joshua needs a ramp up my front steps, for instance. I would like a handrail up the stairs so he can grab on instead of leaning and holding onto me. He lacks balance completely.

These are a number of household adaptations, for instance, that would be nice to have. And I am sure many other individuals with disabilities could use those kinds of things. People with disabilities know what they need to make their life easier.

Senator DASCHLE. So, you do get assistance from the insurance company. And, of course, that would vary, but I would estimate, from what you are saying, that it is probably in the single digits in terms of thousands of dollars. Is that correct?

Ms. SIMPSON. I do not know. I have never actually sat down and calculated how much it would really cost if he got everything that he should have.

Senator DASCHLE. All right. Who else in the community is able to provide you with some assistance? Do you get assistance at all from the counties or the communities?

Ms. SIMPSON. No. I am not eligible for anything.

Senator DASCHLE. Nothing at all?

Ms. SIMPSON. No. I tried to apply to SSI, but I was not eligible based on the means test. I said, could you please take into account my extraordinary expenses for personal assistance service, and they said, no, we are not allowed to do that yet.

They were very sympathetic, and they referred me to the Medicaid office here in the District of Columbia. I went and got the forms, and I basically have to say that my child would be at risk of institutionalization in order to qualify for services.

And I do not feel like he is at risk of institutionalization because I want to take care of my son in my house and lead a regular, normal life. I mean, I do not consider that really an option.

Senator DASCHLE. Well, I thank you very much. Your testimony was just excellent. We appreciate your coming this afternoon.

Ms. SIMPSON. Thank you.

Senator DASCHLE. Thank you, Mr. Chairman.

Senator ROCKEFELLER. Thank you, Senator Daschle. Ms. Simpson, Senator Durenberger, from Minnesota, has been at all of these things far longer than the rest of us in the panel and has a great deal of knowledge. We would welcome his comments and any questions he might have.

OPENING STATEMENT OF HON. DAVE DURENBERGER, A U.S. SENATOR FROM MINNESOTA

Senator DURENBERGER. Mr. Chairman, thank you for your comments. Jenifer and Joshua, both, thank you very much for coming. I would like to make an observation, first, about a couple of points that Senator Mitchell made.

First, that long-term care is a situation that is experienced by people of all ages. I do not know how long it takes to get that notion through people's heads, but your being here goes a long way towards bringing that home to us.

I have been fortunate enough for the last year or so to employ as a volunteer on my Minnesota staff a 24-year-old brain-injured woman who was seriously injured in an automobile accident.

She is the most beautiful person anybody has ever met. The wonders that she does for the other 13 people in that office every single day by what she can accomplish is marvelous.

Secondly, his observations about the fee-for-service system in this country, which applies equally to medical care and long-term care in this country.

The policies and the programs for health, medicine, and long-term care in America are all an accident. And they are a very expensive accident. But they are a more serious accident, to people like you, just waiting to happen.

We now have a $4 trillion national debt, which equals $15,000 a year for every person in America.

I remember looking at a speech I made in 1984 on the same subject, debt, where I said it cost us each $2,000. I can see what is going to happen. In about 12 months somebody is going to say $4 trillion and all of this debt service, we have got to cut back.

And where are we going to cut back? It is going to get to the income support programs because there is a great deal of money being misspent, if you will, because it does not make sense for people like the Simpsons.

As far as I am concerned, one of the first things we ought to destroy in the whole system is the fee-for-service system. We ought to replace that with some kind of a flat rate, risk-adjusted payment to health plans that will treat people like people and meet their needs.

Program eligibility is dividing people. You just illustrated that in your response to Tom Daschle's question. It depends on whether you are in the District of Columbia, or you are in Fairfax County, or in someplace a lot better off.

If you were in Minnesota right now. I am sure they could handle the eligibility much more quickly. You would be eligible for some State support programs, and a bunch of things like that that you referred to.

I mean, you are an American citizen. Why in the world should the accident of where you happen to be located determine your eligibility? The same thing with disability determination—whether it is Joshua, or the young lady who works for me, or whomever.

Think of the rigors. If any of you ever sat in the place of your case workers and tried to do some of these disability petitions that come to you: somebody has been disallowed, somebody got a 20 percent disability and they think it should be a 50 percent et cetera. Walk through Veterans Affairs, walk through Social Security, walk through Workers' Compensation. Walk through this whole crazy system, and it does not make a lot of sense.

So, I am glad the Majority Leader made that point and I am glad that, by your presence here today, you have reinforced that point. For one, I believe that what we are talking about is income security, and those are the kinds of questions you were being asked by each of the people here.

It is not whether or not you got so much for this and so much for that. It is, you ought to decide what you really need, and, under these particular circumstances, what is most appropriate.

A good national income security system using your earnings, using social insurance, using private insurance, using tax policies, ought to make sure that it works. The faster those of us who are in the health reform business get about nationalizing the responsibility for income security and cut this umbilical cord with the States that is strangling too many people like you, the better off we all are going to be.

But I can see that is going to be a tough row to hoe. When the States are balancing their budgets but not meeting people's needs, we are not balancing ours and not meeting people's needs, it is going to be really tough to accomplish.

But, thank you for advancing the cause today.

Senator DASCHLE. Thank you very much, Ms. Simpson. You are welcome to stay, or you may go. Thank you very, very much. Sincerely. Thank you, Josh.

Bill and Carol Eager and Bill Keane, why don't both of you give testimony and then we will ask you some questions after that. Do you want to start, the Eagers?

Mr. EAGER. Sure. I would be glad to start.

STATEMENT OF BILL AND CAROL EAGER, RESTON, VA, ACCOMPANIED BY JUDY WAXMAN, DIRECTOR OF GOVERNMENT AFFAIRS, FAMILIES USA, WASHINGTON, DC

Mr. EAGER. Good afternoon. We are Carol and Bill Eager, and we live in Reston, VA with Billy, Amy, Kevin, Elizabeth, Sarah. Michael, Amon, John, Zeke, and Josh; 10 of our 11 children; along with Carol's mother, who has Alzheimer's Disease, my 90-year-old mom, and my mentally handicapped sister.

I want to thank you, Mr. Chairman, and other members of the panel for allowing us to be here today. It is an honor, and we appreciate being allowed to share our story.

I think, to begin, I would ask Carol maybe just to share a little about the person who is her mom, and the person whom we care for.

Mrs. EAGER. Today I would just like to tell you who my mother is, and, in a sense, tell you why it is frustrating caring for her, and also why it is a privilege to care for her.

I came into this world in 1944. Right then, my mom's world was one of a Navy nurse. She is a veteran; my dad is a veteran. They came together in marriage, started a family, and worked very hard. Dad worked for Hudson County for 30 years. During this time, he also had a night job in Hoboken from 4:00 to 12:00 so that he could give the four children an education.

This was a value to my mom and dad. So, now, I have had my college education. Jim, Eugene, and Tom, my three brothers, have also attended State colleges in New Jersey. Eugene got to go to a private college. Mom and dad worked hard.

We had a good home life; all the things, in a sense, that a mother and father would want to give their children. We had wonderful Christmases and happy birthday parties at the kitchen table, not at Chuck E. Cheese; we did not know about those kind of birthday parties then. But our bills were paid.

My mom, being a Navy nurse, returned to nursing. As we got to be college-aged, she took her renewal course and got back into the nursing role that she loved so well. Dad, in time, became her last patient.

I can still remember as he was dying he was very happy that he had lived to be over 60 so his county pension would be really great for mom; half his annual salary. Well, that great pension dad worried about comes to $4,000 a year.

Now, I would challenge anyone here to live in Reston, VA, or in New Jersey, on $4,000 a year with dignity. Social Security does help mom, also.

What I am trying to say is my mother has done her work as a mom, as a person, as a wife, as a citizen; worked the polls, did all of the good citizen stuff. She raised her family. Now she has a need. She has been blessed with her children; her children have been blessed with good health.

So, I am able to care for her. Let me say, I consider it not a burden to care for my mother. I am not looking for other people to do what I feel is right to do. What I need to say today is that I do need help in doing this. We are all brothers and sisters.

My mother needs me to speak for her today. I have often been asked, how do I do it, why do I do it? Here I am, the mother of 11 children, a wonderful husband who loves me and cares for all of us.

Bill suggested maybe I talk about my day and how it is different. Well, time would not allow it. You probably would not believe half of it, anyway. But I will tell you a little bit about a day I do remember 6 years ago.

I was expecting twins. I went from crying, oh, no, Lord, more babies, to finding out I was having two of them, and I have never been so happy. I said, two, wow, what a gift. My health was very good. I was 42 years old, but with nine children to care for.

My mother was mobile. She was at that Alzheimer's stage where they kind of go around the house, and mom did not really know who I was then, or did not have her mental ability. Physically, she was strong. She was able to care and feed herself, but she had become incontinent.

A day care was available, but it was 18 miles away. All I had to do was get mom ready, and she would go off to this wonderful respite center.

That meant bathing and feeding her. Now, bathing and feeding babies, that is a mess, but it is a joy; it is fun. But bathing and feeding your mother is hard. It is humbling, it is physically hard, and it is at a place you really do not want to be.

Getting her to cooperate because of her state in Alzheimer's, and walk safely upstairs with my 6-month pregnant body was a sight to behold. Remember, incontinent people do not smell good, so you are not sending your mother off to a day care center unless she has been properly bathed. So, upstairs we would go to the bathtub, undress her, bathe her, dress her again, safely get her out of the bath situation and downstairs, hoping and praying that every step of the way she was not going to take a wrong turn and you were not going to both topple down the stairs. I needed help.

My family wanted to help financially. My brothers, my mother's only sister in Chicago was willing to send money. It was not money I needed. I mean, not that we could not have used it; we all could.

But, at any rate, I called agencies, I read ads, I looked at the respite center. There was a lot of physical and mental stress in my day.

Often, as a mom, I could go off-duty for a couple of hours. Maybe it would be a birthday party, the kids would be off, too, or they would go to school for a day or a summer program. And, as a mother, I would just breathe a sigh of relief and say, that is good. But there has been no off-duty as a daughter caregiver.

People—even my good friends, and I mean that sincerely, good friends—shy away from elderly people, especially if they have a disease like Alzheimer's where they are not mentally real sociable.

And, through the grace of God and the birth of the twins, someone came to my home; someone in our county. My twins were born and needed to be on monitors. So, that, in itself, created a situation where a nurse from the country would come in the house to check on them.

And when she came in the house and mom was doing her, dit-dit-ditting, this nurse said, you know, Carol, you really need help. I said, well, thank you very much. I thought so. Twelve years after this long-term journey has started, it is still not easy.

Today it is physical. Mom is now upstairs. My son, Kevin, is with us. He gave up his teenaged, lots of U–2 poster bedroom to make room so my mother could have his room. We re-carpeted and made it white.

Now Mom is not in my living room/dining room where she had lived for the 12 years. Even after she broke her hip we whipped the dining room table out and put her hospital bed in.

She was very much a part of our day. Nobody forgot about Grandma. The kids would jump on her bed and play Nintendo from Grandma's bed and everything. Well, she is upstairs now.

The good news is, Grandma Eager, Bill's mom, since April 1, has been with us. This is a difficult job, but it is worth doing.

In truth, I cannot do it alone. Bill and I are willing to do the work; we want to care for our parents. We do not want a free ride. We are willing to pay as much as we can, but we need your help, we need your support in giving us the people to come and help us. Bill.

Mr. EAGER. I would just like to echo a few things that Carol has said. First of all, I would hope that nothing that we have shared today would come across in the form of a complaint.

I can honestly say that it is not exactly fun to care for Marge, my mother-in-law, however, we clearly see it as our responsibility and we are not trying to shirk from that responsibility. There is a certain joy in the care as well, however.

Before my mother-in-law had Alzheimer's Disease, I was kind of an expert on mother-in-law jokes. My mother-in-law came to live with us for 2 weeks in 1975 when her husband passed away, and she just never left. She became part of our family.

The last 12 years, however, as Carol has shared with you, my mother-in-law has had Alzheimer's Disease. It is hard to remember 12 years ago, but Alzheimer's Disease was not as commonly known as it is today, and people just did not know about it, to include ourselves.

I think the point is that Carol's mother was never looking for a free ride, either. She and her husband provided for their family; they worked hard. And, through no fault of her own, she became a victim of this terrible disease.

In fact, unfortunately, we were not aware of the disease ourselves and it was during this initial period that my mother failed to keep her insurance payments current and to complete necessary paper work.

She, in fact, lost her health insurance. It took me over a year and a half to reinstate any medical coverage that she had. During that time, we paid for all of her bills. And there were quite of bit of bills during that time.

One night she was almost killed on the Beltway when she stopped her car, with about five of our children in it. And real quickly we started to become familiar with this disease.

When we became familiar, we found that there were not many places that could help, but there was one wonderful place, and that was the Respite Center of Northern Virginia.

We were able to send my mother-in-law there several days a week. There was no financial help for this center, however, because it was seen as custodial care, and custodial care is not covered under any of these programs.

As our babies required more work, we tried to get mom to the center more frequently. But, at the cost of $30 a day, that racked up. Yet, it was the only help that we had. Unfortunately, we are not able to send her there any longer because my mother-in-law fell 4 years ago and broke her hip and is bed-ridden.

We made the decision to care for Carol's mom in our home. Because we have done that, however, the vast majority of the costs that we have incurred are paid by us.

My mother-in-law wears disposable diapers, undergarments, for example. These packages are expensive—approximately $20—and there is a need for them about every 3 to 4 days. Because they are disposable items, they are not covered. The same is true of wipes, towelettes, and underpants.

My mother-in-law is on the drug, Dilantin. It is an anti-seizure control drug. Periodically, she must have her blood check to be sure that her Dilantin level is at the correct amount. Because my mother-in-law is at home and bed-ridden, she cannot go to a doctor's office or clinic. They must come to the home.

And I think you would all agree how difficult it is to find a doctor who will come and do house visits. Even if we are able to find one, it is not covered because home visits are not covered.

My mother-in-law requires 24-hour care. I am going to brag a little bit: I think we do a very good job. There are times, however, when we need to leave the house, or even go out of town. My oldest daughter's graduation from college was a prime example. We needed to be gone for several days. The decision of who would watch and care for Marge was a major one.

For other activities, we are allowed to leave certain members of our family at home and our older children have all grown in the knowledge of how to change, wash, and feed their grandmother.

Getting home health aids to care for people in Marge's situation is also considered custodial care, and, again, is another area not covered. We receive a certain number of hours each week in a program called Title 20, which has really saved our lives.

The other evening—I think it was last Thursday—however, I got a phone call that informed me that they needed to have my mother-in-law's financial income verified because this is one of the programs being looked at in our county—Fairfax County—as a possible reduction because of the financial situation in our county.

During the past 12 years, of course, we have experienced a lot of different phases with my mother-in-law. When she was mobile, she would wander away, or she would fall. She had an uncanny ability to get that one piece of homework that was really important, or that one bill, and tear that up.

I guess, as I have shared, my mother-in-law requires us to bathe her, to feed her; that just the normal activity of going to the zoo is a major logistical problem for us. Coming here today, for example, requires a plan on how to be able to get here, both of us, at the same time, and be out of our house.

I again, though, want to make it very clear that it is our decision to care for my mother-in-law. She is a well-loved member of our family. I wonder, though, about the many, many Americans who do not have someone to care for them. What happens to them? Where do they go?

Last month, my 90-year-old mother and my mentally handicapped sister moved in with us. They used to live around the corner. My dad passed away and my mother was no longer able to care for herself.

Last Friday night, Carol and I spent the evening, at the request of friends, at dinner in their house discussing this very issue: their elderly parents and what kinds of decisions they were able to make and what support they could count on for those decisions.

There is no family not going through this, or soon to go through. At some point, each of us will go from caregiver to the recipient of care. And I pray that the major changes, really, improvements, will happen before then.

This is not a simple issue, and we can become overwhelmed and lose sight of the fact that there is a person here; a person who wishes to maintain their dignity; a person who has made their contribution and can continue to do so. And, above all, despite their condition, they are a person who has value. Thank you very much.

Senator ROCKEFELLER. Thank you very much, both of you.

Mr. Keane, let us go to you.

STATEMENT OF BILL KEANE, MEMBER, NATIONAL BOARD OF TRUSTEES, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, PHILADELPHIA, PA

Mr. KEANE. Chairman Rockefeller and members of the committee, I would certainly like to applaud you for having this hearing today and for keeping the issue of long-term care on the health care agenda.

I should like to say that the stories you hear today are not just personal stories. They are also profound histories of experiences that we have had together with the system, with laws that are passed, the effects of those laws, how they work, and how they do not work.

I think that the Eager family and many of the other witnesses provide great testimony to the process of developing a fair system of long-term care.

As a family caregiver and as a person who, today, works in a rehabilitation hospital, I certainly agree with Senator Mitchell and see on a daily basis how much all of these issues cross all ages.

Before I start, I would also just say, Senator Rockefeller, on behalf of our association, how much we appreciated your coming to our meeting last month. More than anything else, keeping this issue alive in discussion and debate is extremely important.

Your quiet, profound words that Sunday afternoon had a tremendous impact on 300 people who went back home across the nation renewed in their commitment to this issue. We are deeply grateful to your persistence.

My mother and my mother's sister, my aunt, both died of Alzheimer's Disease. My father died 2 years prior to my mother, of stress and other chronic complications resulting from his role as caregiver. I, in my own way, was also a victim of this disease and am still struggling to put my life back together again.

My family members were victims of gross neglect: neglect from a political and a health care system that ignored them; a system that continues to ignore millions of other American families facing long-term care crises that will devastate them physically, emotionally, and financially.

It is time, and way past time to end that neglect, to put long-term care at the top of our National agenda, and to enact a public program that will provide basic security for all Americans, regardless of age, income, or cause of disability. It is time to stop talking about why we cannot pass long-term care legislation and start talking about why we must.

Some people argue that we have to deal with health care reform first and that long-term care is just going to have to wait its turn. Mr. Chairman, that is a false distinction that makes no sense in the real world. I have been working for the last 8 years in the health care hospital industry, and I see how inextricably connected they are.

For millions of Americans, long-term care really is the health care crisis in this country. Alzheimer's Disease is the most expensive and the least-insured illness that many families will face. Today it strikes 4 million Americans, and by the middle of the next century it will be 14 million.

Every person who gets Alzheimer's will need full-time care. Their families will easily spend as much as $40,000 a year in today's dollars to provide that care.

When the doctors told me that my mother had Alzheimer's Disease, they said she would probably live a year or two at most. She died more than 10 years later, most of that time spent in a nursing home.

My father spent everything they had, everything that they had saved for 40 years—more than a quarter of a million dollars—to pay for her care. He had worked for the Navy Department for 25 years and assumed that he had good health care protection for their retirement years. It did not pay a penny for my mother's care.

Dick Ghering, the Chairman of our board from Bloomington, MN, has already spent over $400,000 to care for his wife, who has lived with Alzheimer's Disease for the past 18 years.

He and a colleague retired from the same corporation at the same time, with the same health insurance. His colleague's wife got Lou Gehrig's Disease, and insurance paid the bill. Dick's wife got Alzheimer's Disease, and insurance paid nothing.

Even the most sweeping health care reform proposal on the table will fail millions of families unless it includes long-term care.

Some people also say that a long-term care bill is too expensive. But Americans are already spending this money in a very cruel system of Russian Roulette. If you are the unlucky one, you are stuck with the bill you cannot afford, and there is nothing you can do to reduce your risk, particularly with a disease like Alzheimer's.

What we have to do is spread that risk through a system that asks all of us to contribute in a way that each of us can afford. It would cost about $5 a week per taxpayer to finance a comprehensive long-term care program.

That is about $260 a year; a number that taxpayers can understand and, according to public opinion polls, a number that they are willing to pay if it buys real protection against the massive long-term care costs they fear.

We must take an approach to long-term care that is cost-conscious from the very beginning. One of the most important ways to do that is to provide for the full continuum of care, with an emphasis on home and community-based care in alternative residential settings that keep people out of expensive medical care unless they need it.

My mother's condition deteriorated to the latter stages of the disease very rapidly, and my father could no longer cope with her care. I had moved back home to help, but eventually I had to go to work. We might have managed longer at home, and I am sure the quality of my mother's life would have been better if we had been able to get appropriate home care or day care. But there was no such care available. Our only option was the costliest one: a nursing home giving skilled medical care, most of which she did not need.

We have learned a lot in the intervening years about alternatives for Alzheimer's care, and we need to build those alternatives into any public program for both cost and quality reasons.

Some people argue that public funds should not be used to pay for care that families are now providing at no cost to the taxpayer. In fact, there is little evidence to suggest that availability of formal care in any way reduces the amount of care the family provides.

As the Eagers have said, we are not asking for the government to replace what families are doing. We are only asking for the help that makes it possible for them to continue to provide that care longer. Families are the heart and the soul of the long-term care system today and we want to keep it that way.

But long-term care is literally killing them. Caregivers of the frail elderly are at an enormous risk, especially. Their average age is 57; one in three are at least 65. Over 40 percent of caregiver husbands are at least 75.

Caregivers at any age are far more likely to be in poor physical health than others in their age group, and they are three times more likely to be suffering from depression. They suffer from exhaustion, lowered immune function and stress-related illness, and injury directly related to their caregiving.

By ignoring caregivers we are compounding the health care crisis in this country. In my rehabilitation hospital in New Jersey, I see all the time stroke victims suffering from great stress because they are the sole caregiver for a spouse at home.

My father himself ended up in a hospital physically and emotionally destroyed by the unbearable burdens of care. He died in that hospital 2 years before my mother, just as much a victim of the disease as she was.

At least one-third of all caregivers work outside the home, either full or part time. Middle-aged caregivers, most often daughters and daughters-in-law, work the equivalent of three full-time jobs to balance the demands of job, their own children, and their parents. Younger adults put their lives on hold to help provide care.

Senator ROCKEFELLER. Mr. Keane.

Mr. KEANE. Teenagers like the children of Orien Reid, of Philadelphia——

Senator ROCKEFELLER. What you are doing now is reading your testimony, which I have before me and have read.

Mr. KEANE. All right.

Senator ROCKEFELLER. If there are any particular parts that you want to pick out of that, because automatically your statements are all part of the record so there is no need to put it back. If there are any personal comments or judgments that you want to say in conclusion, that would be good.

Mr. KEANE. All right. I would like to say that I would strongly encourage people not to think that private long-term care insurance or Medicaid is going to be the solution to this problem. In today's system, we are forcing older persons who have spent their life's savings on long-term care to compete with others, particularly through Medicaid.

I remember in the beginning, my father knew that there were ways that you could transfer assets under the Medicaid laws so that you could qualify, or my mother could qualify for Medicaid. But he considered Medicaid a program for the destitute, and he said that we were raised to obey the spirit, as well as the letter of the law. So, we continued to pay privately for my mother's care.

The system can be set up to be very unfair to many people who want to abide by the spirit of the law, as well as the letter of the law. Orien Reid, for example, was forced to use the money saved for her children's education for her mother's long-term care.

I would just like to say, then, in conclusion, Mr. Chairman, I commend your leadership in bringing this to the issue, and I hope that we can continue to keep long-term care in the debate on health care reform.

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

Senator ROCKEFELLER. Let me thank both the Eagers and Mr. Keane. There are all kinds of questions, obviously, that occur. But, I think more importantly, is what you have said and how you have said it. There are lots of things you have to ask lots of questions about. I think you have given a pretty clear sense.

There is one that I am going to ask you, Mr. Keane. But it is understood in this impersonal process of politics and Senate/White House gridlock and all the rest of it, that things do get heard.

It is not to say that things, as a result of that, get changed. That is what this is all for, in the hopes that this will change and we will somehow energize ourselves to do what we know we have to do.

But do not think for a moment that by coming and talking to us that this is some sort of ritual that does not lead to anything. Each Senator, each of the Senator's staffers that are listening to this are moved in various ways. Each of us have our own experiences which we can relate to.

So that what you do is you give us courage and determination to sustain the efforts that we are trying to make, all of you, as well as Ms. Simpson before you. So, by not questioning you, it means nothing. It simply means that your eloquence speaks for itself and the pain is clear.

I will just ask, Mr. Keane. You indicated that your father was not very interested in getting into the Medicaid system because of the whole question of stigmatization. I would just like to have a comment on that from you.

Mr. KEANE. I do not know if it was a question of stigmatization, Senator, as the fact that he saw the Medicaid program as something that was for the destitute and the poor.

And, even though his life and his retirement had come to a permanent halt and he was forced to spend all of his assets on nursing home care, he felt that, while legally he might have the opportunity, to shift assets over in various creative ways so that in 2 years my mother would have qualified for Medicaid, he chose not to do that because he felt that was not abiding by the spirit of the law was intended to serve.

And, for that reason, he just said as long as we can we will pay. And, of course, I kept saying to him—because there was no spousal impoverishment protection at that time—that, you know dad, ultimately we will be forced to sell the house to continue to make the payments until we get down to what was at that time a $1,500 burial amount allowed by Medicaid in Pennsylvania. There would be very little for him to take care of himself. But he was willing to do that. Ultimately, he died before he was totally impoverished.

But it was not so much the stigmatization as it was trying to believe that we are going to continue to develop a system that is fair. There was no long-term care system. I can remember when we tried to get some expenses paid for my mother's care and we could not do it. When she had to be hospitalized, the doctors always said, there is nothing that recognizes the diagnosis of Alzheimer's Disease under Medicare. But if we try to get her in under hypertension, we can put her in the hospital for a week or so and get Medicare to pay for some things that are necessary.

Like the Eagers, my father was constantly learning about the system and how unfair it is, how you are sometimes forced to pay unbelievable games to try to manipulate that system to meet some basic needs but, at the same time, preserve the value systems that you have so that others needs are addressed as well. And that is what he felt about Medicaid.

Senator ROCKEFELLER. Thank you, all three of you. In fact, all five of you, including Joshua, and six of you, including you, Judy. And understand, too, that the changes that have to be made have to come from the place where you now are on this Hill and from the other end of Pennsylvania Avenue.

So, when you come and you share yourself with us, be proud not only of what you have done, as you are, but also that you are instruments for millions that cannot be here. The change can only take place from this thing called the Federal Government.

So, your ability to present yourselves and to represent your hurts and your needs is a very, very powerful act that you have each chosen on your own to do. I thank you for that very much.

Mr. EAGER. Thank you for the opportunity.

Senator ROCKEFELLER. Thank you very much. Our next panel is Marilyn Moon, who is the senior research associate at the Urban Institute, and Stanley Wallack, who is the director of the Health Policy Institute, the Heller Graduate School of Business at Brandeis University, and is also chief executive officer of LifePlans, Inc.

We are very happy that you are here. We are going to be a little bit more severe on you in terms of time limitations, and I hope that you will understand that. Marilyn, why do you not start off?

STATEMENT OF MARILYN MOON, Ph.D., SENIOR RESEARCH ASSOCIATE, THE URBAN INSTITUTE, WASHINGTON, DC

Dr. MOON. Thank you, Mr. Chairman. It is a pleasure to be here to testify today. I would like to indicate that my remarks reflect some work that I am doing with my colleague, Judith Feder, of Georgetown University.

In talking about the long-term care issue that you are raising today, you are addressing a major gap in the health care reform world. And you are talking about an area that is not nearly as well developed, but certainly as important as issues in physician and hospital payment.

My testimony today addresses two issues—the need for long-term care, and some options for reform. When we talk about gaps and inadequacies in insurance for hospital and physician services, we are talking just about that: gaps and inadequacies.

When we talk about the long-term care world, we are talking about a world in which there is no coherent system. We are talking about a program, Medicaid, which protects against catastrophe only after catastrophe has already occurred.

Who needs long-term care? Although the probability of needing long-term care is far greater for the elderly than for the younger population, anyone at any age can become impaired, as you have heard here today so eloquently.

Today, an estimated 9 to 11 million Americans, one-third of them under the age of 65, are sufficiently impaired to need these services and are in families like the families that you heard from today. About 4 million of those people are so severely disabled that they cannot dress, bathe, or get out of bed without substantial help from others.

Contrary to popular perception, most people receiving long-term care live in the community, not in nursing homes. Four out of five of the disabled live at home or in the community and depend almost entirely on their family and friends for support.

But many of these families give up so much. The sacrifices that they make indicate how desperate the situation is for them.

Medicaid, the primary payor of long-term care services, is very inadequate in covering home care. And purchasing home care privately is expensive.

With in-home care currently estimated to cost about $60 a visit, just getting four visits a week will total about $12,480 per year for an individual. That is a substantial burden for most Americans, and it is about half the income of a typical elderly couple, for example.

Nursing home care, estimated to cost more than $2,500 per month, is beyond the means of almost all Americans. At that price, even a short stay in a nursing home is catastrophic.

A couple that pays for these services would have to have an annual income of almost $40,000 to leave the community dwelling spouse just at a poverty level of income.

And, again, very few families have incomes above this level in the United States. Only about a quarter of elderly couples, for example, have incomes above $40,000.

And, if they turn to their savings to fill in for the gaps, the typical elderly couple would exhaust their assets in less than a year and a half.

Although Medicaid does finance nursing home care, to obtain its benefits, you have to have catastrophe set in before you get any assistance.

This requirement presents not only a financial burden on families, but also serves as a barrier to access to care for those who fear giving up their financial independence.

Furthermore, it is not clear that Medicaid can continue to bear nursing home costs in its present situation.

Over the last decade, private insurance has emerged as a means for spreading the risk of long-term care. Today, about 2 million Americans have private insurance policies. However, if these policies promise adequate protection against likely costs, they are likely to be unaffordable the majority of senior citizens, and of many younger citizens as well.

The Health Insurance Association of America, for example, has estimated the cost of such a policy as $1,400 at age 65. Private insurance, with the addition of consumer protection standards, can help some American families, and it is certainly beginning to do so.

But, for the vast majority of the elderly, anyone who already has a disabling condition and the younger population with a small but real risk of long-term care needs, the emerging market provides little prospect of protection.

What about options for the future? Expansion of private insurance is certainly one possible way to go, and there are a number of advocates of that. I do not believe that that is going to solve the problem, however, because it will never allow us to achieve universal access.

A full social insurance program also has problems in terms of its costs. Also many are reluctant to provide asset protection for those who are well off.

A more productive approach is to look at intermediate options that have a social insurance component but do not fully protect assets.

It is most important to stress that there is an advantage in starting with a system as underdeveloped as our current one is now, and that is, you start with a clean slate. Hopefully, we can do better than we have done with the acute health care insurance system that we are now struggling to improve.

Senator ROCKEFELLER. Thank you, Dr. Moon.

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

Senator ROCKEFELLER. Dr. Wallack.

STATEMENT OF STANLEY S. WALLACK, Ph.D., DIRECTOR, HEALTH POLICY INSTITUTE, HELLER GRADUATE SCHOOL OF SOCIAL POLICY, BRANDEIS UNIVERSITY, AND CHIEF EXECUTIVE OFFICER, LIFEPLANS, INC., WALTHAM, MA

Dr. WALLACK. Thank you. Thank you, Senator. I appreciate the opportunity to talk to you today. I would like to make one plea for correction, and that the Heller School is a school of social policy, not a school of business. And my dean, Stuart Altman, would be very upset if he ever heard it was referred to as a school of business.

Senator ROCKEFELLER. Actually, just go ahead and say that that is what happened, and write me about his expression.

Dr. WALLACK. All right. I will.

Senator ROCKEFELLER. I stand corrected.

Dr. WALLACK. I hope to share with you a few observations that I gathered over the last 15 years or so. I have had the opportunity to come before this committee a few times on long-term care issues, and the problem of catastrophic health expenditures.

I really appreciate the fact that there is progress being made, this committee in particular.

I took the opportunity after leaving Washington about 15 years ago to try to do something, about the financing and delivery problem on the long-term care. This was after writing a series of options papers and policy papers have in Washington. One of the things we did at Brandeis was create a concept called the Social HMO. I would like to share with you today some of the lessons for this demonstration.

The second thing I did, about 5 years ago, being very frustrated about the progress in solving these problems with regard to long-term care insurance was to take a sabbatical from Brandeis. I started a company called LifePlans to work with private industry and to try to foster what I felt would be comprehensible, high-quality long-term care insurance plans.

I want to use what I have learned over the last 15 years and hopefully add some information to these deliberations.

First of all, we have got to define what is the long-term care population and the services that this population needs. We are talking, as people have said today, about the disabled. Those people have real needs in doing everyday activities and the instrumental activities of daily living.

When we look at the population, it turns out—and I think it is a very important observation—that there are two distinct populations using the long-term care system.

One group is the short-stayers, and the other is the long-stayers. It turns out if you look at the distribution of nursing home use, about 50 percent of individuals leave within 6 months. Usually these are people who had an acute episode and are recovering or in rehabilitation; some are also dying and are at the terminal stage of cancer.

The long-stayers are those—the disabled—that we are trying to deal with today in designing a meaningful public program. These are the permanently disabled; the chronically ill. I think that is very important, because as we look at the short-stayer population and the services they need, there needs are best met by an appropriate addition to Medicare benefits.

I think it is appropriate to include short-term nursing home stays and home care services within Medicare. This would round out the Medicare program. And that is effectively what the Social HMO has done. It has really added a set of services that deal with transitional health problems.

Because the Social HMO is a capitated, case managed system, we have been able to expand the acute care benefit package at no additional cost to Medicare.

I think these short-term benefits are important addition to Medicare, one I would like to have this committee seriously consider. I know the committee is considering these benefits within long-term care financing legislation, but I feel it belongs within the acute care legislation.

The second issue which this committee is dealing with—and I certainly agree with Senator Mitchell and Senator Durenberger—is to include all the disabled population in its deliberations. Disability occurs in all age groups.

But that does not mean that the same solutions, in fact, should prevail for the young and old disabled populations. They have very different needs.

As you know, the time path of disability is the following: everyone enters life dependent, most of us then become independent, and then we become dependent again. During the life cycle, most individuals, accumulate assets, earn income, and purchase a home.

When we look at children who become disabled, before they develop, or we look for those who become mentally ill as young adults, it is a very different situation. Consequently, we are talking about a very different set of needs.

I do not think—and a medical insurance program we have some experience now with Medicaid serves the disabled child very well, it does not serve the mentally ill person very well either.

We do not need a health program basically to solve that problem. We need a very flexible program with some income supports, some vocational training.

When we look at the elderly, we are looking at a population, that for the most part, has income, has assets, has a family, and has a home. Then, the additional benefits of insurance; such as home care, and nursing home care, round out what they need if, in fact, they become disabled.

So, I think that although there is disability across the population, we need different solutions. That brings me to the question before this committee, which is insurance.

The committee should focus insurance on the elderly population. There, we are going to have a public and private partnership.

The question is the form of that public and private partnership. Should it be something like Medicare and Medicare supplements, in which two financing systems pay for the same services?

Should it be a system where you have the public system paying for home care and the private system paying for nursing care, like suggested by the Pepper Commission?

Or should it really be designed different population groups, an improved Medicaid program and, in fact, insurance programs for those who can afford to buy such policies?

I think one really has to begin this discussion of public/private financing deciding what comes first. Do you want to start with a public program and have the private fill in, or do you want to start with a private program and have the public sector come in and provide what the private sector cannot?

I think this has to be the starting point for any discussion. Obviously, where you come out on this and which way you want to go depends on one's judgment as to the governments proper role.

Given the limitations in the Federal budgets and the deficits that were talked about today, we need to ask very tough questions to those supporting a social insurance program?

Unlike 10 or 15 years ago—when I supported a social insurance program—there now exists private insurance market. There was a market failure; it no longer exists.

It is true, when you look at long-term care and all of the personal care issues that we are talking about, that this is a private, as opposed to public, good. Since it is a private good, there is no necessity for it to be provided by the government.

It is important to note before this committee that no country in the world has a social insurance program for long-term care: not England, not Canada, not Germany. In fact, they do not use a social insurance program to take care of long-term care. They basically use a social welfare system and build upon them.

I think the basic rationale for Federal financing and the one that this committee is struggling with is the issue of affordability of private insurance. Marilyn Moon brought that up, and others have brought that up as well. Can, in fact, a private system really develop for a significant percentage of the population, or is it just impossible for most individuals to pay?

Affordability is a very elusive concept. Everything that I know that is good and valuable is expensive: vacations, cars, and homes. Affordability has really got to be judged in terms of whether or not something has value in excess of its cost.

When we look at the income and the assets of the elderly today, and what a good insurance plan cost—the typical plan today is sold to a 70-year-old, and that 70-year-old is buying for about 5 years of nursing home protection at $1,200 a year. This is not very different from Medigap policies given the existing premiums, at the key market for buying long-term care insurance—ages 65–75, 50 percent can afford a policy.

That does not mean they are going to buy it. But what it does mean, if you look at that population that could afford it, is that if we introduced a social insurance program the people who are going to get the benefits are those who, in fact, could pay themselves.

Clearly, there are issues about what the government can afford, and who it is going to give benefits to.

I believe there can be a much larger private insurance market than exists today. But this will be difficult to achieve without government support. The government has a real role to play if, in fact, we are going to develop a very significant private market.

The older person looks to the government because of Social Security and Medicare. It needs the government to give it some guidance, it needs the government to provide some education.

Most older people still think Medicare is going to pay for long-term care. The only entity who can educate them is the government. It is the government's responsibility to educate them right now as they are at risk.

The second thing that the government must do is set standards in this industry. That is a responsibility, again, of government.

A market left to its own will not provide the kind of consumer protection and the kind of quality that we really want. The market requires appropriate kinds of regulation.

This committee and others are considering Federal long-term care insurance standards. I support the need for standard, as well as the necessary tax law changes, that would encourage individuals to purchase the right plans.

I would only plead with you, as my last comment, that as, you consider standards, that you be very concerned about whether those standards will, in fact, really provide consumer protection—not consumer paternalism, but real consumer protection for individuals, and really protect them with regards to product, with regard to sales practices, and business processes, and whether they will make the products just so expensive and Cadillacs, in fact, no one will really buy them.

Federal standards, if you develop them and go forward with them, will very much dictate whether this private sector can approach its potential. Thank you for listening to me, for letting me go beyond the 5 minutes.

I should only add, in summary, that my recommendations today—what I tried to lay out—is a much less expensive program than a social insurance program. My testimony was meant as a road map towards improvements in Medicare, improvements in Medicaid, and development of a private financing system.

Taken together, the three pieces, the provide a way to, in fact, solve a great deal of this long-term care problem. It is going to take leadership and action here in Washington. Thank you.

Senator ROCKEFELLER. Thank you, Dr. Wallack.

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

Senator ROCKEFELLER. Senator Durenberger.

Senator DURENBERGER. Thank you, Mr. Chairman. Let me ask both of you about the caregiving system out there, whether or not you are aware of any recent studies on productivity in the long-term care delivery area. I know Stanley is an expert on SHMO's and things like that.

Is anybody doing any analyses of the way in which we provide long-term care that would guide us in the direction of the most appropriate setting for the most appropriate kind of care for the least amount of money?

Dr. MOON. I do not know of formal studies in this area. One thing to keep in mind is that long-term care services are very labor-intensive activities. I cannot imagine, for example, robots delivering long-term care services.

The one thing that we do know is that home care is probably better for the patient, the individual needing the care, in many instances. But it is not always the least expensive way to provide care.

Senator DURENBERGER. Right.

Dr. MOON. And there certainly are times when people should be institutionalized. The important issue there is that there will always be a role for both home care and nursing home care.

Dr. WALLACK. I think the key issue is there are alternatives to institutionalization. Assisting housing can replace nursery homes.

More importantly, you have heard today from families that are taking care of disabled relatives at home. This is true across the board. A huge number of families are involved in caring for disabled relatives, and that is what we need to maintain as we go forward. We need to give them family respite, we need to keep them able to do all the good they are doing.

A system that does that, a managed system with appropriate kinds of case management, appropriate kinds of respite, is key to making the system affordable.

Senator DURENBERGER. What about the issue of quality? Where are we in the long-term care business in terms of measuring quality of care? I know we are very busy doing accountability standards and telling everybody how many of what to use in the nursing homes and the home health area. But is there some more realistic outcomes-based measure of quality that exists in long-term care today?

Dr. WALLACK. I think you are right. We have set up steps and procedures with regard to the quality. You can regulate inputs and procedures, but you cannot regulate outcome. I think you can recognize a good facility, often, as you walk through it, as you observe the staffing.

As I visit, for example, nursing homes that are part of a housing community, they are very different in terms of the quality of care and the kinds of support.

It relates to the attention people receive in these facilities and how they are integrated within a larger setting.

Senator DURENBERGER. Let me ask you about the financing side, and try to ask you to get the essence of your testimony.

Looking at the typical income security system in this country for most families, if we are going to have to pay for care, the first thing we start out with is earnings. The second thing is an earning supplement, which is usually called a fringe benefit. But let us just call that earnings.

Then, to the extent that people can make savings, we usually use tax policy as an incentive in one way or another to have people save for good things. Those are the typical ways to make money available to somebody if they are going to pay for the service out of their pocket.

Now, on the assumption that the services for many people are beyond their means, we use insurance as a way to have the young pay for the old, the healthy pay for the sick, and the non-accident-prone pay for the accident-prone, and so forth.

That is a way to get the price affordable so that the obvious people are not paying five times or 10 times as much as the other people.

Then, we use either social insurance or tax policy in one way or another. We use direct payments—Medicaid, for example—or indirect payments—such as the deductibility of insurance or tax-favored treatment of certain kinds of IRA's.

We use tax policy as a way to subsidize public subsidies, to spread the cost over everybody in America. Everybody who pays income taxes or payroll taxes will share in the cost of the one person or the 5 percent of the people, whatever it is, that need this care.

Now, have either or both of you thought out the ideal way in which we should use national tax policy, social insurance policy, and insurance policy in this country, to construct an income protection system for all Americans who may or may not be in need of long-term care services.

Dr. WALLACK. Well, a long question, and difficult one to answer. But I think what I was trying to drive at in my testimony is to build upon what we have. We have Medicare, first of all, a social insurance program. We should really be adding to that, expanding that and rounding it out to some of the home care and nursing home care. That turns out, in terms of protecting people, to be very important.

The Brookings study that Josh Weiner and Alice Rivlin did showed, in fact, that just limited long-term care coverage is, the best way to stop a lot of spend down to Medicaid.

You may remember that data which shows that when they enter a nursing home, 35 percent of the people are Medicaid, another 15 percent spend down. So, you get basically 50 percent of the population spending down. It is those who are right near poverty that are, in fact, spending down.

There is another large percentage of the population, 40–50 percent of the older population, who have other income, who have Social Security, who have private pensions, who who have assets, which you did not mention but which is very important. Policies for this population shall be different than those established for the poor.

Remember, one of the revolutions we have had in this country from 20–30 years ago as we look at the elderly is they have income and they have an awful lot of assets relative to the rest of society.

If you look at private and public payments in nursing homes, it is a 50–50 kind of split. Now, I would personally like to improve Medicaid; make Medicaid more humane for the near-poor; raise the assets test; improve the benefits; and get at that 50 percent that, in fact, have not earned over their lifetime the kind of income to be able to support even a private insurance program.

It is the other 50 percent at age 65, who, if we could find a way to spread the risk, could reduce the burden. If 50 cents on the dollar is now privately paid, private insurance could only help but increase that percentage. It is not going to reduce it. And, in fact, if people would buy into a private system, it would reduce public dollars.

I see Medicare improvement, Medicaid improvement, and really saying, let us see how far the private sector can go. We do not know how far it can go; it is very small. But it has not been encouraged. And, as I said before, the only way it will really have any chance is if the Federal Government wants it to happen.

Senator DURENBERGER. But part of the point of the question—and I will just interrupt you before Marilyn responds—was to say that most people do not have enough money when they get to be 65 to afford these things is not true. They have all earned it, it is just that they have consumed it.

They have deliberately chosen to consume part of their earnings or their accumulated wealth in something that they wanted to have at that particular point, or an investment they wanted to make in a child or a parent, or something. That is leaving out Jenifer, Joshua, and the Eagers, and that sort of thing.

The question is: it might be a lot better, facing the kinds of odds that we face in terms of the frail elderly, and dementias, and things like that, if we constructed a system in which people would begin to invest earlier in the kind of protection that they might need in 10 years, 20 years, 30 years, or 40 years, or that somebody might need in their family. Marilyn, why do you not respond? That is one of the reasons I raised the question.

Dr. MOON. Theoretically it makes a lot of sense for people to make some contributions early on. But if I were to counsel a young family right now at age 30 whether they should buy private insurance, I would say absolutely not.

Senator DURENBERGER. Right.

Dr. MOON. I would say this for a number of reasons that have nothing to do with insurance companies trying to do a good job.

The uncertainty about the future and how much you would have to contribute over the years with no lapse in contributions make insurance too risky for young families. Too many things can happen before young families need protection 50 years in the future. It is probably too much to expect a private system that could handle that, or individuals who are willing to take the risks in such a system.

I agree with Stan that we need to think realistically about a mixed system where we have private contributions and private activities, as well as public ones. But I think more in terms of trying to design a system to serve the people that are most in need now—those with modest incomes. The very poor get access to Medicaid. It is not always a great system, but they do not have to sacrifice to become eligible. They are already poor, so Medicaid covers them.

The other individuals, the ones that I worry about, are the folks who spend down substantially to get Medicaid. This is like winning a "reverse" lottery, as one of the other witnesses indicated. If you need care, you lose everything.

Plus, the fact that we do not have good home care under Medicaid needs to be addressed. If we had a Medicaid system with good home care and good nursing home care, paid at reasonable levels, and with spend-downs that were not heinous kinds of income and asset tests, I would not have great difficulty with then saying let us let the private sector fill in. But we are not anywhere near that. And my concern is that we should not start with subsidizing private insurance if we are not willing to improve the situation for people who are most in need.

So, I think you could have a mixed system, but you have to start, first, with the folks who need the most. This includes home care area for everybody, and better protections for those couples who do spend down.

Senator DURENBERGER. Thank you.

Dr. WALLACK. I just want to add one footnote. Not to mislead you with that 35 percent that enter a nursing home on Medicaid. We are really looking again at people who are poor.

If you look at the percentage of the elderly who are poor, there is still a number who are right near the poverty line, or have not earned a lot. And it is really back to what you said before about an income strategy for dealing with other disabled.

I mean, if I look at the population using nursing homes and home care that are poor—there use is very different, Medicaid is a welfare program and we get very high utilization rates because it is a welfare program, because we do not have the home care benefits, are because we do not have other kinds of supports.

So, I think the proper approach is to improve some of those benefits. With an incomes program you will be able to eliminate some of the entries into nursing homes. Nursing home care is what we support, so that is where older people are located.

Senator DURENBERGER. Thank you.

Senator ROCKEFELLER. Dr. Moon, pursuing this a little bit, what Dr. Wallack appears to do is to put a kind of very negative connotation on the whole concept of promoting a limited social insurance program component.

And the argument, I guess, is that we are suggesting that seniors are not capable of acting rationally—I will give him a chance to defend himself here in a minute—and, obviously, in their own self-interest, by requiring stringent standards. It is not my impression that that is what we are about.

In fact, in his own survey of long-term care purchasers—and he had an article recently in Health Affairs—he indicates that seniors are capable of acting very rationally. Overwhelmingly they are choosing, obviously, not to purchase private long-term care insurance because of the very simple reason they cannot afford it.

Well, he says liberalize it. Well, that takes the cost of these programs that David is referring to that are under assault and shoots them up enormously.

So, the question is, if they are not getting much for their bucks now, what are we moving towards under his philosophy? I would like for you to go after what he says and then him to come back at you, if you would.

Dr. MOON. Improving standards in long-term care insurance is a very important thing to do. But it will undoubtedly make insurance more expensive.

It will get rid of the low end insurance policies. That is actually a good thing to do. I do not think we should encourage people who cannot afford care to buy cheap policies that will then simply not meet their needs.

If they buy, for example, policies that require them to pay enormous amounts out-of-pocket in addition to what the insurance coverage will get, then they will spend down on this cost sharing and be on Medicaid anyway. They will not have achieved what they are trying to do.

So, having standards that improve the coverage and assure the purchasers that they are going to get something worthwhile is useful.

I do not think that that is going to help in terms of affordability. I think that will probably segment the market further. That is all right, but I do not believe it is what people think will happen.

Senator ROCKEFELLER. Well, if you accept, as I understand the case now, that there are less than 2 million private long-term care insurance policies out there.

Dr. MOON. I think that is about right.

Dr. WALLACK. It is less than that.

Senator ROCKEFELLER. Yes. So, that is not much. Now, the argument then that he would make is that there is not enough incentive, which means that you have to liberalize that, which then drives up cost.

And, in all of this, we have to consider the matter of cost. You are taking a very different approach. Why would you say his approach is not useful?

Dr. MOON. We are seeing people, as you said earlier, who are deciding not to buy long-term care insurance policies for very good reasons.

If you are not very sure about what the policy is going to offer you eventually and you have to pay $1,200 or $1,500 or $2,000 a year for that uncertain protection by lowering your standard of living for 15 or 20 years, people are making rational choices by foregoing insurance.

Senator ROCKEFELLER. And you would say, Dr. Wallack?

Dr. WALLACK. What we did was to look at people who had income and assets that could afford insurance, so they were equal in terms of their ability to afford it. That was who we surveyed, not the 50 percent or so that cannot afford a decent plan.

And what we found was that they were very rational. People who did not think they had a risk were not, in fact, insuring. Furthermore, there were a lot of people who thought Medicare and Medicaid was going to pay if they needed care. They did not insure.

People, therefore, were wondering about the value. They did not know they had a risk, and, they did not think they were going to have to pay for care. Of course, the private insurance product, therefore, has relatively little value.

Again, I was talking before about affordability. This is not an issue of affordability, it is an issue of whether or not what you are thinking of purchasing has value exceeding costs.

Purchasers have to believe in the insurance product, they have to believe benefits are going to be paid, they have to believe the company is going to be there. Those are consumer concerns and ones for which standards are needed. And they have to understand they have a need and that Medicare is not going to pay. You have got to create in any private product a sense of value.

Older people do not necessarily believe the insurance agent who comes to their home and sits at their kitchen table and tells them they need to buy. He is selling. They have got to be educated by somebody objective. They are not, today. The one thing that stood out in our survey was the desire for education.

I think that is such an important role for the government to play. If, in fact, there is a risk they understand, and, if, in fact, Medicare is not going to pay, that will lead them to think maybe this policy has more value than I really thought.

Senator ROCKEFELLER. Just as a philosophical matter, is it not true that when you take the individual person—take the social insurance concept as one concept and yours as kind of the tax credit approach.

In other words, you take the individual and put the individual against the private insurance market, usually that is a dead loser for the individual because the individual, one, is not educated, the individual, two, does not have buying power, the individual, three, is confused, is intimidated, and often mislead.

What are you asking of people?

Dr. WALLACK. I do not think, first of all, the tax subsidy is all that important. More important is the public perception or attitude.

In economist's jargon, a subsidy will reduce the price and you will go along the demand curve and maybe you will increase quantity with a 20-percent subsidy a little bit.

It is not that kind of subsidy which is going to lead to a real growth in this industry. It is really what we economists say is a shift, in demand, a result of a change in attitude. I mean, the fact that 70 percent of the population have Medigap insurance which does not provide catastrophic benefits, and a lot of them have comparable premiums, and yet they are not protecting themselves against real catastrophic long-term care expenses says to me something about an attitude.

We are talking about an attitudinal issue here, and I think we have got to change the public attitude if we are going to have a market. Alternatively, if we cannot do that—and we do not know if we can—and people are going to shoot the dice, then I think we need to move eventually into a greater public program.

If I am pleading for anything today, it is to say there is potential out there. It is not a question, per se, of income and assets of the elderly. It is not about affordability.

We should give the private approach a shot because we have so many other problems in society that government must pay for. You are facing this issue more than I am, obviously, with your debates about where the public dollars should go.

I mean, I work on substance abuse problems, I am dealing with issues of mental retardation and mental health where there is no alternative to public funding. There is no way at all that these people can pay for it or get needed services. Clear public problems, clear public program and dollar needs.

At some point, social insurance programs are very expensive. They do take away dollars from other programs. There are tradeoffs being made. I am saying that I am concerned about all of those issues working in a School of Social Policy and if I had to make some choices, I would spend public dollars on people who really did not have any other.

Senator ROCKEFELLER. Marilyn, do you have a comment?

Dr. MOON. I believe you cannot have it both ways. You cannot argue that people are rational, but they do not have enough information, so they are not being rational now, and if we give them just a little more information they will suddenly be rational. I am not sure it is going to work quite that way.

Asking people who can afford to pay to contribute to the cost of their care is a reasonable thing to do. Hoping and expecting them to participate in an insurance program to do that is probably reasonable if we are talking about people with enough resources and access to information to handle that. But it is widely optimistic to think that anywhere near half of the population is in that situation. It is also optimistic right now to even assume that a quarter of the elderly are in that situation.

I cannot reconcile the fact that so few people have bought long-term care insurance as simply a failure of people to be rational with the argument that people are rational and they want to buy insurance. I think that that is a little bit circular.

Senator ROCKEFELLER. It is nice work. Dr. Wallack, you indicate that you have got a lot of confidence in the growth rate recently in long-term care policy insurance market sales. And you seem to think that, therefore, that can fill the gap.

Dr. WALLACK. Just the opposite; I do not.

Senator ROCKEFELLER. Oh. You do not?

Dr. WALLACK. I come out thinking that there is a tremendous need out there. People have this unbelievable catastrophic expense and I do look at the income and the assets, and look at what they are paying for Medigap, and look at the price of the policies. I think an awful lot of people could buy them and they are not.

Now, I do question why not, as well. Although the market is growing, and, I guess from a business sense people say it is a good growth rate, it is nowhere near what I think it could potentially be. I do not think that it will ever be until the government clearly states it position.

Because if you ask most elderly, they are looking to the Congress. They are looking to Washington to lead on social policies for older people. To tell them what to do. I honestly believe that. All the polls and surveys we have done really support that.

So, if I am an older person and have to make different choices, I think it is very rational to say that eventually the government is going to come in and offer a social policy. First of all, many think Medicare is going to pay today.

Still, a lot of people think Medicare is going to pay for long-term care. Is that acceptable? Why is this? Why? After all these years and all this discussion, do most elderly people still think Medicare is going to cover them? Whose responsibility is it to educate them? It is the government's. I have a real problem with that, and I hope you do.

Senator ROCKEFELLER. Yes.

Dr. WALLACK. I mean, I think it is the responsibility of government to really try to educate this population. And until they are educated, since they think they are covered, why would anyone buy a private policy? It is irrational to buy if, in fact, you think you are covered.

Senator ROCKEFELLER. You have a virtually non-regulatory atmosphere now in terms of long-term care private insurance.

Dr. WALLACK. Absolutely.

Senator ROCKEFELLER. And there just is not any sustainable response except modest growth to that. Now, is all of that simply due to seniors who do not have sufficient education to make these kinds of rational decisions?

Dr. WALLACK. No. I was trying to separate, sir, the difference between what I consider to be just education, which I consider the number one thing, and a second important issue is, in fact, regulation. I do not support—in a social area like this a growth of a private market without real regulation to make sure that those private products sold are solid, that insurance companies are going to pay the benefits, people get value, and that value is, in fact, maintained.

And I think there is really a need to have that across the board. I get calls all the time as to whether to buy a policy. I think there are a lot of good companies out there who are offering good policies. But I know a lot about this industry.

As a general consumer out there, knowing all of these horror stories and the existence of bad products, I would be very skeptical about buying something. Therefore, I think if this market is going to develop, the industry cannot clean up its own act. That is why we need government.

If we are going to have any kind of acceptable private acute care system or private long-term care system, somebody needs to set up standards for insurers that are universal across this country.

And that, I think, is a prerequisite for development of an orderly, quality private market. They are different issues—education and the development of the acceptable products.

Senator ROCKEFELLER. Dr. Moon, let me just—Joshua, obviously, is not a senior citizen, and presumably has very different needs. Could you talk a little bit about the kinds of needs that are involved with folks that are less than 65 years old that perhaps we have not been talking about relating to Joshua or somebody quadriplegic who is 21?

Dr. MOON. Let me talk about two things. One, financing. I think in the case of younger persons, it is not really feasible to think about adding long-term care to private health insurance, for example, for those individuals.

The risks are pretty small, but as long as we have the kind of fragmented market for acute care where risks are not very well-pooled, I do not think we can expect to see the private market handle that. Younger families will need other solutions for financing long-term care.

Second, in terms of the kinds of needs that someone like Joshua has, home care and other supports for the family are important. The flexibility that his mother was discussing is something to keep in mind in terms of how you design a system.

You want to be able to have a system that does not have a rigid set of services and a prescribed level of care in all instances.

The problem with that, of course, is that you need to also have standards, controls, and accountability for cost containment concerns. Balancing flexibility and accountability is a tricky proposition. But it is important, if we are really going to meet the needs of that population, to take into account.

Senator ROCKEFELLER. All right. Dr. Wallack, do you think that what we did with respect to Medigap a couple of years ago was useful?

Dr. WALLACK. Yes. Yes, I do.

Senator ROCKEFELLER. And can you explain why?

Dr. WALLACK. Well, again, I think we needed some standardization out there. It is very confusing out there. I think the private sector and industry, everybody wants to make it very difficult for individuals to make choices to lock them in. I mean, we are not giving our public, our citizens, enough information. We somehow need to do that in different ways.

I have been supporting education, but we need to take some actions that at least say, these are good products, these are the ones that make sense. And then I think the government needs to take that lead. I think it can be done, then, with setting the goals and left up to the States to enforce some of those things.

Senator ROCKEFELLER. At what point is it that social insurance, as an approach to long-term care, begins to make sense to you? At what point do you begin to say, maybe?

Dr. WALLACK. Well, for long-term care?

Senator ROCKEFELLER. Yes.

Dr. WALLACK. Because, given Medicare, I really think there is real need to expand the Medicare program to include what I call the short-term stayers in nursing homes and home health; people who are rehabilitating, people who are recovering from an illness. There is really a need to expand Medicare and that is a social insurance expansion.

And I want to make it very clear that I think of this as an addition. I think the Medicare program needs to be rounded out. I think it would be a very important addition to the Medicare program.

I guess the broader issue of social insurance is the basic question as we discuss the problems of other disabled populations.

This is the core question. By looking at other countries and trying to learn from those experiences, do we want to have government take it on in toto. How should we do that?

Should we adopt a social insurance program, or as what I call a social welfare program? The word "social" is important; it means government. But do we really want to use more of an income maintenance program, more as a service program, or alternatively more as an insurance program with regards to health care.

If you, in fact, were going to take it over socially and the government were going to do it, I would probably support much more of a service and income program than a health care insurance benefits program as a way to address the problem, much like many other countries have done.

This may be far from your answer. But, if I went to a social program, it would look very different than a social insurance program for just the reasons you saw today. Just for those young kids you saw, for the chronically mentally ill.

A home care benefit and nursing home benefit is not what they need. They need a whole variety of human development support, they need vocational training, rehabilitation, they need a variety of housing services, they need a variety of things. And we have got to take it on in a much fuller, broader program than taking it on as an insurance program that provides a limited set of benefits.

So, I would opt, if we go forward and we think we need a social program, for a very different kind of program than an insurance program. More of a income support and social service program.

Senator ROCKEFELLER. Final response, Dr. Moon?

Dr. MOON. I would only say that one of my concerns about adding the short-term benefits to Medicare is that we may then think of them as medical services and treat them in a way that leads to the over-medicalization that people worry about.

For example, one of the criticisms of the Medicare home health benefit is that it is limited to a skilled nursing benefit. But homemaker aids, and other kinds of home care services go well beyond a strict medical needs. These important services may be hard to add to a program that is essentially a medical program.

And I think that is something that needs to be thought about carefully. You want to have a smooth transition between medical needs and support needs, but you also do not want to create a system that is so formalized and incorporated into a medical system that it causes problems and additional costs.

Senator ROCKEFELLER. Both of you, thank you very much. Our final panel is Sheldon Goldberg, president of the American Association of Homes for the Aging; Val Halamandaris, who is president of the National Association for Home Care; and Paul Willging, who is executive vice president of the American Health Care Association. I do not know who is who yet. I know Val. I guess we will start with you, Sheldon.

STATEMENT OF SHELDON GOLDBERG, PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGING, WASHINGTON, DC

Mr. GOLDBERG. Thank you, Senator Rockefeller, Senator Durenberger. Let me introduce myself. My name is Sheldon Goldberg. I am the president of the American Association of Homes for the Aging. I commend you for both your personal and your public leadership. I commend you both for your energy, your compassion, and your leadership in terms of your commitment to these areas.

These hearings are very, very important and I am delighted to have an opportunity to present my views and the views of my organization.

We have 4,100 long-term care facilities, all of them not-for-profit, throughout almost every community in this country.

They are primarily religious in nature, fraternal, but all of them are eleemosynary in terms of non-profit services. I am really proud of the history of this organization. Some of our homes pre-date the Constitution and have been in continuous service to people in this country for well over 200 years.

I come from a bit of a unique perspective, because not only does my organization represent nursing homes, but also we represent a broad range of retirement housing, CCRC, Continuing Care Retirement Communities, Assisted Living Facilities, Lower Income and Moderate Income Housing, community services such as home care, day care, day treatment, and a broad range of LTC services.

But I have to also be very candid with you. If I said I had a consensus amongst my membership about the solution to the LTC financing problem, I do not. And, just as you are aware, these are very, very complex issues that you are facing.

Senator ROCKEFELLER. Carl Schramm knows the feeling.

Mr. GOLDBERG. There are not clear answers at this point in time. But I, first, want to just address a personal experience. I head a national association; I have done it for 10 years. I have at my access, unlimited assistance to plan for mine or my family's long-term care needs.

I had the experience of dealing with my parents—my father.

I have to tell you, it is no easy task. It is a very difficult task. And even for one who considers himself knowledgeable, perhaps an expert in the field, and has asked for these services.

I ultimately made a decision for my father, and that was to place him in a nursing home for his safety, health care needs, nutritional needs, and a broad range of other concerns.

I have to tell you, prior to that experience I could talk about it, but I do not know that I really felt the empathy of the people you had on your first panel; of what they go through, what they feel, and what they are trying to accomplish for their families.

We have submitted our testimony, so I will focus very briefly on four points and move on with my testimony.

My first issue, and perhaps most important, is that all of a sudden the domestic issues in this country have been rediscovered. And I do not mean that in a critical sense, but we are looking at infrastructure, Los Angeles, but, very importantly, we are looking at health care reform in this country.

AAHA's biggest concern as we move toward health care reform, is that we will forget about long-term care reforms—issues affecting the elderly and the disabled—as we focus attention solely on the more popular issue of health care for the uninsured.

Through your leadership, we feel comfortable that that is not going to happen. Demographics suggest that we cannot truly have comprehensive health reform without focusing on long-term care issues.

My second point—is the issue of nursing home payment reform. Historically, nursing homes throughout this country have suffered with inadequate nursing home reimbursement rates. This has created a great deal of problems. Basically, some of the deficits that have been created have been through cost shifting.

The costs that are paid for by the State and Federal Government under the Medicaid program are shifted to the private pay resident. In many cases, the differential is very, very significant, not to make a profit, but simply to break even, meet people's needs and recognize the actual costs of this care.

It has created such situations as provider taxes, a situation where States which are short of revenues place an additional burden on private pay nursing home residents to make up for State revenue shortfalls and to ensure a higher Federal match under the Medicaid program.

I use this example because I believe these problems are not going away, but becoming increasingly acute and increasingly severe. This Congress, and the industry as well, passed a law—the Omnibus Budget Reconciliation Act, OBRA—to create a more balanced approach and a more participatory approach to quality of care. We have not seen the support from the Federal Government, nor from State Governments, to meet the cost of the expanded requirements of OBRA.

I could talk about ceilings, I could talk about payment lags. We have providers in the State of Illinois that have not been paid for 6 months from the Medicaid program because of shortfalls and other problems. That has a very definite impact upon the quality of care.

The last payment reform problem you'll address is the issue of divestiture. There are issues of fairness. As your earlier speaker talked to this issue, is how do we deal with fairness and how do we deal with equity regarding this one very important issue?

My third point deals with the need for coverage of and access to supportive services. I noted that we represent a great deal of housing facilities, including low- and moderate-income housing.

Sometimes providing a non-medical but supportive environment to these individuals can forestall the need for persons to enter nursing homes, or other more expensive modalities of care.

Sometimes it is very difficult to maintain people in independence. We feel it is cost-effective and critically important that any kind of reform to the long-term care system provide that kind of support, whether it be home care, or other types of supportive services as well.

My fourth and last point, is on the issue of private and public partnerships. I guess I tended to side in the debate that was going on, a very informed debate earlier, towards more the trying out of the public sector. And I do that solely because of the issue and the magnitude of the problems you face as legislators.

The deficits are real. The dollars needed to do a social program are enormous. The problems of this country are pervasive and there are many demands, for children's programs for drug rehabilitation programs and education.

So, we fell it is important to utilize the resources of the individual prior to requiring the Federal and State Governments to meet that obligation. We believe that is probably a more prudent way to start to address these issues.

I would like to close with a remark to a question that was raised by Senator Durenberger on the issue of quality.

I think quality has improved dramatically. One of the things I think we have learned in terms of trying to provide quality is that it is something you do not achieve strictly through regulations. Quality also is significantly influenced by attitudes of caregivers.

And that is what we are learning in American industry. You cannot ensure quality simply by teaching a person to tighten a screw. Quality has to be ingrained in peoples attitudes. I think OBRA has moved us in that direction.

I think some of the regulations help to foster that kind of an attitude. I think quality is improving. But unless we can address the long-term structural needs of financing long-term care, it is going to go backwards. Thank you very much for your leadership.

Senator ROCKEFELLER. Thank you, Sheldon, very much. That was forthright and efficient.

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

Senator ROCKEFELLER. Val.

STATEMENT OF VAL J. HALAMANDARIS, PRESIDENT, NATIONAL ASSOCIATION FOR HOME CARE, WASHINGTON, DC

Mr. HALAMANDARIS. Thank you, Senator. I, too, would like to commend your leadership. The most important thing that you can do is to provide more leadership. You have been doing it for many, many years, and particularly on this issue, the most important issue that our country faces. I would like to commend Senator Durenberger, as well. I know his long and distinguished record in this field.

May I say this is much different than what we experienced years ago. I have spent all of my adult life working on this one issue; over 30 years from the days when I was Counsel for the Senate Aging Committee downstairs.

The Senate Aging Committee was created to make an end-run around the Senate Finance Committee because it was the Senate Finance Committee that was the problem. It would not allow us to enact Medicare.

So, President Kennedy and Wilbur Cohen decided to create the Senate Aging Committee and help bring that about. But, even then, the President failed a couple of times in getting a vote in favor of Medicare. And, in his State of the Union message in 1963, President Kennedy did something different. He had been talking about the economic issues, the social issues, the political issues, and he changed to talk about values.

He quoted the historian, Arnold Toynbee, who said, you can tell the greatness and the durability of a society by one common yardstick: the manner in which it treated the infirm, those at the end of life; by the manner in which it treated the chronically ill among them, the disabled; by the manner in which it treated children.

President Kennedy said that the real issue here was the very survival of our nation and how we would be remembered in the future. And that changed the tide. It began to get people on board about this Medicare program.

And, as I commented a minute ago, it is very unusual—and may I say very refreshing—to have the Senate Finance Committee take the lead in saying we have to do something about this problem, and we have to do something about it now. I commend your leadership also in the Bipartisan Commission on Health Care Reform.

Senator ROCKEFELLER. After 30 years, Val, that seems like a rather small, small and pathetic thing to have to say about the Senate. [Laughter.]

Mr. HALAMANDARIS. Well, it is crucial.

Senator ROCKEFELLER. But I appreciate your spirit, a lot.

Mr. HALAMANDARIS. It is crucial. I say this is the most important problem we face, and I say that for many reasons. I think that it ought to be written into the Constitution. The right to life, liberty, the pursuit of happiness, freedom of assembly, freedom of the press, freedom of speech—none of the freedoms that we value so much in the Bill of Rights and the Constitution mean a damn thing without health care.

And the bipartisan commission that you chaired, the so-called Pepper Commission, established a very fundamental point, which is, health care is a fundamental right for all Americans. Now, either we mean that or we do not. If we mean it, let us get busy and make it happen. I propose a Constitutional amendment. I think we need to get the full force of the Federal Government behind this issue that health care is a right.

I think the Constitution is a value statement and that is what we need to be talking about. What are our values as a society, what do we mean? Do we care about people? If so, how much and in what way?

I think once we come to agreement on the values, the mechanics are easy. This is not rocket science here. We are not faced with a problem that is insoluble. Perhaps it looks that way to me because I have spent all of my adult life, as I said, working on it.

Premise number one: health care is a fundamental right of all Americans. Number two: what is needed is a system which includes long-term care. We cannot have the enactment of some program of health care which does not include now long-term care.

Number three: in remembering absent friends, our dear, good, mutual friend, Claude Pepper, made the judgment that two problems that exist as twins side by side: one of them being access and the other being long-term care. The most crucial of the two is long-term care.

Senator ROCKEFELLER. Can I interrupt you at that point? And I apologize to my senior colleague here. A reporter asked me this morning more or less what you just said, that long-term care seems to have taken a back seat, so to speak, to the question of access, or, as I prefer to say, coverage. And there are a variety of ways of reflecting on that. But you are entirely correct. Why do you think that has happened?

Mr. HALAMANDARIS. Well, I think that it is a little bit ironic that the commission that you Chaired agreed by a margin of 11 to 4 that we needed to do something about long-term care and endorsed the expansion of a program of home care and long-term care, including nursing home care.

Having solved that problem, we went on to wrestle with the one that was difficult, where consensus was difficult. You had eight to seven, a very limited vote, in favor of doing something; in favor of that greater problem of coverage.

So, I think it is a natural human tendency to wrestle with that which we do not know how to deal with. I think we know what we need to do in the area of long-term care. We have not known what we need to do with this access problem.

Senator ROCKEFELLER. All right. That is not taken from your time. Go ahead.

Mr. HALAMANDARIS. Well, I was saying, Claude Pepper is the one member of Congress that, more than any other, had his finger on the pulse of the American public. He knew what the elderly of this country needed.

We did not listen to him when we went ahead with a catastrophic bill which expanded hospital coverage, which provided some drug coverage, but which ignored the problem of long-term care, and we lived to regret it.

That was the reason that the elderly rose up and came back at us. It had nothing to do with the fact that there was a tax in the bill and that they would have to pay the tax. It was that they felt the benefit was illusory. It was not what they needed.

What I am making a plea for today is that we get on with the business at hand, that we enact a program which provides care for the people who need it. In my view, we need a Federal system, we need an entitlement program. We are not going to solve this with some patchwork.

Now, I would like to reserve a couple of minutes to talk about this question of private insurance. You were into that pretty deeply with the previous witnesses.

Why do we insist on treating all of the elderly in this country as if they all fell off a turnip truck? They know that Medicare is limited. They try like crazy to provide some coverage to supplement Medicare by buying those Medigap policies, then they are surprised when they find out they do not cover long-term care.

Why do they not buy more insurance? They do not like insurance companies. They have tried buying Medigap insurance from companies and have been disappointed.

Beyond that, they feel the benefits are illusory, that whatever they are spending will not be returned to them in decent value. There is no economic benefit in those policies. They do not cover home care.

They only provide limited coverage for nursing home care. And, may I add, those policies are being sold to the wrong audience. They are being sold to people in their 70's and people who are, then, affected by adverse selection.

If people had the sense that God gave green apples, they would sell those policies to people like me who are in their 40's and 50's who would buy those policies, invest the money over several years, with some idea of protecting their family members.

So, to summarize my remarks here quickly, the most important thing that we need is what you are providing, which is more leadership. And I commend you.

If you keep doing that, then what is going to happen is all of a sudden we will close ranks around a bill—it may be the one you have introduced—and it will be enacted. And, at long last, I can rest after 30 years with some assurance that Claude Pepper's fight was not a fight in vain.

Senator ROCKEFELLER. Thank you, Val.

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

Senator ROCKEFELLER. Paul.

STATEMENT OF PAUL R. WILLGING, Ph.D., EXECUTIVE VICE PRESIDENT, AMERICAN HEALTH CARE ASSOCIATION, WASHINGTON, DC

Dr. WILLGING. Thank you, Mr. Chairman. I am Paul Willging, executive vice president of the American Health Care Association. The American Health Care Association represents the vast majority, some 70 percent, of all nursing facilities across the country.

The greatest contribution I can make to this hearing, Mr. Chairman, is to make sure I beat not only the red light, but the yellow light as well, given how late it is in the day. And I will do that, or I will make a very valiant attempt to do so.

It becomes easier to do so, Mr. Chairman, because, quite frankly, I could not speak as eloquently as did the first panel on the personal need for long-term care financing reform.

Also, demographic trends speak more adequately than I could to the future need for long-term care financing reform. And the millions of personal bankruptcies over the years, and the dozens of State fiscal crises over the past few years which are largely due to huge increases in Medicaid spending, speak clearly for the need for long-term care financing reform.

I also do not need to speak to the availability of services. You have at this table, Mr. Chairman, the entire continuum of long-term care services, from home care, to housing assisted care, and to nursing facilities.

The difficulty we face is obviously that of how to finance long-term care: how do we pay for it: how do individuals pay for it, how does government pay for it?

I would like to focus, if I could, on a couple of short-term recommendations, because I think it might take some time to grapple with the basic debate that you and Stan Wallack were dealing with.

Namely, whether to pursue private financing as opposed to a social insurance program—and conducting that debate in light of what are continuing constraints on fiscal resources in this country.

But, in the meantime, I think there are some things we can do. We can, in fact, improve the Medicaid program for those most in need. We can do it with respect to eligibility, we can do it with respect to services, we can do it with respect to reimbursement.

You have heard from a couple of panelists of the need for some additional benefits within Medicaid, such as respite care to provide some relief for those who have had the courage, the dedication, and the commitment to care for their loved ones in their own homes.

We have an appalling inconsistency in terms of eligibility for Medicaid across the country. Perhaps we need to deal with that. Would that cost some money? It might. But there are ways within that same program, perhaps, to save that money.

Was the Medicaid program really intended for the middle class? Is it, in fact, somewhat appalling that we have an entire new industry out there brought into being by elder care lawyers who are trying and succeeding in getting middle-class senior citizens to divest themselves of assets so as to become eligible for Medicaid?

Yes, it speaks to the inadequacy of a total social program with respect to long-term care financing that people feel the need to do that. But, in the meantime, I think that Medicaid should be strengthened so that it can better care for those for whom it was intended in the first place: the poor.

I think that if you, in fact, enhance the benefits, you can pay for some of those benefit enhancements by looking at some of the loopholes that people have used to gain eligibility for the program—though Medicaid was never intended for them.

And, at the risk, Mr. Chairman, of engaging in the same insightful, penetrating analysis that you forced Mr. Wallack to engage in, I would like to express support for continued improvements in the long-term care insurance arena.

I think there is no question that we have seen phenomenal growth in private long-term care insurance—though it is true that 2 million policies, compared to what is potentially available, is not much.

It is equally true, Mr. Chairman, that 2 million policies, compared to what we had as recently as 5 or 10 years ago, is, in fact, geometric growth.

And I do have to concur with Mr. Wallack's point that, when people do not know that they are uncovered, it is difficult for them to see the value in long-term care insurance.

A recent poll—as recently as 3 or 4 months ago—shows that still half of the elderly feel that Medicare will cover a chronic stay in a nursing facility. I think that education is an important role in which the Federal Government should take part.

I think—and, here again, I agree with Mr. Wallack—that consumer protection is critical. There is no question that there are still scurrilous operators out there selling policies which, for all intents and purposes, are not worth the paper they are written on. I think that here also is a role for the Federal Government.

So, I think strengthening the Medicaid program for those who cannot afford to protect themselves, and providing greater information and protection for long-term care insurance consumers, are two short-term measures that the Federal Government should undertake.

I have now met my goal, Mr. Chairman. The light is still green. I conclude. Thank you. [Laughter.]

[The prepared statement of Paul R. Willging appears in the appendix.]

Senator ROCKEFELLER. You have done well, Dr. Willging; done a lot better than I have. Senator Durenberger.

Senator DURENBERGER. Great. You all heard the questions I asked of the last panel. Does anybody have any additional observations on what we know about quality and productivity?

Dr. WILLGING. I would like to speak to the quality issue and confirm some of what Sheldon Goldberg suggested.

Quite frankly, even though the industry I represent perhaps had some skepticism when the Nursing Home Reform Act of 1987 was passed for a variety of reasons, I think we also have to agree in all candor and in all honesty that that legislation has been a boon to the residents we serve, and to the industry itself.

A key provision of that legislation, Senator, and I think the most important one, was the concept of a resident assessment when a patient is admitted to a nursing home; getting a snapshot at that point in time as to what that resident's needs are, but, more importantly, what the potential for that resident is, and, in following that resident assessment, developing a plan of care.

So, we have at one and the same time a method for assessing what is needed for that resident; a method for putting together a therapeutic plan which will meet those needs, and, perhaps more importantly, a mechanism for monitoring the quality of that care after the fact.

I think those factors, taken together, have shown—and will continue to show—that we have made the great strides that Sheldon mentioned.

Mr. GOLDBERG. I would like to add to Paul Willging's comments on the issue of quality.

It goes about the environment in which people live. We build nursing homes today, and have for the last 50 years, based on standards which were created by Claire Booth during the Civil War. And that is the standard in terms of double occupancy.

As a matter of fact, I almost want to refer to it as an oxymoron, where they call it semi-private, it is semi-public. We have environments in which we have never asked the elderly what kind of environments they like to live in, how they can help with their own self-care, how we can minimize the humility of having to be cared for. And one of the next great strides we have to take on, is how we design environments for people; the environments you and I may live in some day.

Somehow, I—and a lot of elderly—find objectionable the idea of being in semi-public environments. And that is the only type of nursing home which can be constructed.

And my fear is with much of your initiative on the community-based waivers and new flexibility in Medicaid, we will recreate in the assisted living environment something that looks like a nursing home. I have to tell you we have done a great service to the elderly who have to live in those environments. There are restraints that are chemical and physical, but there restraints by environment, as well.

My hope is that we can restructure and look at how we build facilities to serve people in the future. I think that is the next step in quality.

Dr. WILLGING. Could I give you one statistic, Senator?—just a very quick one, because I was interviewed by NBC News the other day on the issue of restraints and Sheldon's comments mentioned it—just to show you the progress.

In 1988—and I am not necessarily proud of this statistic—40.4 percent of all residents of skilled nursing facilities were physically restrained. ~~This year, 22 percent are restrained~~.

That, I think, is a suggestion of the kind of progress stemming, one, from the leadership the industry itself has exerted, and, two, the help of some of the provisions in the Omnibus Budget Reconciliation Act. We are clearly making considerable progress in the quality arena.

Mr. HALAMANDARIS. May I comment, Senator Durenberger, on the question of quality as it relates to long-term care. In home care, there is not any long-term care. I think you know this better than anybody.

The Medicare program, which provides home care services, is an acute care benefit. I think a previous speaker pointed out, perhaps, the necessity of expanding the Medicare acute care benefit to provide more home care.

Long-term home care services are not generally available as funded by the Medicaid program, or the Medicare program. To the extent that there is any long-term care out there, it is paid for privately by individuals, and, as such, there is very little regulation associated with it.

So, we need some studies, yes, and we need high standards. We also need to have some sort of coverage for long-term home care.

Senator DURENBERGER. Everyone has spoken to changes in Medicaid, and I think the Chairman's bill has some changes and so forth. As far as I am concerned, I cannot wait to get rid of Medicaid. I mean, I wish we could abolish that whole thing today.

But there were people on the Pepper Commission that felt strongly about keeping the States involved. Was it John Heinz? He was going to turn this whole thing over to the States.

In terms of the subsidies, whatever subsidies you have to have to finance access to the system, is there some good reason why State financing, as opposed to Federal financing, is really key to making the right decisions about the most appropriate services, the most appropriate setting, measuring quality, productivity, and things like that in the system?

Dr. WILLGING. It would seem to me that there is clearly a role for State Government, but not in the area of financing. I have found that when State Governments get involved in financing, it is not the needs of the resident that come first, it is the concerns of the State Budget Officer that come first, and the concerns of the taxpayer that come first.

I think long-term care is, however, in the last analysis, such a local issue that, clearly, in certain areas, the closer it is to the resident being served, the better off we are, and the better off are the recipients of long-term care services.

We have all accepted, I think, the reality of the need for something like case management. Case management clearly has got to be conducted at the local level with some supervision by the State.

I think, quite frankly, certainly in the industry I represent, nursing facilities, we will always be a regulated industry. I think the closer one is to the industry being regulated, namely, the local level, the State level, the better that is, as well. But, in terms of financing, I think probably that is an idea whose time should never have come.

Mr. HALAMANDARIS. Well, my response is that bifurcated programs do not work. You have a program where both the States and the Federal Government are passing the buck to the other. Now, somebody has to be able to pin the responsibility on one entity or the other.

In some cases, we have passed the responsibility further down to county agencies. Somebody has to be held accountable, and usually that accountability goes with the dollar.

If the Federal Government is going to be putting in the lion's share of the money, then the Federal Government ought to exercise that degree of supervision that is necessary.

Senator DURENBERGER. In the normal marketplace, if consumers know what they are buying, they can match what they pay against what they can afford and look at the system.

But I think we have appropriately decided that, in terms of the elderly, the disabled, and so forth, the standard of care is something that government should make decisions about. Government should put its stamp of approval on quality. If the costs rise to meet that standard, then it is government's responsibility to subsidize the difference between what people can afford and what people have to pay. Is that not generally the way we have approached the whole system in this country?

Having said that, that does not mean that people cannot make decisions about how best to protect themselves, or how best to plan for the time when they are going to need those kinds of services.

In other words, we could have a system in America where private health plans sold acute care coverage and long-term care coverage. And then, at the time that a person needed access to long-term care services, there would be an expert there to help facilitate access to those services. You do not need to go to the State to decide. Is that not correct?

Mr. GOLDBERG. Senator Durenberger, I guess I would agree with the earlier comments, too. We are finding such unevenness between the States. Your State of Minnesota, which has been very generous in developing human services, is a leader in this country. And that is not true of other States.

And what I really think the American public needs is something that they can count on that is predictable, whether they live in Minnesota, or, as many do, move to the south in their retirement years.

A very critical role for State and local governments is how to deliver cost-effective services which are appropriate to individuals' needs. There is a replication project called Pace going on in this country, and that is to try to keep people out of nursing homes.

And they found that the single most determinant of being successful of keeping someone out of a nursing home was supportive housing.

But what kind of adaptive housing is available to individuals? I think it is critical for both the Federal and State government to examine how they channel people into the most appropriate types of resources, how they do care management. Care-management can help States maximize resources in a time of severe fiscal constraints. To deal with these constraints finding some States going into provider taxes, some are not paying the bill, some have half the rate of someone else. To ensure an equitable distribution of resources, adequate access to needed services and adequate payment rates requires a dominant role from the Federal Government.

Senator DURENBERGER. I did not have the chance to ask the previous panel this question. It would have been appropriate for them, too. When you look at the services that come under the rubric of long-term care, some wise person from the Boston area, a professor, a year or so ago told me to think in terms of board, room, and tuition like we do higher education.

He said the tuition is the experts' fees that is like medical care services. But the room and the board is still there. And, unlike expensive surgical services, in long-term care we have got some combination of medical, board, and room.

As we think about the role that private insurance plays—and I agree with what Marilyn said—I would not advocate anybody buying insurance today until we settle the role that savings and assets and social insurance and Medicaid and everything else is going to play? Why try to protect yourself with private insurance? It is not a good "value."

We are going to have to deal with that. We should deal with that. Private insurance is asset protection. It is a whole bunch of things like that. And it has something to do with the family, it has something to do with the way the family makes decisions about do we spend it all now, do we pass it on, do we accumulate it, for what purpose do we accumulate it.

Have any of you given any thought, or do you have any reactions to the notion that if we separated the medical services from the board and room services, we could look differently at the role that private insurance plays? It seems to me it is much easier to predict actuarily the room and board service and the medical service.

Dr. WILLGING. Certainly. That is one of the many options one can deal with as one looks at this famous phrase that has now been a part of this town and the health care debate for so long, public, private; what is public, what is private. One can deal with it in terms of front-end coverage or back-end coverage.

One can deal with it in terms of a public program for the poor and private programs for those who are not poor. One can deal with it in terms of responsibilities of the public with respect to only the pure health side, which I think is what you are getting at, Senator, as opposed to the custodial room and board side. And that is an option worth looking at.

I think the difficulties, however, in terms of the change in long-term care get somewhat problematic. Is the ventilator patient in a nursing facility today any different, really, than the ventilator patient who, for 10 years, was never in a nursing facility but was in a hospital?

And, indeed, as the acuity levels of residents and nursing facilities get higher, and higher, and higher, how easy is it, then, to distinguish room and board from health care when they are so inextricably intertwined?

I am not trying to throw cold water on the concept, but I suggest it has probably gotten a little more complex to deal with that concept over the last few years as the nature of the service we provide has changed so dramatically.

Senator DURENBERGER. It may well be that I should have turned that around, that the insurance should come on the medical side, because that is the unpredictable, that is the unforeseen.

The tax policy, or the predictable part would be underneath the estate, so to speak, and families can then make decisions there. If there is anybody in the audience that has a reaction that point—not now—I would sure appreciate hearing from you.

Mr. HALAMANDARIS. Well, there is a very serious problem, if I can add, with respect to these children that have congenital problems and birth defects. They are children that very often exhaust their insurance entitlements in the first 2 or 3 months of their lifetime. They burn up a million dollars. Typically, many of these major medical plans have a million dollar limit. That child can never again be eligible for purchase of insurance. Of course, it bankrupts the family.

And I must say I take the sharpest exception with the previous speaker, not on this panel, but the other panel, who said that these children who have chronic problems do not need any home care. Or, his point was even broader than that: they do not need any health care services.

Excuse me, but that simply is not true. Particularly those who exhaust their insurance entitlement altogether and then are wards of the State. And exactly what happens, as you know, is families move from State to State in search of coverage.

One of the last times I was before you, Senator Rockefeller, I talked about a family that moved across the border from your State into Pennsylvania because they could get decent care for their chronically ill child there. It was health care that they were after. They were not after some other kind of supportive services.

Now, both are valuable, supportive services and health care. But the basics must be provided to families; life-sustaining services, and then we go beyond that. So, I wanted to make that point.

The final point I wanted to make is that I am a little bit concerned that if we expand existing government programs, that whatever new money we put into those programs goes to provide care and not to provide employment for people to decide who needs how much care they are going to get. It is a very important point.

The point being also that we burn up a hell of a lot of our health care dollars in paper work in this country. The General Accounting Office says that one out of every $4 we spend in health care in this country goes for excessive paper work. Now, we can do better than that as a society.

Mr. GOLDBERG. Yes. One of the issues on room, board, and tuition as we were talking about a moment ago——

Senator ROCKEFELLER. Can I just interrupt? And I have had something that has come up that has kind of changed my circumstances. Is case management troubling us here, Val? I mean, what is the difference between paper work and case management that is not effective?

Mr. HALAMANDARIS. Well, the issue, whether we call it care management or case management, means completely different things to different people. It is the most janus-like word that I know, other than plastic. It means completely different things to people.

On the one hand, it is the basis for limiting service and keeping people from getting care, in effect, rationing care. On the other hand, it is used humanistically to say in a paternalistic way, we are going to determine who needs what level of services. I think we have to be very careful.

The American public has great difficulty accepting outside constraints, particularly in the most sensitive issue of all, as it relates to personal care.

The issue of when you get a bath, and how often you are going to get a bath, and who is going to give it to you is about as intimate a decision as we make in this society.

And I would posit to you that most people are going to say, I do not want that decision to be made by somebody sitting in the State capital out in wherever that might be; Salt Lake City, for instance, if they happen to live in Grand Junction, or some different part of the country. It is a decision that has to be made close to the individual.

One of the estimates that I think I saw related to one member's form of case management would have meant that we needed 250,000 case managers that we would have to grow in this country, which is exactly the same number of people as we have in all of home health care, providers of services, the current caregivers. We have about 250,000 of them.

I think that the issue has to be managed so that the government has the accountability that it needs, so the people have the services they need, and, most important, that those individuals have some voice in deciding what level of services that they need.

We heard the lady this morning talk about the need to exercise some control over what kind of services were good for her child. I think that control is very, very important. And tied in with human dignity is choice.

And having the choice exercised by the consumer instead of by a bureaucrat is the crucial difference that I am trying to define, if you get my point.

Senator ROCKEFELLER. I do. Sheldon, did you want to add to that?

Mr. GOLDBERG. I think it went to the earlier question relative to how do we separate room, board, and tuition. How do we separate housing from the payment for health care services?

Your home and community-based waiver program begins to address some of those issues of how we can provide community services using the Medicaid dollars to keep people as independent as possible. It has problems with it, but it is moving in the right direction.

Val makes a point about care management, and I think that there are extremes on both sides. Someplace there is a need to be appropriate, there is a need to monitor scarce resources which are going into the system.

And I see any system going forward as requiring some form of care management, whether it comes from a private insurance market, or it comes from the Federal Government, a social model. Someplace we are going to have to make sure we orchestrate.

And I go to a very personal experience. I was the care manager for my father. I did not do a very good job. I thought I was fairly knowledgeable. It is a very complex system by which to orchestrate services for people.

Senator ROCKEFELLER. I have to call this to an end simply because I got called out again by Senator Mitchell, and I have to complete a task within the next half hour, and I have to go do it.

A reporter again asked me, as I indicated, the question, why is long-term care moving more slowly than access, and that kind of thing? One of the responses that I made is that, for whatever reason, that the whole kind of architecture of health care, which means everything from cost containment to outcomes, research, utilization review, malpractice insurance reform, everything, has become much more clearly associated with access coverage than it has with long-term care.

That does not necessarily make it an accurate statement, but I think it is a reflection of what has happened and its momentum has been associated more with that whole architecture, hence, not just delivery, but also cost containment.

Among the questions that I send to each of you, cost containment is addressed because it is one of the phenomenon that has occurred. It had not really taken place when the Pepper Commission came out. It was in the wings, but it was not out on the stage.

Now, with the sense of the earlier points that Dave made about the $400 billion deficit, et cetera, there is a feeling that, in terms of coverage or access to coverage, the doorway through which all of that has to go is now a moral doorway called cost containment.

And, in fact, you do not get to coverage anymore without going through that moral passageway called cost containment.

As that is dealt with, in fact, I think openly and firmly with respect to long-term care, it is possible that long-term care's credibility, so to speak, or moving towards the front burner, will become a more active possibility, which is something obviously I want very, very much to see.

So, in the questions I will submit to you and among other questions, some will deal with that reimbursement level, to Medicare, Medicaid, what does that do; all kinds of things.

Let me thank you enormously. I apologize for having to cut this off. I am not an expert at fast hearings, usually because I do not want fast hearings. Unfortunately, I have to close this one. Thank you all very, very much.

Mr. GOLDBERG. Thank you, Senator.

Mr. HALAMANDARIS. Thank you.

Dr. WILLGING. Thank you, Mr. Chairman.

[Whereupon, the hearing was adjourned at 4:51 p.m.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED

PREPARED STATEMENT OF SHELDON L. GOLDBERG

Mr. Chairman. Members of the Committee, I am Sheldon Goldberg, President of the American Association of Homes for the Aging (AAHA). AAHA is the national organization representing over 4,000 not-for-profit facilities providing health care, housing, continuing care retirement programs and community-based services to more than 600,000 older persons every day. Almost 75 percent of AAHA members are affiliated with religious organizations. The remaining are sponsored by private foundations, fraternal organizations, government agencies, unions and community groups. With strong representation across the continuum of long-term care services, AAHA's members are committed to meeting the physical, social, emotional and spiritual needs of their residents in a manner which enhances residents' sense of self-worth and dignity, and allows them to function at their highest level of independence.

Mr. Chairman, we appreciate the opportunity to testify on behalf of our association concerning the need for reform of our nation's long-term care system. And we appreciate and applaud your efforts to ensure that long-term care remains an integral component of the health care reform movement that has swept this country in the past year. As you well know, dozens of bills have been introduced in the past eighteen months to reform the health care financing and delivery system and to increase access to basic medical protection for the 37 million Americans who currently are uninsured and a roughly equivalent number of individuals who are underinsured.

AAHA's members, of whom about half are nursing homes, have been directly affected by this problem. Of all health care workers, nursing home employees are among the most underinsured. Roughly 20.5 percent of this population do not have basic health insurance protection. Furthermore, my own organization and members have been severely affected by the skyrocketing costs of health insurance protection. Health insurance premiums for AAHA staff have risen annually between 30 to 60 percent in the past four years and our members have seen the costs of insurance increase by as much as 90 percent in one year. Clearly, we recognize and support the need for reform of our nation's health insurance system to improve access to needed services and control the costs of basic health insurance coverage.

Notwithstanding the critical condition of our overall health care system, however, the needs of our elderly citizens must not be overlooked. Two-thirds of our nation's poor elderly are not covered by Medicaid for acute care and emergency services. Roughly 32 million older Americans today are without financial protection against the potentially catastrophic costs of long-term care services. With nursing home services approaching an average annual cost of $30,000, not many elderly persons can afford to pay for this care out of pocket with median incomes of $22,000 per year for households headed by a 65 year old and roughly $9,500 for those not living in families. Yet until last month, with the exception of proposals for a comprehensive system of national health insurance, none of the major health care reform bills introduced in the 102nd Congress addressed the critical need to improve access to and financial protection for long-term care services.

Since AAHA does not believe that the Congress, Administration or the American public is ready to pay for national health insurance, we did not consider such proposals a viable option. Therefore, we commend your efforts and those of Senator Mitchell and Congressmen Waxman and Gephardt and others for the leadership you provided by introducing the Long-Term Care Family Protection Act of 1992. Based in large part on the recommendations you developed as Chairman of the Pepper

Commission, we believe that this legislation provides a serious starting point for discussions regarding the much needed reform of our nation's long-term care financing and delivery system.

CHALLENGES CONFRONTING LTC SYSTEM

Mr. Chairman, consumers, providers and public policy makers have long been confounded by the dual and interrelated problems of access to long-term care services and financial protection for such services. Factors contributing to the access problem include the absence of financial protection for chronic care services, the fragmented nature of our financing and delivery systems, the historical bias toward institutional care embodied in public and private sector programs alike and the often arbitrary nature of eligibility rules for public and private sector benefits.

Absence of Financial Protection for LTC Services

A basic precept of our current health and long-term care systems is that financing drives service access. Those without financial protection either go without needed care and services or are propelled toward service settings for which care is reimbursable, but which may not be the most appropriate and/or cost-effective setting relative to need. In 1990, approximately $104 billion was spent on long-term care services. This figure includes an estimated $54.5 billion for nursing home services, $14.1 billion for equipment and appliances and $10.6 billion for home health services. In addition, about $10, or $25 billion of total hospital costs were spent on psychiatric, rehabilitative and chronic care services.[1] Payment for these services was divided almost equally between the public and private sectors. Medicaid pays for almost 90 percent of public expenditures for nursing home care. Fully 50 percent of nursing home residents pay for their services with Medicaid dollars. In 1990, Medicaid paid for about 48 percent of total national nursing home expenses, while Medicare paid for less than 2 percent and other public payers about 3 percent. Private insurance covered less than 2 percent of nursing home services which left approximately 45 percent of these costs to be borne directly out-of-pocket by the elderly and their families.[2]

Nursing home expenditures represent a significant financial burden for the public and private sectors. Responsibility for community-based services, however, falls almost entirely on the private sector. Almost three-quarters of the severely disabled elderly receiving community-based services in 1989 relied solely on family caregivers and other unpaid assistance. Almost 70 percent of informal caregivers provide the primary care for their elderly relatives and friends and, in a third of the cases, are the sole provider. About 80 percent of caregivers provide, on average, four hours of care daily, seven days a week without compensation.[3]

The emotional and financial burdens of this care, though substantial, are not the only price paid by informal caregivers, most of whom are women. Many women, three-quarters of whom are the primary caregivers for the elderly, are caught in a vice between caregiving responsibilities and employment and must make major adjustments in their work schedules to accommodate their caregiving responsibilities. Approximately 10 percent must give up their jobs entirely and about 30 percent make other changes in their work patterns. For example, about 20 percent cut back on the number of hours worked, one third rearrange their schedules and about 20 percent take off time from work without pay. A large number of female caregivers are the elderly themselves. About a quarter are between 65 to 74 and another 10 percent, over age 75.[4] These women are especially vulnerable to health risks resulting from primary caregiving responsibilities for their spouses risk which translates to a greater burden on the public sector in cases where both spouses become dependent on Medicaid.

Fragmentation of LTC Financing and Delivery Systems

While the absence of financial protection for long-term care services creates a major barrier to service access, fragmentation both within the service system and between the financing and delivery systems also creates major barriers to service access. Based on my own personal experience in caring for aging parents, I certainly can sympathize with anyone forced to negotiate the vast network of complex and uncoordinated services embodied in our long-term care system. As the head of a national organization of long-term care providers, with access to unlimited assistance in finding services for my disabled parents, you can imagine my surprise upon finding that I was unable to assemble a comprehensive package of support services for my disabled father which would enable him to remain in the community. After several attempts at assembling such a package, I finally was forced to place him in a nursing home to ensure that his health, safety and nutritional needs would be met. Imagine the frustration, confusion and fear faced by those who must find their way through this maze of services on their own.

According to the Senate Special Committee on Aging, over 80 federal programs exist to provide long-term care assistance in the form of cash assistance programs, in-kind transfers, or the provision of goods and services. These include, among others, Medicare, Medicaid, the Older Americans Act, Title XX Social Services Block grant programs, and senior housing programs. Furthermore, these are all federal programs and don't begin to account for various assistance funded at the state level. And even accepting that of these programs, Medicaid pays the lion's share for long-term care services, there is little to no coordination among the agencies that administer these services and programs for financing this care. Each program has it's own set of criteria relative to eligibility for benefits and payment for services. For example, Medicare is an insurance program that provides virtually universal access regardless of income. The bulk of Medicare long-term care payments are expended on short-term rehabilitative care provided in the nursing home care or home care settings. Conversely, Medicaid is a means-tested program whose eligibility is based on income. Medicaid will pay for all levels of nursing home care as long as care is needed but only reimburses for home care services in states that have federally approved waivers through the 2176 or 4711 waiver programs.

The Older Americans Act program provides supportive services such as meals, transportation and home repair for those over 65. While this is not a means-tested program, the goal of Older Americans Act funding clearly is to serve the low-income and minority populations with the greatest needs. It is easy to imagine the confusion unfolding for an older person as they work their way through the service system. An individual may qualify for Medicare or Medicaid nursing home services, but upon returning to the community, no longer qualify for public insurance or assistance. And depending on the state and county of residence, access to Medicaid and supportive service benefits will vary. Furthermore, since there is no central point for the coordination of services, the elderly and their families are left on their own to determine which services are available, which services they qualify for, what level of public benefits are available and copayments required under different programs and which services must be paid for directly out-of-pocket.

Shifting the Institutional Bias

Most publicly funded programs are biased towards institutional care, primarily nursing home care. Of the $53 billion spent on nursing home and home care services in 1988, only 18 percent of these expenditures accounted for home care services. This bias toward institutional care is true for both public and private sector programs. A major factor in the discrepancy between payments for nursing home care and community-based services is the concern regarding uncontrollable costs for supportive services and the fear that family members and informal care givers will abdicate their responsibilities if insurance or public sector assistance becomes available. Accordingly to Joshua Wiener of the Brookings Institution, however, most studies do not bear out this concern.

Wiener indicates that the amount of unpaid care provided by families and friends does not change significantly when formal services become available, such as adult day care, skilled nursing services, personal care and homemaker services. William Weissert of the University of Michigan reported that among 53 findings from studies of the effect of paid care on informal care that 41 were not statistically significant, 7 resulted in a significant increase in unpaid care and only 4 suggested a significant decrease. The National Channeling Demonstration similarly found no significant reductions in unpaid care when a generous package of paid supportive services was provided. An analysis of the National Long-Term Care Survey by Raymond Handley and Joshua Wiener also found no significant substitution effects between paid and unpaid care. Numerous other national and state studies have produced similar results.

One particular area of the long-term care service system that warrants further development is supportive housing for the elderly. As residents age in place in senior housing facilities, there is a need to develop supportive services to assist older residents, particularly the frail elderly, to remain in their own homes and to delay unnecessary or premature institutionalization in a nursing home. There also is a need to improve coordination between programs funded by the Department of Health and Human Services which administers health and social services programs and the Department of Housing and Urban Development which funds federally-assisted senior housing projects. Such coordination would improve the access of senior housing residents to supportive services.

Kane and Kane suggest that the goals of health assessment and service provision should shift from an emphasis on diagnosis and cure to a focus on maintaining the ability of individuals to live independently. Adapting to functional and/or cognitive limitations is a principle need in maintaining independence. Numerous research studies indicate a much stronger correlation between degrees of disability and long-term care service use than traditional measures of health status. Medical diagnoses turn out to be poor predictors of long-term care needs and costs. Levels of functional dependence have been highly correlated with the need for nursing home care and supportive services for the elderly living at home.[5]

Since disability levels and the need for supportive services increase with age, it's not surprising that a large number of individuals residing in senior housing facilities need such care. The average age of residents in senior housing facilities is approximately 75. Approximately 20 percent of the population between ages 75 and 79 require assistance with at least one activity of daily living. This number increases to almost 24 percent for those 80 to 84 and to over 45 percent for those over age 85. Of those who do require assistance with activities of daily living between the ages of 75 and 79, about 40 percent require personal care, 66 percent need help getting around outside, 69 percent need assistance with housework and about 40 percent require help keeping track of bills and finances. These numbers increase significantly for those 85 and above. For example, over 51 percent of this age group needs assistance with personal care, 75 percent with housework and 71 percent with finances.[6]

AAHA firmly believes that supportive housing for the elderly needs to be recognized as a cost-effective alternative in the reform of long-term care policies. One clear justification to expedite the development of linkages between supportive services and federally assisted senior housing is to offset the high cost of institutionally-based long-term care. Though nursing homes provide an important service and are vitally necessary for some frail older persons, most experts recognize that institutional-based solutions to long-term care are sometimes used due to the absence of adequate alternatives such as supportive housing for seniors.

One example of a successful model is the Congregate Housing Services Program (CHSP), administered by the U.S. Department of Housing and Urban Development. This program provides non-medical, in-home services, such as meals, transportation, personal care and chore services to residents of several federally-assisted projects in an attempt to prevent unnecessary institutionalization and improve the qualify of life for frail residents. Much of the success of the program can be attributed to a service coordinator for each project, who helps assess residents' eligibility and arranges access to services. This program reduced the rate of institutionalization of residents almost in half, and saved upwards of $5,000 per person every year, compared to institutional care. Clearly, an investment in supportive housing for the elderly could yield significant future dividends by enabling older, frail persons to remain independent and in more cost-effective settings through the development of supportive housing alternatives.

Another effective means of facilitating supportive services is the development of "mixed-use" facilities. AAHA supports the demonstration program embodied in S. 1520, the Medicare Chronic Care Amendments of 1991, and other programs which promote the co-location of supportive services provided in or adjacent to senior housing. For example, Community Development Block Grants and/or other public or private resources could be used to develop a senior center attached or adjacent to elderly housing facilities. senior-centers could provide a place where such community services as meals, counseling, home health care, adult day care and/or transportation could be available both for residents and other elderly residing in the surrounding community. Elderly housing projects could provide a service coordinator to assist older residents in accessing community services.

LTC FINANCING REFORM

LTC Financing Approaches

A variety of social insurance approaches have been proposed for reforming our nation's long-term care financing system, each providing varying amounts of public coverage with different benefits. The cornerstone of all social insurance approaches is the concept of universal coverage for all regardless of age, income or other sociodemographic factors. Virtually all proposals also envision the expansion of Medicare as the vehicle for providing long-term care benefits.

Three of the four types of proposals introduced in Congress to date include a social insurance approach. These may be categorized as comprehensive coverage, catastrophic protection and front-end coverage. The comprehensive coverage model would provide unlimited coverage of all major LTC services from nursing home to community-based care and could be paid for through various combinations of taxes, premiums and copayments. The catastrophic coverage model would provide coverage of long-term care benefits of a catastrophic nature, once an individual had purchased initial benefits through private insurance or personal resources. The front-end model would provide limited benefits for a period of three months to one year, after which the individual would be responsible for the costs of additional care. While the nursing home benefit under each of these models varies significantly, each would offer generous benefits for home and community-based support services.

A fourth type of financing model which does not follow traditional social insurance approaches would offer a variety of incremental reforms to the current systems. Such reforms could include increasing the asset and income limits for Medicaid eligibility to eliminate the need for impoverishment to qualify for coverage; providing premium subsidies to the moderate income at greatest risk of spending down to reduce the burden on the Medicaid program; closing the legal loopholes for Medicaid divestiture to prevent the well-off from divesting assets for the express purpose of becoming Medicaid eligible; and developing partnerships between the public and private sectors to encourage the purchase of private insurance by providing additional asset protection for purchasers.

AAHA has used three criteria in examining the various public sector approaches to long-term care financing to determine which we feel would be most beneficial to the elderly and their providers of care. First, what are the costs of the various approaches and are they affordable? Second, who benefits from the additional federal and state funding under various proposals and does the expenditure represent an equitable distribution of public dollars? And third, how effective are the various proposals in meeting the public policy goals of increased access to services and financial protection?

Long-Term Care Program Costs

The costs of social insurance proposals introduced in the past 4 years range from a low of about $24 billion to a high of $60 billion. It has been estimated that the costs of front-end coverage and catastrophic coverage models would be similar. A front-end program providing one year of nursing home coverage and unlimited home care benefits would cost about $27 billion. A catastrophic approach covering 80% of the costs of nursing home care after two years and 80% of the costs of home care after a $500 deductible would cost about $24 billion. The primary difference in the cost of these coverage is based on the more generous home care benefits provided under the front-end program. A comprehensive program providing full protection for nursing home and home care benefits with modest copayments and deductibles would cost approximately $60 billion.

Whether or not any of these proposals could be deemed "affordable" would be dictated in large part by the willingness of the American public to shoulder the additional tax burden required to pay for social insurance coverage. Given a federal deficit which is rapidly approaching $400 billion, the limits imposed by the 1990 Budget Act and the current Congressional interest in a balanced budget amendment, Congress could not enact, nor would the President sign, legislation that was not financed with new tax revenues and/or premium contributions. While many public opinion polls suggest that the American public would be willing to pay for long-term care benefits with new tax dollars, surveys of ~~employer groups offering long-term~~ care insurance coverage and of buyers and nonbuyers of private insurance are not equally convincing.

The costs of incremental reforms to the current system have been estimated much lower than the social insurance approaches. For example, it is estimated to cost about $3 billion dollars to increase Medicaid eligibility asset limits from $2,000 to $12,000. The costs of providing long-term care insurance premium subsidies have been projected at about $350 million. This assumes a 50 percent subsidy to fund the cost of private insurance for those with incomes below $15,000 and a 25 percent subsidy for those with incomes of $15,000–$30,000.[7]

Distribution of Public Benefits

Research regarding social insurance approaches to long-term care financing suggest that most result in an ineffective user of public dollars. According to a study published by the Health Insurance Association of America, the marginal benefits from new public spending would accrue to those with the highest income levels since those with lower incomes would have qualified for public assistance under the Medicaid program. This would be true both for front-end programs and catastrophic coverage programs. The result would be a shift in responsibility from the Medicaid program to the Medicare program with no tangible improvement in financial protection for the low and moderate income population. Thus the goal of increased coverage for the truly needy would not be met.

To demonstrate, consider a front-end program covering one year of nursing home care and lifetime home care benefits. This program would cost almost $20 billion over current spending. Almost one third of new program benefits would accrue to those with incomes of $30,000 or more and more than one third would benefit those with annual incomes exceeding $15,000. About 34 percent of new spending would go to those with incomes below $15,000. A catastrophic plan providing lifetime coverage of nursing home and home care after a two year deductible is estimated to cost an additional $15.3 billion over current spending. Yet only 25 percent of the additional benefits would go to those with low and moderate incomes. About 75 percent of new dollars would accrue to those with incomes in excess of $15,000 and about half of these benefits would be spend on those with incomes of $30,000 or more. The reason for this distribution is that new public funding would be substituted in most cases for private dollars used to purchase insurance or direct care. Many of the elderly in need of financial protection would never qualify for the federal benefit because they would spend-down to Medicaid before the two year elimination period. Of those individuals entering nursing homes that do spend-down, over half exhaust their resources and become Medicaid eligible within about 11 months.

Interestingly, the more modest approaches noted above to finance long-term care represent a more equitable distribution of public dollars. Both premium subsidies and increases in asset thresholds for Medicaid eligibility disproportionately benefits those with modest means. For example, about 77 percent of new public spending would benefit those with incomes between $10,000 and $15,000 under the premium subsidy. About two thirds of those with incomes below $15,000 would benefit from the asset adjustment.

Nursing Home Payment Reform

The viability of any long-term care proposal is contingent upon a system of adequate payment for care. Historically, Medicaid has paid for almost half of all nursing home care. Payments for care have more often been based on state budget needs, however, than the need of facilities to cover the costs of care provided to Medicaid beneficiaries. Inadequate payments have been exacerbated by a deluge of federally-mandated program requirements, such as the nursing home reform provisions of OBRA 1987, 1989 and 1990; the Americans with Disabilities Act; the Patient Self-Determination Act; the Clinical Laboratory Improvement Act; the Safe Medical Devices Act; and the Occupational Safety and Health Administration's requirements for blood-borne pathogens. AAHA strongly supports high quality of care in nursing facilities. In fact, nonprofit facilities are far more likely than for-profit homes to staff facilities at levels exceeding federal minimum requirements, to hire pool nurses in times of staffing shortages and to provide a variety of other services which are not reimbursed fully by Medicare and Medicaid in order to ensure the highest quality of care. There has been little recognition, to date, however, by the Medicare and Medicaid programs of the costs imposed by federal mandates and the provision of high quality care.

The nursing home reform provisions of OBRA will be particularly costly to nursing home providers. The actual cost of these laws cannot yet be calculated because, almost five years after the law was passed, many critical regulations still have not been published. We do know that in 1990, the National Association of State Budget Officers estimated the costs of nursing home reform to be $628.1 million in state dollars alone. Adding federal dollars would almost double that amount. Yet Medicaid payments for OBRA costs in 1990 averaged $1.45 per day, and Medicare payments, $1.44.

OBRA payment problems have been exacerbated by the Health Care Financing Administration by assuming that OBRA 1987 costs have been fully paid, and by instructing states that OBRA 1990 amendments are budget neutral. HCFA has informed states that they will not have to submit a cost analysis with their state plan amendments, demonstrating the methodology used to determine costs, nor cost out requirements for assuring the highest practicable physical, mental and psychosocial well-being, as required by OBRA. AAHA believes that these instructions violate both Congressional intent and specific amendments in OBRA 1990.

In addition to not paying the full costs of OBRA and other federally-mandated requirements, states are attempting to solve their Medicaid budget problems by reducing payments to providers, taxing providers to match federal Medicaid dollars and delaying payments to providers. Some facilities have experienced delays of up to six months. While these schemes may temporarily assist state Medicaid bureaus, they erode the quality of care and undermine the quality reform mandated by OBRA. In addition, they jeopardize the problem of access to services discussed earlier by putting providers at financial risk. For example, providers in the state of Illinois have had to take out bank loans just to meet payroll due to payment delays. Some of these providers have exhausted their credit lines and wonder where the dollars will come from next to maintain facility services. It is estimated that upwards of 53 facilities in the state of Indiana are in jeopardy of bankruptcy and could close if payment problems are not resolved in the near future.

Payment problems have increased in severity in recent years, as the residents of nursing facilities have become sicker. It is well-documented that hospitals discharge patients to nursing facilities "sicker and quicker" and that the acuity levels of nursing home residents have increased dramatically since 1983 as a result of the Medicare DRG hospital payment system. Our current residents need more care and more staff time than before, but few reimbursement systems have accounted for this change in acuity.

Several states have developed "case mix" payment systems to more appropriately match higher payments to residents who require more care. The Health care Financing Administration is engaged in demonstrations on case mix for Medicaid and Medicare in five states. While the concept of case mix is appealing conceptually, AAHA is extremely concerned that it will be used, as it has in most states where it has been implemented, simply as a tool for cost containment. AAHA opposes HCFA's efforts to base the system on price rather than on cost, as yet further erosion of the payment base, and impairment of providers' ability to provide the level of care mandated by OBRA.

When state Medicaid programs do not pay adequately for nursing facility care, providers are forced to resort to litigation to secure sufficient payment. Litigation is a costly and time-consuming process and one which providers do not enter into lightly. Yet at least 14 states are involved in litigation over nursing facility rates, or have been recently, and provider groups in at least seven other states are considering litigation as a last resort to securing adequate payment for care.

A reformed long-term care system must provide adequate payment to providers to recognize the true costs of care, as well as to ensure access and high quality services. Quality of care cannot be sacrificed as a trade-off for cost containment or expanded coverage.

Medicaid Divestiture: Legal Loopholes

I stated earlier in my testimony that AAHA believes public assistance should be provided to the truly needy. This statement is born out by the fact that over 50 percent of the residents in AAHA facilities pay with public dollars via the Medicaid program at great expense to AAHA members. Shortfalls of $500,000 annually as a result of underpayment by Medicare and Medicaid are not uncommon; some are as high as $2 million annually. Many of our members are eroding their endowments to pay for operating expenses to continue subsidizing public programs. Private pay residents also subsidize inadequate payments through higher private rates. The capacity of even not-for-profit providers to lose money, however, is limited.

The nursing home payment problem is exacerbated by Medicaid estate planning, a growing practice whereby individuals shelter their assets in order to qualify for Medicaid coverage while preserving these resources for relatives and heirs. It has long been contended that individuals qualifying for Medicaid often do so by impoverishing themselves through catastrophic expenditures for acute and long-term care services. The high cost of nursing home care has been blamed as the primary culprit for spend-down, though more recent studies acknowledge that the high costs of acute care and prescription drugs and the extended use of home care services have also contributed to depletion of personal resources. While previous research indicated that as many as 75 percent of elderly nursing home residents spend-down to Medicaid eligibility, several studies conducted in 1989 refute this claim. According to research conducted by the Brookings Institution, the Urban Institute and SysteMetrics, the rate of spend-down for residents entering nursing homes is actually closer to 15 percent.

The more recent spend-down research raises serious questions regarding asset and income divestiture. According to a study conducted by SysteMetrics in 1991, state policy officials believe that Medicaid estate planning is rapidly growing and causing a serious policy problem for the Medicaid program. It is speculated that much of the "spend-down" taking place is actually the result of individuals transferring assets to become eligible for Medicaid and that the majority of elderly are not depleting their resources through catastrophic long-term care expenditures. Many attorneys have developed "elder law" practices and specialize in counselling residents how to legally divest their resources to qualify for Medicaid.

Common estate planning practices include transferring countable assets into exempt assets; sheltering assets in trusts, annuities and other financial vehicles that are deemed unavailable to the Medicaid beneficiary; transferring assets through joint bank accounts and other property held in joint tenancy; and manipulating spousal impoverishment rules to divert income and assets to a community spouse.[8]

Other less ingenious methods for transferring assets are recommended in several publications available in local bookstores. Armand Buuish and others recommend transferring assets directly to children, tax-free; passing assets to children through a spouse; paying children for help with care; writing a durable power of attorney; making home improvements and purchasing exempt assets. For example, in Massachusetts, an individual sheltered $62,500 by purchasing an annuity in this amount. Since the annuity was considered fair market value, it was not subject to transfer of asset rules. A couple purchased a condominium for $165,000 which was also exempt since housing and land is exempt from transfer rules. There are no limits on this exemption as long as the owner expresses the intent to return home if institutionalized.

The practice of estate planning has intensified since the enactment of the Medicare Catastrophic Coverage Act of 1988. Provisions designed to reduce spousal impoverishment were left intact when much of the Catastrophic Act was repealed in 1989. These provisions have intensified inappropriate divestiture by creating legal loopholes in the law based on the method for calculating the period of ineligibility for Medicaid. The Catastrophic Act extended the "look back" period for transfer of assets from 24 to 30 months. However, the period of ineligibility is calculated as the lesser of 30 months or as a ratio of the total amount of assets transferred divided by the average monthly cost of nursing home care. In the later case, the period of ineligibility is determined by counting assets from the month in which resources are transferred.

To illustrate how this loophole works, consider the following. If an individual transfers $21,000 and the average cost of nursing home care is $3,500 per month, the period of ineligibility will be six months ($21,000 divided by $3,500). Accordingly, an individual with $50,000 in assets could transfer $21,000 to a relative, keep $21,000 to pay for the cost of nursing home care for six months, and only have to "spend-down" $6,000 prior to Medicaid eligibility, assuming an asset limit of $2,000. Assuming the same average nursing home costs and asset limits, an individual with $100,000 could transfer half of these assets and still qualify for Medicaid coverage in 14 months—less than half of the 30 month look-back period specified by the Catastrophic Act.

AAHA believes that there is a serious flaw in a law which effectively creates inheritance insurance, thus reducing scare resources for the truly needy. Over ⅔ of the elderly and half of all poor children are not covered by Medicaid even for acute care. Perhaps the greatest irony of the Medicaid estate planning practice is not only that it is legal, but also, that those who least need public assistance are those most likely to access Medicaid dollars through divestiture. This is because the middle and upper income population is more likely to engage in financial planning, better able to afford legal and financial counseling, and more apt to reap the benefits of this unconscionable method of asset divestiture. The low-income with the fewest resources and most in need of public dollars are the least likely to participate in or be able to afford estate planning. What meager assets they do possess will quickly be depleted in qualifying for Medicaid benefits.

AAHA POSITION ON LONG-TERM CARE REFORM

One of AAHA's major public policy goals in the area of health care is to increase the elderly's access to the full continuum of long-term care services and financial protection for these services through a system that provides care in the most cost-effective fashion. AAHA historically has supported a public/private sector partnership in addressing the long-term care coverage and financing dilemma for several reasons. First, due to the sheer magnitude of expenditures required to finance national long-term care expenses, federal and state governments must forge a strong partnership with the private sector to ensure adequate coverage for all. In 1990, long-term care expenditures for nursing home, home care, chronic care services and equipment approached $104 billion. This represented approximately 16 percent of total health care spending and underscores the need to concurrently tackle the health and long-term care system problems if we are to effectively address access, cost-containment and quality of care issues. Second, we do not believe that a comprehensive social insurance approach is economically or politically feasible today in light of a federal budget deficit approaching $400 billion and virtually all states drowning in a fiscal morass.

AAHA also has long believed that those who can afford to finance their own care should do so, conserving scarce public resources for the truly needy who either can't afford private insurance coverage or who do not qualify for such coverage based on their health status. If fewer people spent-down to Medicaid eligibility, the severe strain on federal and state Medicaid budgets could be eased, reducing access problems for the truly needy. Furthermore, contrary to popular belief, a significant proportion of the over 65 population and a large segment of working Americans could afford to purchase private long-term care insurance.

It has become fashionable to quote a study published by a leading consumer organization stating that 84 percent of the elderly cannot afford private long-term care insurance. Other equally reputable research conducted by national experts in long-term care risk management have estimated that up to 40 percent of the over 65 population could afford reasonable private long-term care insurance coverage, using a combination of discretionary income and liquid assets. In fact, a study conducted by the Health Insurance Association of America revealed that over 60 percent of those purchasing private long-term care coverage in 1990 did use such a combination. Those with assets to protect apparently felt that it made sense to use a small portion of liquid assets to purchase a long-term care policy covering the bulk of their resources.

Finally, although the absence of private long-term care insurance protection has been blamed on "market failure," the private sector has spear-headed virtually all major efforts to improve financial protection for the elderly since 1987. Since that time, the number of carriers has grown over six-fold to a total of 143 companies offering individual and group coverage. The number of individuals purchasing long-term care insurance has increased nearly ten-fold for a total of almost 2 million buyers. Furthermore, while the "first generation" products were riddled with restrictions and exclusions, the current product market has improved dramatically. Most products sold today offer extensive coverage of institutional and community-based services, do not require prior levels of care to qualify for lower-level benefits, are guaranteed renewable, cover Alzheimer's Disease benefits and include inflation protection. Carriers also are beginning to offer nonforfeiture benefits which guarantee that the individual will receive some benefit upon cancellation of coverage based on premiums paid prior to policy termination.

AAHA COMMENTS ON THE LONG-TERM CARE FAMILY PROTECTION ACT

Although the expressed purpose of this hearing is not to focus on the legislation recently introduced by you and Senator Mitchell, AAHA would like to offer some preliminary comments on this legislation. Given the comprehensive nature of The Long-Term Care Family Protection Act and the complex nature of the payment systems outlined in the legislation, AAHA needs additional time to analyze the impact of this bill on our membership before offering fully inclusive comments. We would be remiss, however, if we failed to offer our strong support for your efforts to keep the long-term care issue before Congress as it considers various proposals for health care reform. Below are our comments on selected aspects of the legislation.

Public/Private Partnership Approach

For the many reasons enumerated above, AAHA is strongly supportive of a public/private partnership approach to the long-term care financing dilemma and commends you for introducing legislation that embodies this approach. We believe that several specific provisions promote a public/private sector partnership approach. First, the legislation calls for shared responsibility between the public and private sectors for financing long-term care services. Second, the bill promotes the private long-term care insurance market through tax reform, asset protection for those who purchase private coverage and federal standards ensuring that consumers receive fair value in the long-term care policies they purchase. Third, the LTC Family Protection Act would affect important reforms of the Medicaid system by closing divestiture loopholes and increasing asset limits to prevent spousal impoverishment.

Public Benefits for LTC Services

AAHA has a diverse membership that serves very different populations with, in some cases, diametrically opposed needs. AAHA's analysis of the various social insurance approaches to long-term care financing reveal that different approaches benefit different segments of our membership and the resident populations they serve. For example, many of our assisted living and federally-assisted housing members that their residents would benefit substantially from the comprehensive long-term care program you have introduced. Since many of the residents in these facilities have moderate to low incomes, the front-end nursing home benefit and extensive supportive services could dramatically improve their access to long-term care services and prevent impoverishment through both the direct benefits and the improved asset protection provisions.

Alternatively, our nursing home members and their residents are at greatest risk for long nursing home stays. While many moderate income families could afford a short term stay of 3–6 months in a nursing home, fewer could afford nursing home stays in excess of one year and very few, stays in excess of 2 years, in the absence of private insurance coverage. Accordingly, catastrophic protection would better help our nursing homes offset payment shortfalls by reducing the total number of Medicaid patient days.

AAHA recognizes that LTC financing reform is a complex issue and we continue to struggle with which combination of public and private sector resources are best suited to achieving our public policy goals of increased access to and financial protection for long-term care services. One of the concerns I will address below relates to the interrelationship between public and private sector programs and how various public sector approaches influence private sector responses. The development of an effective public/private partnership will require that the public and private sector roles articulated compliment and support and not undermine each other. Another concern addresses equity issues with respect to the distribution of scarce public resources. At this time we would like to share some of our key social insurance approaches to coverage for long-term care services. We will continue to work with you, your committee members and staff to craft the most appropriate solution.

Access To Care

The research described above suggests that new public spending for all social insurance approaches would disproportionately benefit those in the higher income categories. AAHA also recognizes that criteria other than the distribution of new public dollars need to be considered. For example, the LTC Family Protection Act which provides coverage for up to two six month nursing home episodes clearly would increase financial protection for individuals experiencing relatively short stays. Research regarding nursing home utilization suggests that 44 to 51 percent of nursing home episodes last three months or less and about 20 to 23 percent last between three and twelve months. Estimates for the average lifetime use of nursing home services indicate that about one-quarter of nursing home residents use three months of care or less over their lifetimes and about 20 percent use between three and twelve months.

AAHA also is concerned about the interrelationship between public and private sector financing programs and the impact of various public sector approaches on the market for private long-term care insurance. We understand that the intent of your legislation is to provide universal public insurance for a selected level of long-term care services and public assistance without impoverishment for those who cannot afford to pay for care exceeding these levels. Since three out of five elderly individuals and couples have total assets of approximately $30,000 and $60,000 respectively, provisions expanding asset protection would result in comprehensive coverage for many older Americans. We understand that the limits on coverage—particularly nursing home coverage and supportive services for the moderately impaired—recognizes the need for private sector responsibility for those who can afford services beyond the coverage limits contained in the LTC Family Protection Act.

The program you have developed envisions a significant role for the private insurance industry. Since your program would pay for up to two six-month nursing home episodes, individuals with the ability to finance care beyond these limits could do so through private insurance coverage. Among longer-stay nursing home residents, the average length of stay is about 2.5 years. Approximately 6–10 percent of those admitted to nursing homes have lifetime use of five years or more. Obviously, the private sector can play an important role in financing nursing home services in excess of the six-month limits. Similarly, your legislation provides home care and supportive service benefits for those with impairments in three or more activities of daily living. The private insurance sector could therefore provide coverage for the substantial proportion of elderly (and young) persons requiring assistance with 2 or fewer ADL limitations. Private insurance coverage would also be required to offset the 20 percent copayment costs associated with both nursing home and home care services under your program.

Notwithstanding the very real need for private insurance protection under your proposed program, AAHA is concerned that the public perception of benefits embodied by the LTC Family Protection Act may have a deleterious effect on the market for private long-term care insurance. Research abundantly documents the historical public misperception that Medicare provides far in excess of the benefits actually covered under this program. We are concerned that the same public perception will occur with your proposed program for a few reasons. First, despite the best efforts of the public and private sectors to educate the public about long-term care risk, there is still a tremendous amount of denial going on. Public opinion polls document the fact that many people believe they will never need nursing home care or significant amounts of such care. Accordingly, AAHA believes that many individuals will feel the nursing home benefit included in your proposal will be sufficient to cover their nursing home risk and will not purchase additional private coverage. In addition, since private insurance coverage often is purchased as a means of asset protection, and your legislation expands income and asset limits, this may provide an additional disincentive to purchase coverage.

Second, although AAHA would argue that the benefit eligibility criteria established for home and community-based services will effectively limit such care to the severely disabled—those who would be considered nursing home eligible by most standards—we are concerned that the public will also overestimate the supportive service coverage afforded by your legislation. If this perception is correct, individuals also will be unlikely to purchase private insurance protection for supportive services to cover moderate impairments. And as our current system demonstrates, the absence of coverage for lower-level supportive services may result in premature, unnecessary and costly institutionalization.

While AAHA applauds your efforts in concept to provide some level of universal access to long-term care services for all Americans, we feel that this approach is unrealistic in today's fiscal climate. Rather than providing access to six months of nursing home care for all Americans regardless of income, we suggest that you consider basing eligibility for front-end financing of nursing home services on income. The savings achieved by eliminating public benefits for those who easily can afford to purchase short-term nursing home benefits through private insurance or resources could be used in one of two ways. First, it could be used to expand eligibility for home care and supportive services for the moderately impaired, where moderate impairment is defined as having two or fewer disabilities. Alternatively, these savings could be used to extend the nursing home coverage period for those with the greatest financial needs. Since your legislation increases income and asset limits for Medicaid eligibility, this approach would not require people to impoverish themselves to access public benefits. In fact, as a starting point, the income and asset limits could be raised even further with respect to eligibility for the six-month nursing home benefit.

AAHA also recommends consideration of a catastrophic nursing home benefit as a more equitable use of public resources. While the research referred to above does suggest that new public dollars would disproportionately benefit the upper income, AAHA suggests that this outcome could be modified by altering the eligibility for catastrophic coverage from a two year deductible to a 12 to 18 month deductible. In combination with the increased income and asset limits contained in your proposal, such an approach would reduce the number of individuals spending-down to Medicaid before they could qualify for Medicare catastrophic nursing home benefits.

A second reason for AAHA's interest in a catastrophic benefit relates to the impact of public sector programs on the market for private long-term care insurance. AAHA speculates that several factors related to private insurance coverage under a publicly funded catastrophic program of long-term care could have a positive influence on long-term care insurance purchasing decisions. First, individuals may be more likely to purchase long-term care insurance protection if they viewed it as an extension of their Medigap coverage. That is, if the public knew that they had a 12 to 18 month coverage gap to fill, and were assured that Medicare would cover services in excess of this elimination period, this could create a greater incentive to purchase private insurance protection than a front-end approach. Second, since over 70 percent of the elderly already own a Medicare supplemental policy, the educational process could be achieved through an existing market. There may be less market resistance to expanding an existing benefit than buying a completely new insurance policy. Third, the costs of a one year long-term care rider to a Medicare supplemental policy would also be substantially less than the cost of purchasing a private policy providing catastrophic nursing home coverage. Since price, regardless of affordability, is a serious deterrent to the purchase of private long-term care insurance, the additional cost of a long-term care insurance policy covering less than two years of nursing home services likely would be viewed as reasonable and affordable by most consumers. This would be true of young and older purchasers alike.

Access to Continuum of Care

As a membership organization representing providers across the continuum of long-term care services, AAHA applauds your efforts to ensure access and coverage to a wide array of home and community-based support services through generous benefits for home care, adult day care and respite services. We also support the use of functional and cognitive disability criteria for determining eligibility for services. Such a measure is far more equitable to consumers than arbitrary "medical necessity" criteria which require subjective judgments regarding service need and often may result in inappropriate and inconsistent eligibility determinations. Functional measures are more objective and statistically reliable and will result in greater consistency in benefit eligibility determinations. The use of objective measures also will provide more effective tools for projecting and controlling program costs.

AAHA is concerned that the actual eligibility standard included in your legislation may be too stringent. Virtually all insurance companies using functional criteria require persons to be disabled in three or more ADLs to qualify for nursing home benefits. In addition, most ADL index measures consider disabilities in two or less ADLs to represent moderate impairment and three or more ADLs to reflect severe impairment. Yet your legislation defines moderate impairment as limitations in three or more ADLs and requires this disability level to access home and community-based supports as well as nursing home services. This standard will effectively prevent many individuals from qualifying for federal home care benefits until they are nursing home eligible. As such, though we believe your legislation has tremendous potential to increase the linkages between supportive service providers and senior housing facilities, we also are convinced that the ADL eligibility standard, as proposed, will undermine this great potential.

To render a more meaningful home care and supportive service benefit, AAHA strongly urges the Committee to consider reducing the eligibility standard from three ADL dependencies to two. Since we assume that part of your intent is to ensure the provision of long-term care services in the most appropriate setting, and to prevent costly and premature institutionalization, we submit that our proposed modification is in keeping with this intent.

AAHA also assumes that the home care eligibility standard of three ADL dependencies is intended to control the costs of a federal home care program. Recognizing the need to control total long-term care program costs, AAHA proposes as an alternative benefit package which could increase the amount of funding available for the moderately impaired, helping more elderly individuals to remain at home and creating potential savings by delaying or eliminating nursing home placement. AAHA's recommendation for financing additional supportive service benefits within the proposed program budget of $45 billion originates from our recommendation that public sector benefits be reserved for the most needy.

Promotion of Private Long-Term Care Insurance

AAHA supports several provisions in the LTC Family Protection Act intended to encourage the development of the private long-term care insurance market. Among the more significant provisions included in your legislation which would promote this goal are the following:

Tax Treatment of Long-Term Care Insurance: AAHA firmly believes that clarification of how LTC benefits, premiums and reserves will be treated by the IRS could have a significant impact on LTC insurance supply and demand. This could be accomplished by reducing the cost of long-term care insurance for individuals and employers thus encouraging more people to purchase policies. Your legislation would provide the needed clarification, modifying the IRS code to treat long-term care premiums as accident and health insurance premiums, thus providing pretax advantages for employees. It also would recognize the cost of long-term care insurance premiums for purposes of calculating medical liabilities on tax returns.

Additional Asset Protection for LTC Purchasers: AAHA has long supported the demonstration project funded by the Robert Wood Johnson Foundation which has been approved in four states to date. Like this demonstration model, your legislation will encourage individuals to purchase private long-term care insurance by providing purchasers with additional asset protection beyond the $30,000/$60,000 standard limits. AAHA believes that this additional protection will serve as a positive incentive to take personal responsibility for long-term care risk.

LTC Insurance Regulation: AAHA supports the need to ensure that consumers receive fair value under private long-term care insurance policies and that they be protected against unfair marketing and sales practices. Enforcement of regulations promoting these goals would be enhanced through uniform regulation of the long-term care insurance market. In addition, since consumers have a difficult time comparison shopping among different long-term care products, a certain degree of product standardization is desirable to promote consumer understanding of long-term care products and their ability to comparison shop. Your legislation provides for greater uniformity among products through federal regulation.

Medicaid Reform: As noted earlier in my testimony, Medicaid estate planning and legal divestiture of assets for purposes of Medicaid eligibility pose a significant threat to nursing home providers and public program budgets alike. Your legislation would take important first steps toward closing Medicaid transfer of asset loopholes by extending the "look-back" period of program eligibility from 30 months to 5 years and by prohibiting the exclusion of certain assets from Medicaid eligibility determinations. This prohibition would be effected by preventing individuals from "sheltering" assets in legal financial instruments such as trusts and annuities. AAHA believes that the Committee should also consider an additional safeguard against inappropriate transfer of assets through mandatory estate recovery programs at the state level.

CONCLUSION

Mr. Chairman, I appreciate the opportunity to share AAHA's views on the reform of our nation's long-term care system in general and selected elements of the LTC Family Protection Act. Once again, I applaud your efforts and those of your colleagues cosponsoring this legislation to address the long-term care financing dilemma as an integral part of the movement for health care reform. The Association supports many aspects of your long-term care legislation and looks forward to working with you and your staff in the days to come in further examining the impact of this legislation on long-term care consumers and providers. AAHA stands ready to assist you and the Committee to achieve the implementation of a national long-term care insurance program which represents a responsible partnership between the public and private sectors and appropriate roles for each.

ENDNOTES

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PREPARED STATEMENT OF SENATOR CHARLES E. GRASSLEY

Thank you, Mr. Chairman. And thank you for holding this hearing on long-term care. One of the greatest sources of anxiety and fear for older people is that they may be faced with the need for long-term care. This may even be the greatest source of anxiety for them.

They have good reason to fear the need for these services. very few people can afford the cost of long-term care, even for relatively short periods of time. And, if the need for such services lasts longer, it is almost certain to cause impoverishment or near impoverishment.

It is also clear that the psychic costs of care-giving are tremendous and can have consequences for physical health also. For instance, the National Institutes of Mental Health has sponsored research which has shown, as I understand it, that the immune function is hindered in those who undertake heavy-duty caregiving.

Now, the long-term care issue is certainly not a new one. The 1971 and 1981 White House conferences on aging focused attention on this problem. Several current members of the Finance Ccommittee introduced long-term care legislation many years ago. I think of Senator Bradley, Senator Hatch, Senator Packwood, and of course, our chairman, Senator Rockefeller, has had a long-standing commitment to address this long-term care issue. I held two hearings on long-term care policy, and workshops and hearings on Alzheimer's disease, when I was chairman of the Subcommittee on Aging starting in 1983.

It seems to me that what has held up action on this problem over this long period of time is the projected cost of any comprehensive long-term care program. Estimates of the near-term cost of comprehensive programs usually show that they are very expensive. Furthermore, the future costs of such programs, after the baby boomers begin to retire around 2010, are usually projected to increase greatly.

Of course, the advocates for long-term care reform are correct when they remind us that the families of those who need long-term care are now paying most of those costs. Nevertheless, that does not alter the fact that launching a very expensive new federal program in the context of our current budget deficit would be very difficult.

I have co-sponsored the legislation introduced by Senators Packwood and Dole, S. 1668, the secure choice long-term care program. This legislation would create a public/private program which would try to facilitate the purchase of private long-term care insurance for the middle income and would provide a public program for low income people. This legislation would be relatively cheap at $7 billion a year.

It certainly seems to me that the long-term care question has been shunted aside in the debate on health care system reform, at least to this point. Of course, some of the reform proposals do contemplate including long-term care programs. Nevertheless, it does seem to me that most of the debate has focused on the acute health care system.

As we debate the health care reform issue, we should try not to lose sight of the fact that we have to do what we can to improve and humanize long-term care policy.

I hope your hearings can help us do that, Mr. Chairman.

PREPARED STATEMENT OF VAL J. HALAMANDARIS

My name is Val Halamandaris. I am President of the National Association for Home Care (NAHC), which represents approximately 6,000 home health agencies, home care aide organizations and hospices. On behalf of these organizations and the beneficiaries they serve, I would like to take this opportunity to thank Chairman Rockefeller and Members of the Finance Subcommittee on Medicare and Long-Term Care for holding this very important hearing.

Thanks to your efforts, Mr. Chairman, in heading the Pepper Commission activities and incorporating many of its recommendations in legislative proposals, I feel we are closer now than ever before to the enactment of a universal program for long-term care.

In the brief time I have today, I want to address essentially four points:

1. The crisis in health care is becoming even more acute, and no reform legislation should go forward without addressing the issue of long-term care;
2. Long-term care is not only a concern of the elderly, but is also a problem faced by individuals of all ages who are disabled, cognitively impaired, or chronically or terminally ill;
3. The primary components of any long-term care program should offer a comprehensive array of home care and hospice services, base eligibility on disability rather than age, provide appropriate mechanisms for eligibility determination and patient management, and include progressive and broadly based financing mechanisms; and
4. While private long-term care insurance will never be a total solution for financing long-term care, it can protect some people against large out-of-pocket expenses; and appropriate reforms in the way of minimum federal standards should be implemented.

LONG-TERM CARE AND HEALTH CARE REFORM

The Pepper Commission in 1990 reached bipartisan consensus on the significance of the long-term care problem and called for swift and comprehensive reform. Yet Congress has instead focused its attention on proposals to improve access to acute-care health care services, which for the most part do not provide for the equally significant need and public demand for long-term care. It is unclear why many of the reform plans being considered by Congress and the President would repeat the mistake of the Medicare Catastrophic Coverage Act, which was repealed only a year after its enactment because it failed to provide long-term care benefits.

Long-term care is one of the most devastating problems America faces today. Between 9 and 11 million individuals of all ages depend on others for help in the most basic tasks of daily living. This number could double by the year 2030 to more than 19 million. During the same time, spending for long-term care could more than triple from current estimates of $57.8 billion. The aging of the baby-boom population, improved longevity and the prospect of price increases for labor-intensive services that exceed general inflation all contribute to this rapid change.

Public programs are already stretched to their fiscal limits yet they come nowhere close to meeting the need; and very little help is available through private insurance. Families exhaust their emotional and financial resources providing and purchasing long-term care. A million Americans a year go bankrupt trying to meet the cost of long-term care left uncovered by insurance. Only the most wealthy of Americans are insulated from the potential financial devastation. The rest can have their lifetime savings wiped out in a matter of months paying for long-term care. It is clear that major new efforts are needed in both the public and private sectors to improve the organization and financing of long-term care.

Mr. Chairman and distinguished Members of the Subcommittee, I commend your attention today to the issue of long-term care and urge you to take action on health care reform legislation that creates a new federal program for long-term care, such as the Long-Term Care Family Security Act, (S. 2571 and H.R. 4848), legislation recently introduced by Democratic leaders in the Senate and House.

LONG-TERM CARE AN ISSUE FOR INDIVIDUALS OF ALL AGES

Individuals of all ages may need long-term care for a variety of reasons and durations. Many require long-term care because of disabling physical conditions that limit their capacity to perform independently certain "activities of daily living" (ADLs) such as bathing, transferring from a bed or chair, dressing, using the toilet, and eating. Others are limited in performing "instrumental activities of daily living" (IADLs) such as shopping, housecleaning, using the telephone, managing finances, doing laundry, and taking medications correctly. The disabled, chronically ill or cognitively impaired individuals may need indefinite help with ADLs or IADLs. Individuals recuperating from acute conditions may need only temporary assistance before resuming their prior lifestyle and level of independence.

Nearly two-thirds of the long-term care population are elderly; and pressure on the long-term care financing system is bound to grow with anticipated increases in the nation's elderly population. If disability rates remain what they are today, the number of elderly persons needing help with basic tasks is expected to double between 1990 and 2030—increasing from about 7 million to almost 14 million. The number of elderly requiring nursing home care will more than triple—rising from about 1.5 million to over 5 million. In addition, the AIDS epidemic may significantly increase the demand for long-term care.

Individuals under age 65 account for about one-third of the long-term care population. Their numbers also are expected to increase as the use of high-technology and new medical breakthroughs continue to extend the lives of more mentally retarded, developmentally disabled, and physically disabled persons.

PRIMARY COMPONENTS OF LONG-TERM CARE

Swift and comprehensive reform, along the lines of the recommendations proposed in 1990 by the Pepper Commission, will be necessary to address the nation's long-term care problem. The Pepper Commission appropriately targeted home card as the best answer to the nation's long-term care needs. Long-term home care improves the quality of life because it is more humane. It reinforces and supplements the care provided by family members and friends and maintains the recipient's dignity and independence, qualities that are all too often lost in even the best institutions. Home care can also be cost effective. New York State's experience with its Nursing Home Without Walls program is that clients who would otherwise need to be' placed in a nursing home can be cared for at home for about half the cost.

I would like to outline four components that NAHC believes are crucial to the success of a federal long-term care program: the scope of benefits, eligibility requirements, eligibility determination and patient management, and financing.

1. *Scope of Benefits.* Services provided under the federal long-term care program should include a comprehensive array of home care and hospice services and include skilled nursing, home care aide personal care and chore services, physical therapy, occupational therapy, speech therapy, grocery shopping, transportation services, medication management, training of unpaid or family caregivers, respite care, adult day care, and nursing home care for a limited time with the primary purpose that individuals would return to their homes.

2. *Eligibility Requirements.* Eligibility for services should be based on an individual's functional or cognitive disability rather than age. Many of the legislative proposals under consideration recognize ADLs as an eligibility trigger; however, some require an individual to need assistance with as many as 3 ADLs before becoming eligible for services under the public program. In considering ADLs, it is important

to note that an individual unable to carry out even one ADL can be extremely disabled and in need of long-term care. For example, an elderly individual, living alone with no family or other caregiver close by, who needs assistance with only one ADL, such as eating, would benefit greatly from a relatively small amount of long-term home care.

3. *Eligibility Determination and Patient Management.* There are many different opinions on the best way to structure these "case management" services. NAHC believes that the division of responsibilities between payors and home care agency providers should recognize the payor's obligation to protect the program against excessive costs while acknowledging the caregiver's responsibility for managing client's care, and serving as the client's advocate. It is the agency caregivers who are trained for assessments and are in personal contact with the client on a continuing basis. They are the ones ultimately responsible to the client for his or her care.

NAHC supports an approach that enables the provider to remain responsible for care management and that allows the payor to carry out its utilization responsibilities without an unnecessary, costly and administratively burdensome duplication of client care planning and review functions. For example, New York State's highly successful Nursing Home Without Walls program has made use of joint assessment visits by professionals representing provider and payor. Another example is the use of the interdisciplinary team within the Medicare hospice benefit as a form of case management. A prior approval for the utilization of services, after an assessment has been done by the home care agency who provides a plan of care, could also serve as an effective safeguard.

4. *Financing.* NAHC supports the Pepper Commission's recommendations on financing guidelines, specifically, that the revenue-raising mechanism should be as progressive and as broad-based as possible and that it should keep pace with benefit growth.

There are a variety of revenue-enhancement measures that meet this test, including increases in the high-income tax rate. Further revenue might come from so-called "sin" taxes on alcohol and cigarettes.

PRIVATE LONG-TERM CARE INSURANCE REFORM

Private insurance to protect against financial losses from long-term care has only recently become available. And although private long-term care insurance will never be a total solution for financing long-term care, it can protect some people against large out-of-pocket expenses.

There are now more than 1.5 million long-term care insurance policies, which were almost unknown a decade ago. But from the beginning, insuring long-term care has presented problems for both insurers and insured. Fearful of runaway costs and unsure of how the market would evolve, carriers have often written tight limits into their policies, in some cases setting benefits too low to be really protective and in others restricting circumstances in which coverage would apply.

These policies were widely criticized and insurance companies set about drawing up new plans that would offer better protection at an- affordable price. Unfortunately, a 1991 Consumers Union (CU) survey found the industry still has some distance to go. CU looked at 94 policies. While about 25 policies were rated as "good," none was rated very good or excellent. Several were rated not acceptable because the premiums increase rapidly as the policyholder ages, perhaps causing people who could afford the policy at first to drop it later.

Major problems included inadequate inflation protection, little protection against premium increases, and generally confusing and hard-to-compare policy provisions. Probably the biggest drawback to private long-term care insurance policies is their heavy price tag. The Health Insurance Association of America estimates that a fairly comprehensive policy sold to a 65-year-old would cost about $1,400 in 1990; for a 79-year-old, the price is $4,000. In addition, two House subcommittees last year conducted investigations that uncovered numerous problems with long-term care insurance agent practices.

NAHC supports the establishment of federal minimum standards to ensure the sale of high-quality long-term care insurance products and protect consumers from fraud and abuse. NAHC believes that federal intervention is necessary because state attempts to regulate the market have had only limited success.

Even with improvements in benefit coverage, however, private insurance will probably not be a viable option for the currently disabled elderly population or for younger adults or children who need long-term care.

SUMMARY

Long-term care is one of the most devastating problems America faces today. With rapidly changing demographics, this problem will only get worse unless prompt action is taken. The Pepper Commission recognized this fact and has shown Congress the way to meet this nation's long-term care needs.

The Pepper Commission appropriately recognized that health care is the right of all Americans, and that this right does not terminate with the advance of age or with chronic disability. The Commission also recognized that in-home care should be at the core of a long-term care program, and set forth guidelines on how to fund this program that are reasonable.

On behalf of the National Association for Home Care, I urge you to take action now on legislation, such as S. 2571, that would create a national long-term care program.

I appreciate the opportunity to testify before the distinguished Members of this Subcommittee and look forward to working with you as you continue to work toward enactment of a federal program for long-term care.

RESPONSES OF VAL HALAMANDARIS TO QUESTIONS SUBMITTED BY SENATOR MITCHELL

Question No. 1. In your testimony you comment on the use of 3 ADLs as an eligibility requirement for services under a public program.

Would you please comment on the cognitive impairment and ADL eligibility requirement contained in S. 2571—our long-term care bill.

Answer. The National Association for Home Care (NAHC) is pleased that S. 2571 recognizes the importance of keying eligibility to functional disability and cognitive impairment rather than age. Many families face destitution because of the costs of caring for their chronically ill children and young or middle-aged adults at home. While public and private benefits are sometimes available to pay for the care of these clients in a hospital and nursing home, long periods of institutionalization are destructive to the family and often unnecessary.

NAHC is concerned, however, that the bill's requirement to limit eligibility to those individuals who need assistance with *three* activities of daily living (ADL) (i.e., eating, transferring, toileting, dressing, bathing) may be too restrictive. An individual unable to carry out even one ADL can be extremely disabled and in need of long-term care. For example, an elderly individual, living alone with no family or other caregiver close by, who needs assistance with only one of these ADLs, such as eating, would benefit greatly from a relatively small amount of long-term home are. NAHC understands that some initial limitations are necessary because of financing, but would like, at a minimum, to see eligibility broadened to include individuals who need assistance with *two* ADLs.

Question No. 2. You also mentioned in your testimony the need for "appropriate reforms in the way of minimum federal standards" for private long-term care insurance.

Would you please elaborate on what minimum federal standards you think are appropriate?

Answer. NAHC supports federal standards for private long-term care insurance that:

- Base eligibility for services on "functional and cognitive ability" rather than medical necessity;
- Require an annual inflation factor adjustment sufficient to ensure the benefit is adequate many years in the future;
- Prohibit requirements that policies condition the receipt of benefits on prior use of other services;
- Prohibit exclusion for, or condition benefits based on, pre-existing medical conditions;
- Require replacement policies to waive certain waiting periods;
- Require guaranteed renewability;
- Require approval of premium rates and increases in rates;
- Require additional consumer protections such as simplified policy language and standard policy formats, the "free-look" policy; and
- Set responsibilities for issuers and agents regarding restrictions on sale or issuance of duplicate coverage, provision of a consumer guide on the purchase of long-term care insurance policies, disclosure of utilization of benefits and payments, lapse rates, rescissions, application and payment denials.

NAHC would also make the following recommendations:

1. Benefits

NAHC recommends that each long-term care insurance policy should provide coverage of and payment for both nursing facility services and home care services, and that the home care services covered include the following:

- Skilled nursing services and incidental services;
- Physical, occupational, nutritional, respiratory, and speech therapies;
- Homemaker-home health aide services; including personal care and social/environmental services (i.e., cleaning, cooking, laundry, meal preparation, shopping);
- Social services (guidance and counseling for social or emotional problems, such as chemical dependency, and other long-term counseling);
- Respite home care or respite nursing home care (provided to the home care patient to give a family member or other unpaid individual who cares for the patient a respite);
- Transportation services;
- Meals (home delivered) and nutrition counseling;
- Emergency life line responses and linkages;
- Companion services (part-time or live-in);
- Hospice care, including all covered home care services and bereavement counseling; and
- Adult day care.

This comprehensive array of home care services is necessary to maximize the individual's chances for successful at-home treatment and to minimize the chances for a costly nursing home placement or other form of institutionalization.

2. Minimum Standards for Home Care Providers and Services

NAHC recommends that the minimum home care standards include a definition of care provider which states that all in-home services must be provided by an individual employed by an organization that: (1) is a Medicare-certified home health agency; (2) is accredited through a national accrediting organization, such as the Joint Commission on Accreditation for Healthcare Organizations (JCAHO), National League for Nursing (NLN), or the National HomeCaring Council (NHCC), whose training and testing standards are comparable to Medicare training and testing curriculum; or (3) is licensed in a state whose licensure laws are applicable for home care services and require training and testing curriculum comparable to Medicare training and testing curriculum.

This minimum standard would allow wider access to services while at the same time setting limits to ensure high-quality care and adequate consumer protection. The training, testing and supervision requirements imposed by Medicare, JCAHO, NLN, and NHCC are important to the provision of high-quality care. Providers not subject to these quality assurance mechanisms are likely to put underqualified and unsupervised individuals in the position of providing personal care that could be of substandard and inconsistent quality. In these situations, there is greater incidence of institutionalization, and subsequently higher costs to the payor. The risk of fraud and abuse against elderly and disabled clients also may increase.

PREPARED STATEMENT OF SENATOR ORRIN G. HATCH

Thank you, Mr. Chairman. I commend you for holding a hearing on the subject of financing and delivering long-term care for the chronically ill. This subject is complex and poses several public policy challenges.

Although there is no consensus on a definition of long-term care, the Employee Benefit Research Institute characterizes it as "the organization, delivery, and financing of a broad range of services and assistance to people who are severely limited in their ability to function independently on a daily basis over a relatively long period of time." Long-term care services include medical, social, personal, and supportive services.

According to a recent Congressional Budget Office study on the *Policy Choices for Long-Term Care* (June 1991), people of all ages need long-term care, although about three-quarters of functionally disabled adults and 90 percent of nursing home residents are age 65 or older. Much of the focus is on long-term care use by the elderly population while less is known about the use of the nonelderly disabled population. I look forward this morning to learning from our panelists about needs of the nonelderly disabled population, as well as the elderly.

Long-term care is a matter of relevance for the young and old alike. A recent American Association of Retired Persons survey found that 64 percent of Americans are "very concerned" about the costs of long-term care; 53 percent are "not very" or "not at all confident" that they would be able to pay for long-term care, and 73 percent believe that nursing home costs would impoverish them. Anyone who has undertaken even a cursory study of long-term care issues must conclude that these fears are justified.

As I see it, any proposal designed to reform long-term care financing and delivery must address six problems. First, the catastrophic costs of long-term care. A 65-year-old today has about a 20-percent chance of spending a year or more in a nursing home at an annual cost of approximately $30,000. In the absence of adequate public and private coverage for long term care, most people pay long-term care costs on an out-of-pocket basis. Unfortunately, this development threatens to impoverish many elderly and their families.

Second, there is lack of risk pooling for long-term care. Public programs provide 52 percent of the funds spent on nursing homes, but these programs do not provide long-term care risk pooling. Medicare, for instance, aids only post-acute patients, while Medicaid provides long-term care only for the poor. At the same time, private insurance markets, according to the recent Steelman Commission, have increased during the past few years, but they still reach less than 5 percent of the elderly.

Third, access to and variations in long-term care services occur among the states. Very little coverage currently exists for the home and community-based services the elderly and their families often prefer over institutional care. Many states have extremely limited Medicaid home care programs so there is a substantial variation in the home care services offered by Medicaid.

Moreover, fourth, the quality of some long-term care services is questionable. Several factors contribute to inadequate quality: lack of understanding of the process of effective care; knowledge about the effect of licensure, certification; low staffing standards; lack of consumer information; and low reimbursement rates. I am aware that the Health Care Financing Administration is currently working on the implementation of the Omnibus Reconciliation Act of 1987, writing regulations to cover nursing home reform, including survey certification and enforcement regulations for nursing home.

Fifth, the expenditures for long-term care are high and increasing. The Steelman Commission reports that 53.1 billion dollars was spent on nursing home care in 1990; another 6.9 billion dollars was spent for home care services. These expenditures do not include the commercial value of informal caregiving—a responsibility usually assumed by family members. No doubt the value of those services are estimated in the billions. Given the increase in the cost of long-term care and our aging population, these expenditures can be expected to grow substantially in the future.

Finally, there is the problem of financing long-term care. The method of financing, the cost of the program, types of covered services, eligible populations, characteristics of the beneficiaries, and—I think—risk pooling approaches are all considerations of financing long-term care. Proposed solutions to the problem of financing requires balancing these various considerations. From the number of very different bills now pending in Congress, it is obvious that Congress has not yet reached a consensus on an agreed strategy for addressing them.

Today the long-term care debate is largely preoccupied with the question of what is the appropriate role for the public and private sectors in providing solutions to these problems and who should pay for the expanded financing.

I am convinced that the delivery and financing of long-term care should not be considered in isolation from the larger health care reform debate now waging in Congress. We need to be mindful of how our deliberation this morning fits into the whole health reform picture. I believe there are four major objectives that must be operative in reforming any of our health care programs, including any new legislation on long-term care. They include:

- Access to health care and financial security for American families;
- Reduction and control of the health care cost growth rate;
- Improvement of the long-term health and well-being of Americans; and
- Maintenance of the quality of care.

These principles are no less relevant for our discussion today. I commend them to my colleagues on this subcommittee.

Mr. Chairman, as I listen to our experts this afternoon I will be considering their insights from the perspective of these fundamental principles. Thank you.

PREPARED STATEMENT OF BILL KEANE

Chairman Rockefeller and Members of the Committee. My parents were victims of Alzheimer's disease. They were also victims of gross neglect—neglect from a political and health care system that ignored them, a system that continues to ignore millions of other American families facing long-term care crises that will devastate them, physically, emotionally and financially.

It is time—way past time—to end that neglect, to put long-term care at the top of our national agenda and to enact a public program that will provide basic security for all Americans, regardless of age, income, or cause of disability.

It is time to stop talking about why we cannot pass long-term care legislation, and start talking about why we must.

I. LONG-TERM CARE AND HEALTH CARE REFORM

Some people argue that we have to deal with health care reform first, and that long-term care is just going to have to wait its turn. Mr. Chairman, that is a false distinction that makes no sense in the real world.

For millions of Americans, long-term care is the health care crisis.

Alzheimer's disease is the most expensive and the least insured illness millions of families will face. Today, it strikes 4 million Americans. By the middle of the next century, 14 million people in this country will be living with the disease, and every member of their families will be affected.

Every person who gets Alzheimer's will need full time care. Their families will easily spend as much as $40,000 a year, in today's dollars, to provide that care. And they may have to provide it for a very long time.

> *When the doctors told us mother had Alzheimer's disease, they said she would live a year or two at most. She died more than 10 years later. My father spent everything they had, everything they saved over 40 years—more than a quarter of a million dollars—to pay for her care. He had worked for the Navy Department for 25 years and assumed he had good health care protection for their retirement years. It did not pay a penny for my mother's care.*
>
> *Dick Gehring of Bloomington, Minnesota has already spent over $400,000 to care for his wife, who has lived with Alzheimer's disease for the past 18 years. He and a colleague retired from the same corporation, at the same time, with the same health insurance. His colleague's wife got Lou Gehrig's Disease and insurance paid the bill. Dick's wife got Alzheimer's disease; insurance paid nothing.*

Even the most sweeping health care reform proposal on the table will fail millions of families, unless it includes long-term care.

II. THE COST OF LONG-TERM CARE LEGISLATION

Some people say that a long-term care bill is too expensive. There is no question that it carries a large price tag. But Americans are already spending this money, in a cruel system of Russian roulette. If you are the unlucky one, you are stuck with a bill you cannot afford—and there is nothing you can do to reduce your risk, particularly with a disease like Alzheimer's.

What we have to do is spread that risk, through a system that asks all of us to contribute in a way that each of us can afford. It would cost about $5 a week per taxpayer to finance a comprehensive long-term care program. That is $260 a year—a number taxpayers can understand and, according to public opinion polls, are willing to pay, if it buys real protection against the massive long-term care costs they fear.

We must take an approach to long-term care that is cost conscious from the very beginning. One of the most important ways to do that is to provide for the full continuum of care, with an emphasis on home and community based care and alternative residential settings that keep people out of expensive medical care unless they need it.

> *My mother's condition deteriorated rapidly, and my father could no longer cope with her care. I had moved back home to help, but I had to go to work every day. We might have managed longer, and I am sure the quality of my mother's life would have been better, if we had been able to get appropriate home care or day care. But there was no such care available. Our only option was the costliest one—a nursing home—even though she did not really need that level of care for most of the years she was there.*

We have learned a lot in the intervening years about alternatives for Alzheimer care. We need to build those into any public program, for both cost and quality reasons.

III. FAMILIES AS CAREGIVERS

Some people argue that public funds should not be used to pay for care families are now providing at no cost to the taxpayer. In fact, there is little evidence to suggest that availability of formal care in any way reduces the amount of care the family provides. We are not asking government to replace what families are doing. We are asking for the help that makes it possible for them to continue to provide care longer.

Families are the heart and soul of the long-term care system today, and we want to keep it that way. But long-term care is literally killing them.

Caregivers of the frail elderly are at enormous risk. Their average age is 57. One in three are at least 65. Over 40% of caregiver-husbands are at least 75. Caregivers at any age are far more likely to be in poor physical health than others in their age group, and they are three times more likely to be suffering from depression. They suffer from exhaustion, lowered immune function, and stress-related illness and injury directly related to their caregiving. By ignoring caregivers, we are compounding the health care crisis in this country.

> *I work in a rehabilitation hospital in New Jersey. I see all the time stroke victims suffering from great stress, because they are the sole caregiver for a spouse at home. My father ended up in the hospital, physically and emotionally destroyed by the unbearable burdens of care. He died in the hospital, two years before my mother—just as much a victim of the disease as she was.*

At least one-third of all caregivers work outside the home, either full or part-time. Middle-age caregivers, most often daughters and daughters-in-law, work the equivalent of three full time jobs to balance the demands of job, their own children, and their parents. Younger adults put their own lives on hold to help provide care.

> *Teenagers, like the children of Orien Reid of Philadelphia, give up their own childhood to share the responsibilities of caring for their grandmother.*
>
> *Bill Gold of Detroit dropped out of law school to take care of his mother.*
>
> *I left a job in upper New York State, because long-distance caregiving could not work. My parents needed me at home.*

As our population ages, the numbers of people needing long-term care will mushroom. Spouses and adult children providing the care will be older and frailer. And changing family structures—smaller and more widespread families, larger numbers of women in the work force, more single parent households—will leave fewer family members available to help.

If we lose our family caregiving system, it will add another $54 billion to health care costs. The costs in human terms would be immeasurable. But we are much more likely to lose family caregivers if we do nothing, than if we begin to support them.

IV. PRIVATE INSURANCE AS A SOLUTION

Some people suggest that private insurance can provide the long-term care protection most Americans need, particularly with appropriate standards and perhaps with some public subsidy through tax incentives or Medicaid.

According to a report just released by the Alzheimer's Association, private assurance cannot do the job. We looked at some of the best policies now on the market—industry leaders. Our findings were very disappointing.

> *If you are 68 years old, the average age of people buying long-term care insurance today, you can spend more than $4000 a year for the best available coverage, but you will not have the protection you will need if you get Alzheimer's disease. Very few older Americans have that kind of extra money to invest in long-term care insurance. And if you already have Alzheimer's disease, or even symptoms that suggest you might be getting Alzheimer's, you cannot buy a polity at any price, no matter how much money you have.*

There is no way an insurance company can write a policy that fully covers Alzheimer care, is affordable to most consumers, and assures the company a reasonable profit. The Alzheimer's Association is not saying that a public program has to do it all. Within a public program, there may be considerable room for private insurance to play an appropriate role, particularly for consumers who are interested in protecting substantial assets.

But without a sound social insurance program, private insurance will be no more than a band-aid on a major hemorrhage. We certainly should not be using tax dollars to subsidize these inadequate policies in lieu of real benefits for those who cannot afford private insurance.

V. THE INADEQUACIES OF MEDICAID

Some argue that Medicaid provides the ultimate safety net for long-term care and that, perhaps with some tinkering, it can meet the need.

The problem with Medicaid is that people who desperately need help cannot "qualify, benefits are limited and biased toward inadequately reimbursed institutional care, and the system itself demeans the people it does help by forcing them into poverty in exchange for meager benefits.

Even the limited long-term care Medicaid now provides is in jeopardy. States are eliminating medically needy programs that have given people access to long-term care, reducing Medicaid nursing home bed supply, cutting back on home and immunity care.

We are forcing older persons who have spent their life savings on long-term are to compete with poor mothers who need basic health care for their young children, in a system that does not work well for anyone.

> *My father knew that there were ways he could qualify my mother for Medicaid. But he considered Medicaid a program for the destitute. We were raised to obey the spirit as well as the letter of the law, so we paid privately for my mother's care for over 10 years.*

He and my mother, and millions like them, were victims of a system that provides help at the economic extremes—private insurance for the wealthiest and a public program for those who have nothing at all.

We act like we don't know that long-term care crosses all economic lines, that almost no one can pay the staggering costs, that other family needs do not go away just because a parent or a spouse or a child develops a chronic illness that requires expensive long-term care.

We just assume that somehow people will manage. But we are asking families to do too much.

> *Orien Reid, a single mother from Philadelphia, was forced to use the money she had saved for her daughter's college tuition to pay for her mother's long-term care.*
>
> *Catherine Brewer of Long Island was forced to remortgage their home when her husband got Alzheimer's and lost his job, because they had already spent everything else to pay for his mother's long-term care.*
>
> *Eileen Draganc of Skokie, Illinois is being forced to spend all of her resources to pay her husband's nursing home bill, even though he qualifies for Medicaid, because it would be too traumatic to move him to a facility that will accept Medicaid.*

We have to do better. It is time to put in place a long-term care program that provides financial security for all Americans, spreading the costs and the risks among us all in a way that every family can afford.

Mr. Chairman, we commend your leadership in bringing to the Senate a responsible long-term care proposal that can lead us toward a solution to this problem. The Alzheimer's Association supports S. 2571, the Long-Term Care Family Security Act. It would provide a critical social insurance underpinning for long-term care, asks families to continue their commitment, and leaves a role for private insurance that is reasonable to expect the industry to fill.

We also commend you for holding this hearing today, to underscore that long term care is and must be an integral part of the health care reform debate.

The Alzheimer's Association is a 50-state network of 215 local chapters, more than 1600 support groups, and tens of thousands of volunteers. Almost all of us come to the Association from a personal caregiving experience. Long term care is our top priority and we are ready to work with you and the Committee to enact meaningful health care reform that includes long-term care.

RESPONSES OF BILL KEANE TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. One of the concerns that has often been expressed about expanding home care it the so-called "woodworking" effect. Do you believe that there would be a major change in behavior among family caregiver of Alzheimer's patients if a long-term care benefit were available? In other words, would informal caregivers stop giving care voluntarily in favor of paid care?

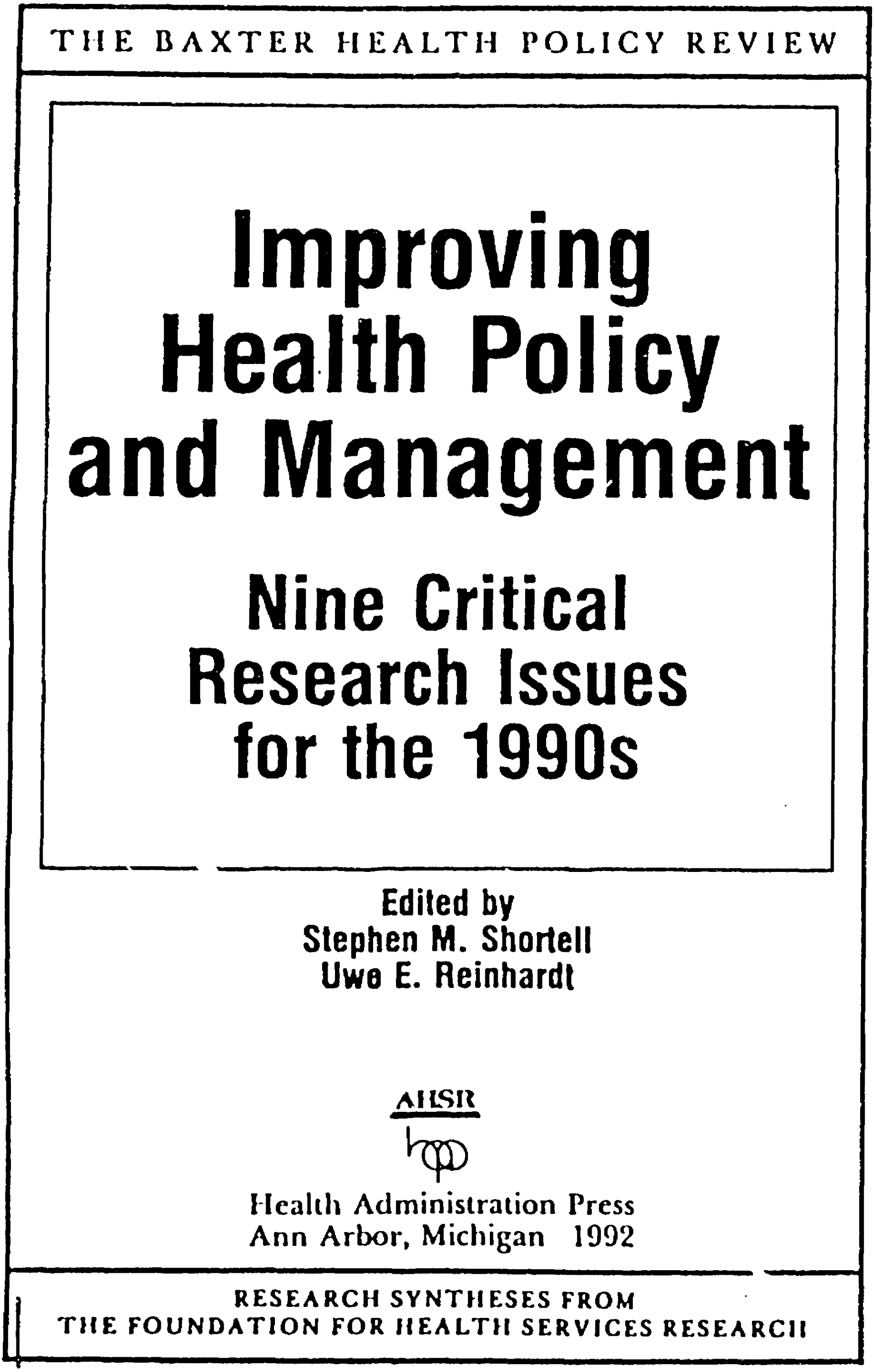
Answer. Absolutely not. The Alzheimer's Association works with families all across the country who are desperately trying to continue as caregivers. They do not want to give up their caregiving roles, but they do desperately need help, as the Committee heard from all of the witnesses who testified before you.

Virtually all of the research that has been done on this subject confirms what we know from the families we see every day. They show that families continue to provide the majority of long-term care to frail elders even when formal services are used. They have discovered that higher rates of formal service use are directly associated with increased provision of informal care—because the person needs more, and more skilled care, not because families are substituting formal services for their own role. The consensus among studies that have specifically examined this question is that the effect of formal care on the provision of informal home care is small or statistically nonsignificant. (See attached excerpt from "Caring for the Disabled Elderly: There's No Place Like Home," in *Improving Health Policy and Management.*)

If anything, what actually exists is just the opposite of the "woodwork" effect. One of the interesting things that has been learned in the many demonstrations of home care 15 that the real problem is not substitution, but rather convincing family caregivers that it is alright to accept help and that they do not have to relinquish their role as primary caregiver.

None of the long-term care proposals on the table would provide the full time round the clock care that a person with Alzheimer's disease living in the community needs. The Long-Term Care Family Security Act would provide at most 58 hours of home care a month—about 3 hours a day—even for the most severely disabled. That will be an enormous help to families, but they will still be left to do most of the job themselves. The provision of that care—enough to get some relief from the constant demands of caregiving or help with some of the tasks that the caregiver may not be able to do alone—may make the difference between keeping a person at home or putting that person in a nursing home. But it is not going to lessen the commitment of the family caregiver.

The reality is—and there have been studies that show this—even when a person with Alzheimer's disease enters a nursing home, the family caregiver does not abandon his or her caregiving role. It just becomes different.



THE BAXTER HEALTH POLICY REVIEW

Improving Health Policy and Management

Nine Critical Research Issues for the 1990s

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RESEARCH SYNTHESES FROM
THE FOUNDATION FOR HEALTH SERVICES RESEARCH

Will Paid Home Care Erode Informal Support?

One of the main barriers to the expansion of home care programs is the fear that policymakers have that paid home care will cause friends and relatives to stop providing informal care. In short, lawmakers do not want the public paying the bill for home care that otherwise would be provided free, because the potential costs to the health care system would be staggering. One study estimates that over 27 million days of informal care were provided to the nation's disabled elderly each week in 1982, an average that exceeds 5 days per week per disabled person.[42]

The bulk of research suggests that more paid help does not mean less unpaid care. Thus, policymakers should not assume that the provision of formal in-home services to care for older persons will result in a widespread substitution of formal for informal care. Indeed, most findings imply that paid care increases the overall amount of care provided and thus should result in fewer unmet needs among the disabled elderly. In 1984, one-third of the elderly with ADL disabilities reported some unmet ADL needs.[43]

An ambitious review of nearly all home- and community-based long-term care studies conducted since 1960 concluded that "informal social support tended to decline with home and community care use."[44] Close inspection of the studies presented, however, suggests just the reverse. Of the 53 evaluation findings presented on informal care, 41 were statistically nonsignificant, 7 suggested a statistically significant increase in unpaid care, and only 4 suggested a statistically significant decrease (1 finding was indeterminate). Moreover, none of the significant findings reported necessarily reflected a reduction in the total amount of informal support. An alternative explanation would be that the results reflected a change in the type of unpaid care received.[45]

In fact, with only one exception, the consensus among studies specifically designed to examine the substitution of formal care for the provision of informal home care is that the effect was small or statistically nonsignificant. In the federally sponsored Channeling demonstration, the case management model that provided a rich array of formal in-home services found only a small reduction in the percentage of disabled elderly receiving any informal care.[46] It also caused a nonsignificant decrease in the number of visits per week by informal caregivers and a nonsignificant increase in the number of hours per day of care provided by the primary informal caregiver. In terms of specific areas of help, there were a few areas of small but significant reductions in the provision of informal help, more by nonfamily than by family caregivers. However, these small reductions in unpaid care were associated with much greater increases in paid care. For meal preparation, housework, laundry, and shopping, for example, a 4 percent to 5 percent increase in the number of clients receiving services from paid providers was associated with a 1 percent decrease in the number of elderly receiving the same service informally.

Similar results were found in studies of California, Chicago, and Minnesota home care programs. A small reduction was found by California's Multipurpose Senior Services Project evaluation.[47] For persons living with others, a 10 percent increase in formal care led to a 1.2 percent decrease in informal care. The effect was less for elderly living with a child and for those with a sibling nearby, with no detectable effect for persons living alone. A recent analysis of the Five Hospital Program community care project in the Chicago area found no evidence of a significant decrease in the total number or volume of services provided by informal caregivers between baseline and the 9-month and 48-month follow-up, despite a significant increase in formal services.[48] A study of the Minnesota Pre-Admissions Screening/Alternative Care Grants Program also found that informal caregivers did not reduce support following the introduction of formal home care services.[49]

The one study using a nationally representative sample of disabled elderly found that the amount of informal home care received was not significantly affected by the level of formal care being provided.[50] This conclusion also held for subgroups of elderly formal care users who were most likely to exhibit substitution: those without cognitive problems, the disabled elderly with above average income, and persons who live alone. The more severely disabled elderly with three or more problems with the activities of daily living or cognitive impairment, who are the target of most proposals to expand paid home care, also did not show evidence of any substitution of paid for unpaid care.

In contrast, one stud' found informal caregivers withdrawing from 1.35 areas of help (bathing, toileting, shopping, housework, meals, and so on) in response to the provision of formal care in one additional area.[51] Again, this finding may reflect redirection of family help rather than a reduction in their overall level of effort.

Overall, the findings suggest that advocates of home care face an important dilemma. On the one hand, the results strongly support the contention that paid-home care can be expanded without eroding the amount of informal care. Indeed, the disabled elderly with paid care receive more care than similar persons who do not receive these services.

On the other hand, one rationale for expansion of home care is to relieve the burden on informal caregivers. But most research suggests that providing paid home care may not substantially reduce the burden because many elderly have unmet care needs and most caregivers will continue to provide virtually the same amount of care. This may also help to explain the perplexingly small impact that prior paid home care demonstrations have had on caregiver burden. It does not mean that informal caregivers are ungrateful or do not want home care, but rather that caring for a disabled relative is such a major responsibility that receiving modest amounts of paid care does not radically change their global perception of burden. What paid home care can do for caregivers is give them a needed respite and allow them to arrange their hours and tasks more efficiently. Families welcome the relief, but their burdens remain great.

PREPARED STATEMENT OF MARILYN MOON

Mr. Chairman, members of the Committee, it is a pleasure to testify before you today on long-term care financing reform. My remarks today reflect work I am doing with my colleague Judith Feder of Georgetown University, an expert with twenty years of experience on health and long-term care issues. My own work in health and long-term care has focused on reform and financing issues and on the ability of older Americans to meet their needs for health care. We began our collaboration during the Pepper Commission when Dr. Feder was staff director and our effort is continuing under a grant from the Retirement Research Foundation.

In turning your attention to long-term care, you are addressing a critical but often missing piece of the health care reform agenda. Today virtually all Americans—young and old, rich and poor—face the risk of impoverishment if they become impaired and in need of assistance in the basic tasks of daily living we call long-term care. Economic security in the event of illness requires protection against these risks, just as it requires protection for needed care from physicians and hospitals.

My testimony will address two questions: First, why we need long-term care financing reform; and second, what alternative strategies exist for pursuing that reform. In brief: we need reform because, under current law, families bear the full financial as well as emotional burden of providing and financing long-term care; we have no mechanism or system for spreading or insuring that cost. The challenge before you in choosing a strategy for reform is to develop a long-term care system that guarantees universal protection, an equitable distribution of financial burdens, and affordable costs—for individuals and the nation.

THE NEED FOR LONG-TERM CARE REFORM

From your deliberations on health care reform, you are accustomed to hearing about the gaps and inadequacies in insurance for hospital and physician services. When it comes to getting and paying for long-term care services, the problem is far more fundamental. It is not that we have an inadequate or insecure system for insuring long-term care; instead, we have no system at all. Individuals pay for home care or nursing home care out of their own resources; and, when those resources are exhausted—or if they have none to begin with—they turn to the welfare-based Medicaid system for support. Unlike insurance, which protects people against financial catastrophe, our current system provides people protection only after catastrophe occurs. Medicaid is thus not an insurance program; it is a welfare program for those who have impoverished themselves. And even after becoming eligible, families must devote most of their incomes toward the cost of that care.

Who Needs Long-term Care? Although the probability of needing long-term care is far greater for the elderly than for the younger population, anyone at any age can become impaired and in need of support to sustain themselves or their households. A child born with cerebral palsy, a young mother or father injured in an automobile accident or a grandparent with Alzheimers—all have in common the need for personal and household support services. Moreover, it is extremely difficult to predict who will ultimately need this care.

We do know that when people need care, they often do not have the means to provide it for themselves. Among the elderly, for example, those with disabilities are older on average and have fewer resources than does that group as a whole. The most likely group to need long-term care services, unmarried women over the age of 85, have rates of poverty in excess of 20 percent. And many more of them have incomes just above the official poverty levels.

Today, an estimated 9–11 million Americans, one-third of them under age 65, are sufficiently impaired to need these services. About four million, one-fifth of them under age 65, are so severely disabled that they cannot dress, bathe, or get out of bed without substantial help from others.

How do people get care? Contrary to popular perception, most people receiving long-term care live in the community, not in nursing homes. Four out of five of the disabled (and more than half of the severely disabled) live at home or in the community and depend almost entirely on their family and friends for the support they need—or do without needed care.

In part, reliance on family support reflects the commitments families have, and should have, to caring for their impaired relatives. But the fact that many caregivers themselves tend to be elderly, to have low incomes and to experience less than good health, coupled with the intensity of the care they provide (four hours a day, seven days a week, on average) suggests that families find themselves with no viable alternative. Medicare pays for in-home care only when people need skilled nursing or rehabilitation services—not when they simply need the personal and support services that are the essence of long-term care. And even Medicaid, the primary public payer for long-term care services, covers relatively little care at home, as compared to the population in need.

Purchasing home care is expensive. Monthly payments averaged $439 per month for the most severely impaired purchasers in 1982. With in-home care currently estimated to cost about $60 per visit, most people in need of long-term care lack the means to purchase it or to purchase it in adequate amounts. Four visits per week would cost $12,480 per year for an individual-totalling nearly half the total income of a typical elderly couple. And most home care is supplemented by family caregivers who may take time off work in order to provide care. These costs are not captured in any of the formal figures.

Nursing home care, estimated to cost more than $2,500 per month, is beyond the means of almost all Americans. At that price, even a short stay in the nursing home is "catastrophic." If a couple pays on its own for these services, they would have to have an annual income of almost $40,000 to afford the nursing home services and leave the community-dwelling spouse with just a poverty level income. Only about 28 percent of elderly couples have such incomes. If they turn first to savings to try to stretch their resources further, the average family will exhaust its financial assets in less than one-and-a-half years. And since many older families rely on financial assets to provide income to meet their basic living expenses, depletion of assets may still result in great hardships for the community-dwelling spouse.

Among older persons with out-of-pocket spending of $3000 or more, 83 percent went for nursing home care. Long term care, not acute care services, accounts for the catastrophic spending on health care by many of our citizens. Individuals and their families pay about half the costs of all formal long-term care in any given year.

Although Medicaid does finance nursing home care, to obtain its benefits people give up all their assets and all their incomes—essentially impoverishing themselves before they can get assistance. This requirement presents not only a financial burden, but also a barrier to access to care for those who fear giving up their financial independence and becoming dependent on welfare. Furthermore, it is not clear that Medicaid can continue to bear nursing home costs. In 1990, Medicaid spent more than $25 billion on nursing home care (almost three-quarters for the elderly; the rest on facilities for the mentally retarded). As the Medicaid program-faces enormous cost pressures—not only from long-term care but from its role as a health care safety net for the poor and uninsured—serious questions arise as to the adequacy and quality of the nursing home services Medicaid buys.

Over the last decade, private insurance has emerged as a means for spreading the risk of long-term care. Today, about 2 million Americans have private insurance policies. However, if these policies promise adequate protection against likely costs (a standard many do not meet), they are unlikely to be affordable by the majority of senior citizens, most in need of protection. The Health Insurance Association of America estimated the cost of such a policy at $1400 for a sixty-five year old in 1990; over $4000 for a seventy-nine year old. And part of the "cost" of making such insurance affordable is precluding anyone with a long list of health problems from purchasing policies.

Estimates prepared for the Pepper Commission indicated that only 6 percent of today's elderly population could afford such a policy without spending more than 5 percent of their income—and even then, they would not be fully protected against the costs of care. Many older Americans wishing to protect themselves from the costs of long-term care would have to lower their standards of living for many years in order to obtain partial protection.

Private insurance, with the addition of consumer protection standards, can provide some Americans some security against the financial risks of long-term care. But for the vast majority of the elderly, anyone who already has a disabling condition, and the younger population with a small but real risk of long-term care needs, the emerging market provides little prospect of protection.

What are the prospects for the future? If the current picture of long-term care financing-looks bleak, the future looks even worse. Projections are that the elderly population will double in the next forty years. The population over age 85 and most likely to need long-term care is projected to increase fivefold. At least so far, longer lives have not translated into healthier lives. Increased survivorship of disabled children and the traumatically injured, along with the spread of AIDS, will increase the need for long-term care among the younger population as well.

Private insurance coverage may continue to grow, as future older Americans with higher incomes are better able to afford its costs or to purchase it at younger ages. However, even optimistic projections of private insurance growth suggest that 30 years from now, no more than half the nation's senior citizens are likely to have long-term care protection. As a result, the demands on the welfare-based Medicaid program will rise with the growth in the elderly population. Projections are that even to keep pace with current levels of service—deemed inadequate by consumers, providers, and experts—expenditures on long-term care, net of general inflation, would be triple today's levels.

OPTIONS FOR REFORM

While there is widespread agreement that long-term care should be covered by some form of insurance and that government must play a role in the development of that insurance, there is disagreement as to the roles the public and private sector should play. As in acute care, options range from strategies that would promote private insurance as the most appropriate strategy for the majority of Americans, limiting public activities to the role of safety net for the poor, to strategies for developing a universal social insurance system to protect all Americans, regardless of income, for long-term care needs. In between are strategies that would provide limited social insurance—combining social insurance for some benefits with a public/private partnership for others.

Private insurance/Medicaid expansion. Some argue that government can most efficiently promote insurance for long-term care by facilitating the expansion of private long-term care insurance—primarily by extending the favorable tax treatment of health insurance to premiums and benefits paid for long-term care insurance. Some would add subsidies for private insurance, through tax credits or the provision of public "back-end" coverage, to promote broader purchase of private insurance. These subsidies would help to lower the costs of insurance to those with the resources to purchase coverage. Such expansion, they argue, would minimize the need for government-financed care, although they might be accompanied by some improvements in Medicaid protection of income and assets.

Preferential tax treatment, accompanied by public education, could be expected to facilitate growth in the number of people purchasing long-term care insurance. Furthermore, public standards and oversight to ensure adequate value for the dollar and other consumer protections in the developing marketplace could reduce some of the fears about abuses. Finally, some enhancement of Medicaid benefits—to cover more care at home, and to raise the low levels of income and assets nursing home residents are allowed to retain—could improve upon the current system and enhance the quality of life for the currently impaired population.

However, such a strategy also poses many problems. Even with preferential tax treatment and subsidies, private insurance would remain too expensive for most elderly to purchase without substantial financial sacrifice. Subsidies would therefore disproportionately benefit the better-off relative to the moderate income elderly. Even more important, such a strategy will not be adequate to provide universal protection against long-term care risks—unless the subsidies and Medicaid expansion were much greater than that usually proposed. As indicated above, even optimistic projections indicate that it would be decades before significant numbers of elderly had the resources to purchase private long-term care insurance. In the meantime, inadequacies and impoverishment would persist. And even forty years from now, long-term care insurance would remain too expensive for more than half the elderly to purchase at a price less than 5 percent of income.

Pursuing such a strategy would seem ironic, indeed, given public outrage at today's combination of Medicaid and private insurance for the population under age 65. To repeat the nation's experience in health insurance—to intentionally build a system that will inevitably leave out vast numbers of Americans, entail innumerable inefficiencies, and produce uncontrolled increases in health care costs—would seem to be a tragic and avoidable mistake.

Social Insurance. The virtual absence of any system for long-term care insurance in the current environment provides policymakers an opportunity. Rather than struggling to mitigate the inefficiencies and inequities developed over the years, it is possible to build from scratch an efficient, effective system for financing and delivering long-term care.

A social insurance system—providing in-home and nursing facility benefits to all disabled Americans, regardless of income—has considerable advantages in this regard. It could cover everyone in need and spread costs equitably and progressively across the full population, limiting burdens relative to ability to pay. Evidence from state experience indicates that government can manage such a system—in ways that support, rather than replace family-provided care, and manage the growth in service costs. Finally, such a system would not eliminate a private sector role. Rather, it would limit that role to supplementing the publicly-determined, basic protection.

Despite these advantages, even advocates of this approach question the wisdom of embarking on an extensive public commitment at a time when the nation faces limited fiscal resources and so many worthy claims upon them. Most particularly, people question the appropriateness of using public resources to provide unlimited protection of assets or estates for older Americans, when the standard of living for so many younger and more vulnerable Americans is in jeopardy.

Limited social insurance. Most people needing long-term care are not seeking to protect their estates. They are at home, struggling to obtain care and maintain their standard of living. Even many nursing home residents return home after their stays. Estimates are that as many as half of nursing home residents stay in the home less than six months and that half these "short-stayers" are able to return home.

Thus, a third alternative approach to solving the problem builds on the more critical needs of preserving standards of living for those who will remain or return to the community. Here the goal is to design a system to distinguish between standard of living and asset protection—using public resources efficiently and providing economic security in the face of impairment. Such a system would have three parts: social insurance, without regard to income, for people at home or able to return home after short nursing home stays; a floor of asset protection to prevent impoverishment in the base of long nursing home stays; and, for the better off, who have additional assets to protect (or who want additional benefits), promotion of private health insurance that satisfies standards for consumer protection.

This approach (endorsed by Senator Mitchell, Senator Rockefeller and other members of this committee in S. 2571) provides the potential to achieve the risk-spreading and public support associated with universal entitlement, while targeting public resources to the low and moderate income population. This approach then leaves a role for private insurance to serve those with substantial resources who would wish further protection.

CONCLUSION

The United States faces a large and growing need to offer protection against catastrophic long-term care expenses for persons of all ages. We are now spending over $25 billion in public monies for a Medicaid program that offers protection as a last resort—a system that satisfies almost no one. Although the costs of providing long-term care benefits would be substantial, there are some advantages as compared to acute care. That is, in designing a system you face a relatively clean slate. The insurance industry is not yet so well established -that it would be displaced by social insurance; most interest groups favor expansion of public programs; and voters—of all incomes and all ages—are seeking government help and, according to polling data, seem willing to pay for it. There is consequently an opportunity to build an efficient, effective long-term care system, with the public and private sectors each playing an appropriate part.

RESPONSE OF DR. MOON TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. One of the concerns that has often been expressed about expanding home care is the so-called "woodworking" effect. Do you believe that there would be a major change in behavior among family caregivers if a long-term care benefit were available? Do you believe informal caregiving would greatly diminish in favor of paid care?

Answer. I do not believe that the "woodworking" effect poses a substantial problem. This does not mean that there would be no change in the behavior of caregivers, however. There would likely be changes—many of which would be desirable. We know that caregivers suffer great stress and often lowered physical health as a result of their experiences. And institutionalization of the impaired person often comes as a result of the caregiver being unable to continue in that role. Thus, we should welcome some tradeoffs. Indeed, offering paid care that would relieve some of the current burdens on caregivers might result in no overall change in how much care was delivered. Caregivers might be able to extend the period over which they offer care if they periodically get some relief from formal services, for example.

Another area where there may be increased substitution of paid services would be when care is reluctantly given. Such care is unlikely to be of very high quality and indeed may be associated with abuse of the impaired person. Again, increased reliance on formal care would be appropriate in this instance.

Most caregivers feel that what they do is important and studies have indicated that even when formal services are available, family and other unpaid caregivers continue to play a pivotal role. The most likely effect of adding formal services is an improvement in the quality of life for the patient as these additional services *complement* rather than substitute for informal care.

Use of services will rise, but this is likely to be a positive change on balance and not a negative one.

PREPARED STATEMENT OF SENATOR DAVID PRYOR

Good afternoon. Mr. Chairman, I want to commend you for your leadership in convening this hearing today. Comprehensive health care reform seems to be on everyone's lips lately.

Unfortunately, discussions about reform too frequently ignore the issue of long-term care. And, in my opinion, reform of our health care system cannot be defined as complete without assuring that Americans of all ages are no longer vulnerable to the catastrophic costs of long-term care. I am pleased that Senator Rockefeller, Senate Majority Leader Mitchell and other members of this subcommittee are working to put long-term care back On the health care reform agenda.

In February, I had the privilege to chair a hearing on long-term care and prescription drugs in my home state of Arkansas. A standing-room-only crowd of almost 1,000 people showed up, a powerful illustration of the enormous interest and need for these services. Our witnesses talked about how important their caregiving responsibilities were to them, but how much better their lives would be if they could just get a little bit of help in the home. Or, if their loved one became so ill that nursing home care was the only alternative, why did they have to spend all of the money they had worked so hard to save so that they could become eligible for Medicaid.

I also heard from fellow Arkansans who had such high drug costs that they were making decisions as to whether or not to buy groceries that week. And it is not a problem exclusive to the elderly. I remember several months ago a young father, permanently disabled by an accident, telling me that Christmas gifts were an impossibility in his family because his prescription drug costs barely left them enough money to pay the rent.

I suppose by now that it has become a cliche to wonder how these financial and emotional catastrophes could happen in a country as prosperous as ours—but it does, every single day. And Mr. Chairman, our constituents are asking us what are we going to do about it? Finally, we have the beginnings of an answer to that question. Last month, Senator Mitchell, Senator Rockefeller, Senator Riegle, myself and many other of our distinguished colleagues took a step in the right direction by introducing S. 2571, the Long-Term Care Family Security Act of 1992. This bill, which is based in large part on the recommendations of the Pepper Commission, is not perfect. It does serve, however, to end the deafening silence that previously surrounded the issue of long-term care.

This legislation, which provides coverage of nursing home and home- and community-based care, and private long-term care insurance consumer protections, also includes the establishment of a Prescription Drug Policy Review Board. This board will evaluate the feasibility of using cost containment mechanisms, such as those used in Canada and England, to help us control skyrocketing prescription drug costs. A Prescription Drug Payment Review Commission, charged with determining mechanisms to make prescription drugs more accessible and affordable, is also established.

At first glance, most people do not think that prescription drugs have anything to do with long-term care. However, it is important to remember that the average elderly American over 65 takes about 15 to 16 medications each year, year after year. Up to 7 of every 10 prescriptions filled for elderly patients are to treat chronic, long-term medical conditions, such as high blood pressure, heart problems, glaucoma, diabetes, and an array of other conditions. When you consider these facts, it becomes evident that the cost of prescription drugs is one of older Americans' biggest long-term care expenditures.

The Subcommittee has assembled an impressive array of witnesses here today, and I look forward to hearing their testimony. Again, I want to commend Chairman Rockefeller for his leadership on long-term care. The elderly and disabled have a true advocate in him, and I am proud to be a part of his endeavors. Thank you.

PREPARED STATEMENT OF SENATOR DONALD W. RIEGLE, JR.

Mr. Chairman, today we will discuss an issue that will touch each and every one of us at some point in our lives, meeting the long-term care needs of our society. Almost all of us have personal knowledge of the devastating financial and emotional effect that caring for an elderly or disabled relative or friend can have on families and communities. I hear from many people in Michigan about the difficult decisions they and their families face because they can't afford long-term care.

Virginia Moore, of Ada, Michigan, recently wrote to me about her husband, Robert. The Moores have a personal assistant who comes to their home for four hours each day to help Mrs. Moore care for her husband, who is completely paralyzed. Having a personal assistant means that Mr. Moore can stay at home, and the Moores can lead a fairly normal life. They get help paying for part of the assistant's fee from a community agency, but they pay a large amount out of their own pocket. When Mrs. Moore became ill a few years ago, Mr. Moore had to enter a nursing home until she was well. Despite the hard work Mrs. Moore puts in to care for her husband, and despite the fact that getting home care help has cost them almost their whole life savings, their family is committed to keeping Mr. Moore at home instead of in a nursing home.

NEED FOR COMPREHENSIVE REFORM

There are many in Michigan who face the same dilemmas as the Moores. In fact, there are over one million residents who are 65 or older. The *Lansing State Journal* reported that 1.5 million residents of the state of Michigan have disabilities. Many of these people will eventually need some kind of long-term care. Yet few people are planning for these needs by buying long-term care insurance because private insurance policies are often limited and expensive.

Currently, the major source of public funding for long-term care is the Medicaid program. Medicaid funding for long-term care is primarily limited to nursing home care, and people must spend down their assets to near-poverty just to qualify. As Chairman of the Subcommittee which oversees this program, I believe we need a better safety net than this to give elderly and disabled persons and their families a sense of security. The time is right for a comprehensive, national long-term care policy.

Over the past several years, I have held numerous hearings in Michigan and written to almost 400 groups to solicit suggestions for long-term care reform. Listening to their concerns has made it clear to me that any long-term care strategy must address the following issues: financial protection against the high cost of long term care; expansion of the range of services covered, including home health care, nursing home care, respite and hospice care, and other social support services, while building on existing family and community support; and methods to ensure that costs are controlled in the long run.

I have been working with Senators Mitchell, Rockefeller, Kennedy, and others to develop S. 2157, the Long-Term Care Family Protection Act. Our goal is to provide a comprehensive strategy for long-term care reform which incorporating both public and private sector actions. It allows individuals flexibility to best meet their own needs by building on the existing support they get from their families and communities. It will provide the combination of home and community based services and nursing home care that will give people the highest quality of life possible, without subjecting them to impoverishment. And it will enable elderly and disabled people to meet their long-term care needs.

Incorporated in the Long-Term Care Family Security Act are some of the private long-term care insurance safeguards included the Long-Term Care Insurance Consumer Protection Act, S. 846, a bill I previously introduced with Senators Pryor and Daschle. As we move to a consensus on comprehensive long-term care reform, we should adopt these provisions to implement safeguards for private long-term care insurance which are similar to those that now apply to Medigap plans.

I thank Chairman Rockefeller for holding this important hearing, and commend him, along with the Majority Leader, George Mitchell, and Senator Kennedy for their leadership and dedication to improving our health and long-term care systems.

PREPARED STATEMENT OF JENIFER SIMPSON

Mr. Chairman, Members of the Subcommittee, I am Jenifer Simpson and I am here today to talk about my experience with getting personal assistance and other long-term support services for my seven year old son, Joshua, who has cerebral palsy. Josh is one of some 500–700,000 children and adults with cerebral palsy in the United States today.

Overall, there are an estimated 7 to 9 million Americans with varying disabilities of all ages who need some type of long-term support services to be fully participating and productive members of our society. I am testifying today both as a parent and representing the Consortium for Citizens with Disabilities (CCD) Task Forces on Personal Assistance Services and Long-Term Services/Medicaid. CCD will submit within the next ten days further written testimony on its concerns and recommendations regarding these vital matters.

Mr. Chairman, I'm grateful to be here today to tell you about the struggle I and thousands of other parents face, trying to get access to such vital supports for our sons and daughters with disabilities and chronic illnesses. I also would like to describe what life could and should be like for families like my own.

In many ways, Joshua is a typical little boy. He likes computers and playing with toy trains. He's sociable, alert and attends school. He's skipping it today to be here with me. What makes Josh different from most other kids, though, is his disability. Or, rather, our nation's failure to support my decision and efforts to raise him at home, where he belongs.

Cerebral palsy is not a disease or illness. Rather, it is a lifelong disability that can affect a person's ability to express themselves and/or perform everyday activities independently that you or I do almost without thinking. Such individuals, and those with other disabilities, must often rely on assistance from others or from assistive devices (such as motorized wheelchairs, communication aids and the like) to make the otherwise impossible both possible and easily within reach. This is the dream of freedom embedded in P.L. 101–336, The Americans With Disabilities Act, and one I would like to see made real for Joshua.

Joshua's disability makes it difficult, if not impossible, for him to walk, talk, eat, drink, use the bathroom, get dressed, or do most anything without a lot of help. He gets much of that assistance from me. But, besides being a full time single Mom, I am also a full time Policy Associate with United Cerebral Palsy Associations' Governmental Activities office here in Washington. Increasingly, therefore, I must pay others to meet Joshua's extraordinary personal assistance needs when I cannot be there to do it for him myself. And finding the money to pay for that care and those individuals to do personal assistance is a constant challenge.

I love my son, but caring for him is a big challenge. I feel that I have two jobs, one at the office and another as a case worker or service coordinator for a child with disabilities. I think this contributed greatly to my marriage falling apart. You can't expect a family, even a regular middle class family with college educated parents who have decent jobs, to stay together under the kinds of stresses we have endured. The needs of a child with severe multiple disabilities are so many and so immediate that any committed parent will try to meet those needs first. What gets sacrificed is the marriage.

Only once in the five years of our marriage could we afford to arrange respite care for two days, and that was paid for out of our own pockets. Government is there to institutionalize a child after his or her family has fallen apart, but it is not there to support a family trying to cope! And I hear it now costs about $85,000 on average a year of taxpayer money to keep someone, like Joshua, in an institution. Where is the logic, much less the justice, in doing that? The federal government should be investing in people with disabilities and their families, not in bricks and mortar.

In Joshua's brief life, he has already been covered by a total of seven different health insurance companies. (Two job changes, a move out of state and employers buying into new plans are the reason.) Each of these policies has pre-existing condition clauses, "benefit" packages, and a lot of fine print. I have a two-drawer file cabinet at my home, just for insurance paperwork for Joshua.

And, what has my son gotten out of this? Very little in terms of long-term supports. This is because even the best private insurers do not pay for what Josh and others with varying disabilities of all ages and backgrounds need most: expanded and more equitable access to a full array of lifelong personal assistance, therapies, technology, training and community support services to enable them to lead lives more of their own choosing.

There ought to be a law. One that nurtures and supports the efforts of parents who want to do the right thing by their kids with disabilities. And one that enables adults with disabilities to gain the personal assistance and other supports they require to lead independent, productive lives in the community like all others. However, to date Congress has not seen fit to pass a comprehensive program which meets the needs of all people with disabilities.

There have been changes to the Medicaid program which support community and family life for people with disabilities. The Medicaid waiver for home and community based services provides the option for states to fund the kinds of services Joshua needs to live at home. The new Community Supported Living Arrangements authority under Medicaid gives eight states the opportunity to fund these kinds of services, emphasizing the choices of the consumer and promoting real life activities, rather than institutional living. But both of these programs are limited in terms of eligibility and funding; neither is available to my son as he is not eligible for Medicaid and the District of Columbia where we live does not make either available for someone in Josh's circumstances.

More often than not, therefore, parents like myself are faced with the ultimatum of either going it all on our own or placing our son or daughter in an institution, for which Medicaid will pay. What we really need is federal legislation that assures access to an array of long-term supports and assistance to Americans of all ages. Individuals with disabilities and their families need to be afforded choices and support, not forced to react to either/or ultimatums.

The primary needs of Joshua and all other kids with disabilities are like those of other youngsters: To be raised by a nurturing and loving family and attend school in a safe neighborhood. The only difference is, of course, that children with disabilities often have additional needs which must be effectively addressed in order for their families to meet the more basic ones.

Federal legislation and other efforts are badly needed, therefore, to provide whatever it will take to "support" the family to enable a child with disabilities to live at home and attend their neighborhood school. Some states are already beginning to do this on their own. Michigan and Minnesota, for example, provide cash subsidies or vouchers to families with children with disabilities to address these added needs in the way they best see fit. This is money that can be spent on diapers, respite care or whatever the family or parent thinks most appropriate.

A national entitlement program should be created to invest in and fund a comprehensive array of personal assistance, therapies, assistive technology, training, and other vital community support services for all who need them.

Eligibility for these services should be provided to a child or an adult with a disability based on an individualized assessment of their real life needs and capabilities. Eligibility should not be based on a limited diagnostic category or on an arbitrary description of limitations, such as use of the activities of daily living as sole criteria for determination of need. Many states now have exclusionary eligibility criteria based on categories like cognitive disabilities and not on the real and similar needs of people. Furthermore, eligibility should take into account disability-related expenditures of the individual or family.

Services and supports available should include a variety to meet individual needs and should be designed to assist people to lead full lives and achieve full potential.

Josh, for instance, will need many kinds of support as he grows to adulthood. He will continue to need physical therapy, occupational therapy, and speech therapy. He will probably need assessments and services from speech pathologists, and will certainly need service coordination assistance. He will also need training and other supports to get and keep a job.

Joshua also will need access to a wide range of assistive technology, such as a computerized communication device to better express himself. Later on as an adolescent and adult, he will need assistance to live independently. He may need assistance with such things as making meals, shopping and paying bills, or what are called "instrumental activities of daily living." However, most of these services are not covered by any health insurance plan or social service system that I know of or for which I might be eligible.

Moreover, Josh's greatest need is for personal assistance services to help with bathing, dressing, and other day-to-day activities—what I call feeding him and wiping his bottom. Right now, as I said, I meet much of this need myself. But what would happen to my son if I developed an illness or was forced to take another job to try to make ends meet. Would Josh have to go into a nursing home? Probably so. The personal anguish of such a decision would devastate me; and I would not be the first parent compelled to make such a choice.

As both a parent of a child with a disability and a taxpayer, this makes no sense to me. If Medicaid monies can be used to support individuals with disabilities and their families at home and in the community, all States should be urged, if not required, to take full advantage of this provision. Similarly, individuals with disabilities and families should not be forced to become poor in order to qualify or become eligible to receive these vital support services.

Access to personal assistance, therapies, technology, training and other long-term community support services must be viewed as a right, not a privilege in our nation. I am trying to care for my child at home where he belongs, and for that I get no help. Joshua has a right to full participation in the American dream, and that won't happen if he is hidden away—that is, segregated—in some big institution away from society.

I have been a responsible worker in the American work force since I was 16. I have always paid taxes. There is no equity in a system which compels me to go to incredible lengths to get what he needs and to live under such stresses which have caused a family system to break apart.

I am pleading with you to enact meaningful change as soon as possible so Joshua and the thousands of children with disabilities and chronic health care needs can get the personal assistance and other long-term community support services which they and their families so desperately need. And we need it now! Joshua and I can't afford to wait any longer. Thank you.

RESPONSE OF JENIFER SIMPSON TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. Do you have suggestions for an expansion of the ADL and cognitive impairment eligibility criteria contained in our long-term care bill, S. 2571?

Answer. In reviewing the bill, the CCD Task Forces on Personal Assistance Services and Long-Term Services/Medicaid believe that several changes must be made in order to make the eligibility criteria more responsive to the real life needs of Americans with disabilities and chronic illness of all ages.

In particular, we strongly recommend the following changes be made in definitions contained in S. 2571 relating to individuals with moderate or severely disabilities.

These definitions should be revised to read as follows (**note: changes from the original are in bold**):

(page 6, line 11 through page 7, line 10)

In general, the term moderately or severely disabled means—

> *In the case of an individual 6 years of age or older, an eligible individual who (without regard to income or employment status):*
>
> > *needs substantial assistance or supervision from another individual with at least 3 activities of daily living* **or 3 instrumental activities of daily living or a combination thereof;**
> >
> > **needs supervision** *due to cognitive or other mental impairment and needs substantial assistance or supervision from another individual with at least one activity of daily living* **or instrumental activity of daily living** or in complying with a daily drug regimen;
> >
> > *needs substantial supervision from another individual due to behaviors that are dangerous (to themselves or others), disruptive, or difficult to manage; or*
> >
> > *In the case of an individual under six years of age, an eligible individual who has any medically determinable physical, cognitive, or other mental impairment of comparable severity to that which would make an individual six years of age or older meet the requirement of clause . . .*

CCD recognizes that any changes in eligibility may affect cost estimates. It is critical that such changes in costs and possible offsets be closely examined by the Senate Finance Committee as it formulates a comprehensive federal entitlement to a long-term services program.

CCD is committed to working with you on these and other matters crucial to crafting a comprehensive federal long-term services and supports entitlement program that meets the needs of Americans with varying disabilities of all ages.

Moreover, further work should be done to ensure that final eligibility criteria language, including the definition of Instrumental Activities of Daily Living (IADLs) is comprehensive enough to cover the needs of people with disabilities over the lifespan and a variety of disabilities. Of particular importance is the application of IADLs, the definition of which should cover, *at a minimum, housekeeping, laundry, meal planning and preparation, shopping, transportation, financial management, decision-making, use of medication, and communication, including use of the telephone.*

Finally, attention should be given also to the term "dangerous (to themselves and others)" on line 1 of page 7 of S. 2571. Advocates for the legal rights of people with mental disabilities have raised objections that a finding of eligibility under this criteria could be used as evidence for a state commitment proceeding. The use of another term could convey the same meaning without raising the commitment issue.

On behalf of CCD, I appreciate greatly this opportunity to further the Senate Finance Committee's work on these critical long-term support and service needs for children and adults with disabilities. If you have additional questions or concerns please do not hesitate to contact me.

PREPARED STATEMENT OF STANLEY S. WALLACK

I appreciate the opportunity to testify today before the Subcommittee on Health of the Senate Finance Committee on the health and long-term care needs of the elderly and the need for program enhancements. The deliberation of this Committee will undoubtedly include both the limitations in the current Medicare program as well as the inadequate financing of long-term care.

I have been actively engaged in both of these issues over the past 15 years. Because of the deficiencies in Medicare benefits and, more importantly the need to bring greater efficiency to the acute care system, the Institute for Health Policy, developed and implemented the Social/HMO program. The S/HMO merges financing and delivery permitting the care of the elderly to be managed more efficiently and comprehensively.

My own efforts in addressing the financing of long-term care go back to my time at the Congressional Budget Office in the mid-1970's. At that time there were no private sector alternatives. This has certainly changed. Today, there is also the realization that through risk pooling individuals can protect themselves against catastrophic long-term care costs which are currently paid out-of-pocket. In 1987, I started LifePlans, Inc., to work with private insurers in expanding the benefits provided under their long-term care insurance programs. LifePlans, through it's national network of community geriatric agencies, The Family Caring Network, provides assessments and assistance to insured elderly that need long-term care services, making managed long-term care insurance programs feasible.

There is good reason for supporting an increased governmental role in addressing the health and long-term care needs of the elderly. I believe, however, the major activities needed in these sectors are quite different. While the government must direct system reform in acute care, the major new challenge for the government in long-term care is to establish the boundaries of public and private financing and to guide the development of the private sector.

My testimony today will focus on the financing of long-term care. With Medicare paying for most acute health care costs, long-term nursing home and home and community care costs have become the major catastrophic expenditure faced by the elderly. A single year in a nursing home can cost more than $25,000 and nearly two in five individuals over age 65 will spend at least some time in a nursing home during their remaining life. For this population, about 50 percent of these expenditures are paid for by the recipients of care or their families. Risk spreading, either private or public, will help relieve this burden. While members of this committee have been seriously considering substantial new federal programs to pay for long-term care, I believe significant improvements can be achieved for relatively little additional government dollars. What is needed, however, is leadership, which only the government can provide, in solving the long-term care financing problem.

While my testimony will concentrate on long-term care and the Federal government's role, I will touch briefly upon improvements in Medicare; ones believe are important and could be a significant step in clarifying the Federal governments' role in the financing of health and long-term care of the elderly. In developing Federal long-term care policies, there are two population related issues that must be clarified. The first has to do with utilization patterns and the second the difference between the elderly and non-elderly disabled. I will discuss these two issues before moving on to public and private roles in the financing of long-term care.

THE UTILIZATION OF LONG-TERM CARE SERVICES

The use of long-term care services and the distribution of costs varies greatly. The distribution of lifetime nursing home costs for those in the 65–74 age group is presented in Table 1. The lifetime probability of entering a nursing home for the over age 65 population is approximately 40 percent, and, of these, the vast majority stay less than one year. As a result of this distribution of use, about 15 percent of the population account for 90 percent of expenditures, and the four percent that stay for more than five account for approximately 50 percent of the expenditures.

A very important observation to keep in mind in designing financing programs for the elderly is that the population of nursing homes is made up of two populations: the short stayers, about 50 percent leave in six months or less and the long stayers, the 13–15 percent that account for 90 percent of the dollars. The short stayers are often in a nursing home as a result of an acute episode: temporarily bed ridden, recovering from a fracture of being in a late stage of cancer. The long-stayers are more likely to be there because of functional loss or cognitive problems.

The much higher health care needs of the short-stayers differentiates them from the maintenance needs of the long-stayers. A short-nursing home benefit of 6 months or less and a limited home care benefit are appropriate additions to the Medicare benefit package. Today, these extended or transitional benefits may be denied by Medicare because an individual does not meet Medicare's criteria for benefits.

Certainly adding these benefits to Medicare will entail additional costs. However, as we have shown in the Social Health Maintenance demonstration, these additional benefits when case managed can be provided for less than the savings from reduced hospitalization. The success of the Social Health Maintenance Organization can be tied to managed care and having all financing being integrated. As you know, having Medigap supplement Medicare in a fee for service environment has led to greater Medicare health expenditures.

Two important lessons can be derived from The Social Health Maintenance Organization experience. First, expansions in benefits at little or no additional expenditure are possible within a managed system. Secondly, a system in which Federal and private financing exists for the same services can be very inefficient.

THE LONG-TERM CARE POPULATION

It is the needs of the chronically ill or the long-stayers that we will want to address in long-term care financing and service programs. The resulting services are quite varied. Long-term care consists of a wide range of services—personal, social, health and housing—needed over an extended period of time by individuals with limitations in basic life activities because of chronic illness, disability or injury. (Meltzer 1988, Financing Long-Term Care: Obstacles to Reform)

A number of points with regards to this definition of long-term care need to be highlighted. First, chronic disability occurs in people of all ages. Secondly, the condition causing the limitation could be mental or physical. Finally, the limitation in everyday functioning refer to the well known Activities of Daily Living (ADL's)—bathing, dressing, toileting, transferring, continence and eating; and the Instrumental Activities of Daily Living (IADL's)—such as meal preparation, cleaning, shopping, supervision over financing.

These limitations in carrying out everyday activities begin at birth. However, the vast majority of the population become increasingly independent. As one's life span nears an end, one begins to incur IADL and ADL problems because of chronic illness. The loss usually goes in reverse order to how dependence was gained. That is, one first becomes independent in eating and it is eating that is the last function usually lost.

This life cycle of dependence-independence-dependence may not occur. There are a significant number of individuals who do not develop normally and a significant number, particularly because of mental illness, who become disabled prematurely. While the likelihood of the people over age 65 needing long-term care services is about 10 times higher (see Table 2), the larger number of individuals below age 65 results in about one-third of the total number of disabled being less than 65 years of age.

Does the existence of similar disabilities mean that the disabled above and below age 65 should be treated similarly in a financing reform of long-term care? While such equal treatment may have some appeal, I believe the needs of the young disabled are quite different than the needs of the elderly. Most elderly have their own home, income and assets and receive care from family or friends. The young disabled have much broader social and personal needs. These populations often receive a range of services—acute health care, vocational rehabilitation, special education, human development, housing—reflecting their lack of resources and age. For example, about 80 percent of the developmentally disabled are on Medicaid and receive SSI.

The poor elderly may need an array of services to be provided, but it is not clear that most elderly would want to be cared for within our social welfare system. Likewise, I do not believe the needs of the young disabled can be handled within a social insurance program which provides a limited array of services, e.g. home health and nursing care. Private long-term care insurance can meet the additional needs of many elderly caused by functional loss because the elderly have Medicare, housing and discretion income. As we discuss the potential of long-term care insurance, whether private or public, I believe we will be best served by focusing the program on the elderly.

FINANCING OF LONG-TERM CARE

This brings me to the financing of long-term care for the elderly and whether this should be done through an expansion of public programs—either to all individuals or those close to the poverty line—or private insurance. The history of social welfare programs in this country as well as the particular interests of the private and public sector strongly suggest that over time the financing of long-term care services will be addressed with a mixture of public and private financial programs. Social problems are not the primary responsibility of one or the other sector. The correct combination of public/private financing is unclear, but one would hope it would be tied to social goals of adequately providing access to care and ensuring quality of services at the least total cost.

There are two basic views regarding the public roles in the solution to the long-term care financing problem. One view holds that government should take the lead in solving the problem leaving the private sector to fill in small gaps such as is now the case with acute health care for the aged—Medicare with Medigap policies. An alternative view is that public intervention should be determined by the inability of the private sector to meet social goals.

In terms of whether or not private insurance should be considered a minor or major player, it is important to note the evolution of the industry and the ability of individuals to purchase high value insurance plans. Just a few years ago, there were no private insurers offering long-term care insurance plans. The market began to develop in the mid-1980's and since then the products have evolved rapidly offering deeper and more comprehensive plans.

With regard to the affordability of high quality plans, the problem is that individuals purchasing private insurance are likely to wait until they perceive a real risk of needing services. The average age of purchase has hovered around 70 years of age for the last few years. A recently completed study of purchasers and non-purchasers of LTC insurance by LifePlans shows that individuals at about age 70 are buying, on average, over 4 years of coverage at a premium of about $1200. Based on income and assets, LifePlans has estimated (see Table 3) that whereas 50 percent of those 65–74 years of age could afford a meaningful long-term care policy, only 8 percent of those above age 85 years of age can. Private insurance could ease the financial burden for those spending out-of-pocket today. In doing so, it can only help to raise the proportion of dollars which come from the private sector as opposed to the public sector.

In choosing between public and private programs, one also needs to keep in mind the public's willingness to provide personal care and social services to those who are poor, from providing these services to all individuals. Long-term care services such as bathing are very personal. These are private, not public, goods. Because of the catastrophic costs of long-term care, there is discussion of the need for greater risk spreading through an insurance mechanism. However, a study completed by LifePlans shows that social insurance programs to finance long-term care mostly would provide benefits to the wealthier elderly because of the existence of our current social welfare program—Medicaid. It is important to note that many of those who would begin to receive benefits under a social insurance plan are capable of purchasing private LTC insurance to protect against catastrophic costs. Moreover, it should be remembered that no other country in the world—not Canada, not England, not Germany—has a social insurance program for long-term care.

Before developing a comprehensive social insurance program for long-term care or a major portion such as home care, the Federal government should encourage a private solution for those capable of affording one. At the same time, the Medicaid program should be enhanced by increasing the assets one can maintain, to perhaps $12,000, and by including home and community care benefits. This would not add substantially to program costs. The private/public financing would in essence have a publicly supported program for the poor and near poor and a private sector strategy for those able to pay their own way.

Having said that it is feasible for a private insurance market to address a major social problem, does not mean that there is not a significant need for Federal leadership in this area. First, if we are to have a significant number of individuals purchase a long-term care policy, it will be necessary for the government to encourage this development. The elderly looked to the government to be concerned with their social needs. Consequently, they look to the government with regards to long-term care financing. The fact that most elderly still believe the government will pay for their long-term care services under Medicare points out the need for general education in this area. Only the government can provide such education. By not doing so, the government has not fulfilled a very basic role. Also, a private insurance market cannot be allowed to operate independently of government regulations. In any market where the good or service is difficult to understand, poor quality products can emerge. Often, these poor products drive out the better ones. Lemons do drive out peaches!! In insurance, regulating the products sold, sales and marketing practices, business practices, and the financial well being of insurance companies are all crucial in protecting the consumer and making sure that insurers are adequately meeting a communal need.

Various legislative committees are considering the establishment of Federal minimum standards for private long-term care insurance and the needed tax law changes. I support such standards and tax law modifications. It is important, however, that those standards contribute to consumer welfare by increasing good choices and not reduce it by incorporating excessive requirements.

Over the past six months, I have co-chaired a coalition composed of insurance companies, provider groups and consumers in the development of a set of standards that would assure that long-term care insurance products of value are purchased and maintained. This coalition believes that well informed individuals and a responsible insurance industry will result from the suggested standards. The standards developed by the Coalition for Consumer Protection through Quality and Affordable Long-Term Care Insurance will be available in the very near future. We look forward to sharing these with this Committee.

CONCLUDING COMMENT

I have made three recommendations to this committee which follow from my understanding of the acute and chronic healthcare needs of our elderly.

- An enhanced Medicare program, providing nursing home and home health services for those needing extended care following an acute care episode and/or transitional benefits for those who may become chronically disabled.
- An improved, more humane Medicaid program through eligibility and benefit enhancements so that individuals who cannot afford private insurance or choose not to (and become truly impoverished), will receive appropriate care.
- Federal minimum consumer protection standards and tax law changes to encourage the development of a quality private long-term care insurance market.

Taken together they provide a roadmap for improving the financing of long-term care for older Americans. While the public sector programs I am suggesting are much less expensive than other social insurance programs being considered, the program envisioned will require systemic changes and, most importantly, leadership by the Federal government. While operating programs that solve social problems does not need to be the sole province of government, establishing the overaching policies and the roles and ground rules for the private sector are. Finally, I believe that the success or failure of the private sector in solving the long-term financing problem will depend on the nature and scope of Federal government intervention.

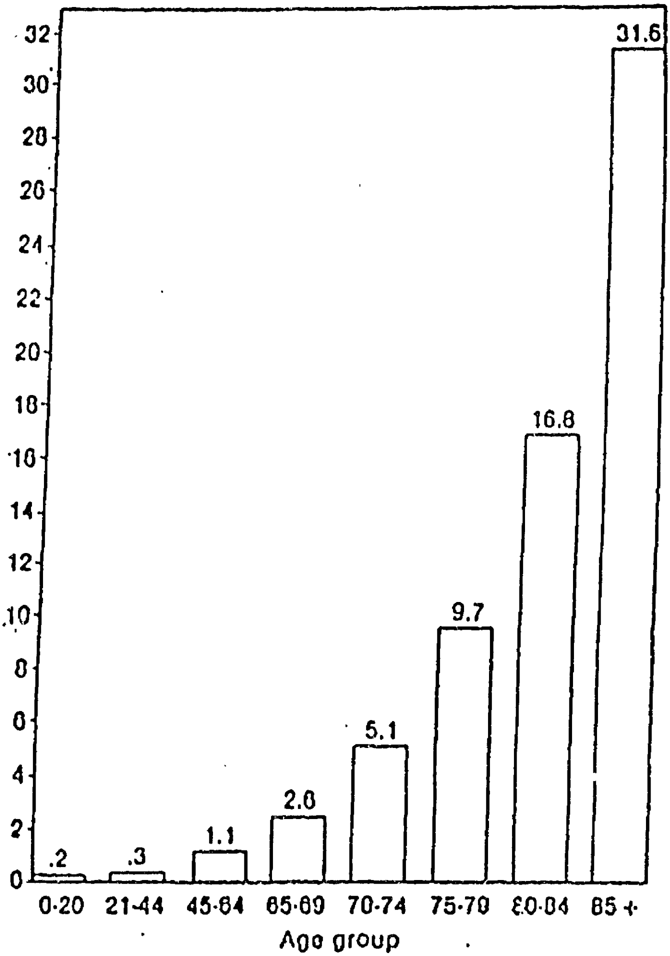
TABLE 1

RISKS AND COSTS OF LONG-TERM CARE FOR PERSONS AGED 65-74 YEARS

LENGTH OF STAY IN NURSING HOME	PORTION OF POPULATION STAYING THIS LONG	AVERAGE LIFETIME COST AT $80/DAY
ZERO DAYS	56%	$ 0
UP TO 1 MONTH	13%	$ 1,200
1 TO 3 MONTHS	9%	$ 4,800
3 TO 12 MONTHS	9%	$ 18,000
1 TO 2 YEARS	4%	$ 43,800
2 TO 5 YEARS	5%	$102,200
5 YEARS OR MORE	4%	$204,000

Source: Cohen, Tell, Wallack, The LifePlans Risk and Costs of Nursing Home Care Among the Elderly - Medical Care - December 1986.

TABLE 2: EFFECT OF AGE ON NEED FOR LTC



Source: National Nursing Home Survey and the Health Interview Survey and the U.S. Bureau of Census.

TABLE 3

ELIGIBLE ELDERLY MARKET FOR LONG-TERM CARE INSURANCE

PERCENTAGE INELIGIBLE BASED ON

AGE GROUPS	INCOME & ASSETS	DISABLED IN NURSING HOME	DISABLED IN COMMUNITY	TOTAL COMBINED*	TOTAL PERCENTAGE QUALIFYING
65 TO 74	48%	1%	7%	50%	50%
75 TO 84	54	6	10	62	38
85 AND UP	82	21	24	92	8
WEIGHTED TOTAL	52	5	10	58	42

* THE TOTAL PERCENTAGE INELIGIBLE REFLECTS THE OVERLAP OF THOSE NOT QUALIFYING BECAUSE OF INCOME, ASSETS AND HEALTH STATUS

RESPONSE OF STANLEY WALLACK TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. In your testimony you state that you've co-chaired a coalition composed of insurance companies, provider groups, & consumers in the development of a set of standard for private LTC insurance. Would you please elaborate on the standards developed by their coalition?

Answer. Senator Mitchell, this is in response to your question about the standards developed by the coalition of insurance companies, provider groups and consumers. **The Coalition For Consumer Protection Through Quality And Affordable Long-Term Care Insurance** represents the coming together of a diverse group of researchers, leading insurance companies, provider associations, and consumer purchasers committed to the goal of assuring consumer protection. This group was formed to develop strong consumer protection standards that would encourage the orderly development of a private insurance market. without appropriate standards, the consumer would be at risk of purchasing plans that might not preserve value over time, and the specter of bad products would restrict the market for innovative quality products. However, if standards are excessive the consumer could lose if desirable alternatives are forbidden!

We have developed standards so they can be used by legislative leaders. We, for example, support the tax clarification in your Bill and believe if tax benefits are going to be provided then they should go to insurance plans of high quality.

Long-term care for the elderly has emerged as one of the most important health care financing issues facing the country. As a result of current financing arrangements for acute care, long-term care is the catastrophic expense facing the elderly. Private insurance policies have been developed to fill this gap. Over the last five years, growth in the long-term care insurance market has been significant- from less than 100,000 policy holders in 1986 to more than 1.6 million policies sold by 1991.

In contrast to many other countries, the tradition in the United States is to have the private sector perform activities that are needed to be done on a communal basis. Social problems are not the sole province of the government. Insurance products have evolved to address the financing of social issues on a communal basis. when this occurs, the government is called upon by the people to regulate the industry. Market regulations are needed to provide adequate consumer protection. Given the complexities of long-term care insurance the government needs to establish appropriate policies and procedures if consumers are to be well served by private insurance. Further, the relationship between insurer and consumer, in which the purchase decision is made considerably before services are used, makes it necessary to reduce the uncertainty faced by the consumer and eliminate the risks attributable to arbitrary insurer actions.

Given the importance of regulation, it is necessary to construct appropriate policies and know their implications. In setting standards, we must be concerned with goals. we believe the primary goal of consumer protection is to enhance consumer welfare by providing good product choices. This occurs when consumers understand the value of the products being offered, receive fair value for the products they purchase, and consumers are not harmed because they take on undue or unknown risks. Proponents of setting high product requirements for long-term care insurance believe that by doing so consumer protection will be enhanced. High requirements raise the cost of policies, and reduce the options available. If consumer protection is having more people protected from risk, it is not evident all consumers can afford the very best. To the extent that the regulations are very extensive, design specific and do not differentiate among groups of consumers, the impact on the private market for long-term care insurance is likely to be greater.

Regulatory programs can enhance consumer choice or replace it with government decision. The coalition view is that the government should not replace consumer choice with it's own decision i.e., decide value, but rather should be concerned with consumers knowing the value of the plans purchased and assuring that the value is maintained. Shifting the focus of regulation to the maintenance of value implies that regulation must be more concerned with the procedures and processes of those offering products.

The coalition's vision of the goals of consumer protection and the role of the federal government are reflected in the guiding principles on which our recommendations are based. These principles are:

1. The role of the Federal government should be one of leadership and direction and not of implementation. The Federal government should establish standards to assure that long-term care insurance products sold provide value to the consumer and this value is maintained. Two clearly stated goals of the Federal initiative should be the "demystification" of the market place and the creation of the "educated consumer."

2. The goals of consumer welfare is best achieved within a market setting when consumers can make educated choices and make educated choices and insurers are held accountable for their actions or that of their representatives.
3. States should maintain their oversight and monitoring of plans.
4. when desired outcomes can be directly tied to standards, such as product features, then such features should form part of legislation.
5. when outcomes pertain to procedures and operations, the Federal government should state the goal, leaving it to States to establish more explicit guidelines.
6. The industry should be responsible for coming up with specific data so that consumers and regulators can measure their performance.

Our underlying belief is that well informed individuals can make the best choice as to whether they need long-term care insurance and if so, what should be the level and type of protection. This results in our opposing measures that arbitrarily dictate the design of the policies offered. For example, we do not support mandated inflation protection and non-forfeiture provisions. Individuals at risk of needing long-term care services in the near future should be purchasing increased daily coverage and not insuring against future price increases or building up a savings account by choosing non-forfeiture. Our approach is to mandate that these features be offered, but that the choice of purchase should be left to the consumer.

On the other hand, we strongly urge standards be established that assure that individuals know the value of what they are purchasing and that they receive value from the policies they have purchased. The coalition suggested standards are much stronger with regard to protecting value and delivering the value purchased than other proposed standards. we believe insurance plans must be understandable, fairly and appropriately priced, and clearly articulated. To assure value over time is maintained procedures are incorporated that result in appropriate product pricing establishment of required loss reserves and financial strength of insurance companies—areas over which the consumer has little or no control. Also, standards must be established at the outset so as to assure that benefits will be paid as promised.

We look forward to discussing the proposed standards with you and this Committee in the future.

Prepared Joint Statement of Judith G. Waxman and Bill and Carol Eager

Mr. Chairman, thank you for inviting us to testify before your subcommittee. Families USA is a national non-profit advocacy organization devoted to working for families on health care and long-term care reform. Today, we have brought with us Bill and Carol Eager who have experienced firsthand the struggle to provide long-term care for their relatives who now live with them.

I will provide you with the facts about who needs long-term care and what the financial cost is. The Eagers will provide you the facts about the human cost of trying to do the best they can for their relatives who need lots of help and the impact that providing this care has on their entire family. Their testimony follows mine.

WHAT IS LONG-TERM CARE?

Long-term care refers to the services provided over a long period of time to persons with chronic illnesses who need assistance with regular, everyday activities such as eating, bathing and getting dressed. Long term care can be provided in the home (such as by a visiting nurse), or in the community (such as adult day care) or in an institution (such as a nursing home.) It is most often provided by family members.

WHO NEEDS LONG-TERM CARE?

Recent poll data indicates that over 80 percent of the American public have some experience—in their own families or through close friends—with the need for long-term care. More than one in two of those without experiences anticipate facing the problem in their immediate family within the next five years.

Long-term care is a family issue: it is a grandfather with Alzheimer's Disease; a husband or wife who has suffered a stroke; a worker disabled by an accident; a grandmother immobilized by a broken hip; a child with Cerebral Palsy.

- Approximately 7 million elderly Americans are disabled and will need some long-term care. By the year 2000, the number will grow to 8.9 million; by 2020 to 12.3 million.
- There are about 4 million working age-non-elderly adults and children with a major activity limitation or disability that requires some long-term care.

- One in two persons age 65 and older will spend some time in a nursing home, and one in four will spend a year or more. Between 1989 and the year 2000, the elderly nursing home population is projected to increase form 1.6 to 2.2 million and more than double again to 4.6 million by 2040.
- In 1989, an estimated 5.5 million elderly living in the community needed some long-term care because of disabilities. The number of older persons living in the community who need long-term care is projected to grow to 6.7 million by the year 2000, and 9.4 million by 2020.

WHAT IS THE COST OF LONG-TERM CARE?

- In 1987, nursing home care for the elderly cost the nation $41.6 billion. Of this total bill, families and patients paid 51% ($21.2 billion) out-of-pocket. Another 41% was paid by Medicaid, with Medicare picking up only 2% of the tab and other sources paying 6%. Private insurance paid less than 2% of the bill.
- Families are shouldering a greater portion of the financial burden for long-term care. Between 1980 and 1987, the share of nursing home costs paid by families rose from 44% to 51%.
- Nursing home costs average more than $30,000 a year. Nursing home stays account for over 80 percent of the expenses incurred by older persons who experience very high out-of-pocket costs for health care (over $2,000 per year).
- Almost five in ten elderly living alone will spend down their income and financial assets to the poverty level after only 13 weeks in a nursing home; over two-thirds will do so in a year.
- Care provided at home by professional caregivers costs an average of $45 to $60 per visit and $50 to $200 per day.
- The cost of caring for Alzheimer's Disease patients alone exceeds $80 billion annually.

WHO PROVIDES LONG-TERM CARE?

- 71% of all long-term care is provided in the community rather than in institutions. 85% of all home care is provided by family members and friends, many of whom themselves are in need of assistance. Only 15% of home care is rendered by paid providers, such as nurses and home care workers.
- Two of three caregivers (72% of caregivers) have provided care for at least a year, and four out of five are involved in caregiving seven days a week. Of those with jobs, approximately one-fifth have worked fewer hours, one-fifth have taken time off without pay, and one-fourth have rearranged their work schedules to meet their caregiving responsibilities. About nine percent have had to quit their jobs.

WHAT COVERAGE IS AVAILABLE FOR LONG-TERM CARE?

There is almost no public insurance coverage for long-term care. Medicare covers less than 2 percent of nursing home expenses, and its home health coverage is limited to skilled services related to acute, rather than chronic, care problems. Medicaid does provide coverage for nursing home care, but to qualify a person must become impoverished, spending nearly all their income and assets.

Private insurance is inadequate to meet the need for long-term care protection. Policies are expensive and now cover only 1.4 percent of long-term care costs. Most private policies provide limited coverage: most have pre-existing condition limitations and prior hospitalization requirements; many do not cover the full costs of nursing home care and provide limited home care coverage; they pay benefits for only a limited period of time (usually 2 to 4 years) and benefits often are not indexed to inflation, significantly diminishing the value of the benefits over time. As a result, analysts predict that private policies will meet only a small portion of long-term care needs in the future.

WHAT SOLUTIONS ARE NEEDED?

American families are being stressed beyond their capacities because of the emotional and financial strains of providing long-term care.

Long-term care services should be available to all who need them, regardless of age or income. The financial risk for long-term care should be spread as broadly as possible, through a public insurance program like Social Security or Medicare.

A national long-term care program should provide a comprehensive range of facility-based and community-based health and social services. The program must recognize the needs of the family caregivers and support their efforts, as well as the person receiving the care.

Since the problem of long-term care is a family problem, affecting virtually all American families and all members of those families, financial support for the new public program should come from all generations. The new public program should be supported by sources of financing that are as progressive as possible. Recent national poll data reveal that Americans want the federal government to step in and help solve the long-term care problem with a program like Social Security or Medicare. And, they are willing to pay higher taxes for such a solution.

Families USA strongly supports speedy enactment of a federal comprehensive long term care program. We applaud Senators Rockefeller, Mitchell, Kennedy, Pryor and Riegle for introducing S. 2571 which goes a long way to provide the care that families need.

We also support legislation, such as S. 846 and S. 2141, introduced by Senators Pryor and Kennedy, respectively, that will protect American consumers from the hollow promises held out by much of the private long-term care insurance industry. Many private long-term care insurance policies sold today offer little real protection. Agents regularly pressure and confuse potential buyers. Companies count on consumers to drop their policies before they need them, recouping none of their investment, and many policies do not keep pace with inflation. These bills would begin to correct these deep flaws and force insurance companies to offer meaningful products through above-board sales practices or to get out of the long-term care insurance business.

RESPONSE OF BILL AND CAROL EAGER TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. If your were to design a long-term care policy, what benefits would be most helpful to families in your situation?

Anwer. While we are very willing to care for my mother at home, we need help. We don't really need housekeeping assistance. What we need is a well-trained health aide who we can trust to come into our home and help care for Mom. We need assistance in bathing her, for example. Also we sometimes need to go out of the house and would welcome a trained person whom we could trust to care for her while we left the house for various responsibilities.

RESPONSE OF JUDY WAXMAN TO A QUESTION SUBMITTED BY SENATOR MITCHELL

Question. In your testimony, you cite the cost of long-term care to the nation and individual families.

As you know,the bill I have introduced would cost the Federal Government about $45 billion when fully phased-in.

Do you believe the American people are willing to share the financial burden of a federal long-term care program?

Answer. The following information on public and senior polls indicates that Americans are willing to pay for a long-term care program:

Four different surveys found that approximately two of three Americans are willing to pay increased taxes for a federal long-term care program. In all four polls, a majority of respondents in both political parties and across all age groups supported paying higher taxes to fund long-term care.

—In a RL Associates poll, 68 percent of registered voters said they were willing to pay specific mounts in additional taxes (corresponding to their income) to fund a federal long-term care program.

—In a Peter Hart poll, 65 percent said that a long-term care program was an important investment and were willing to see taxes raised to pay for it. Only 13 percent said the program should wait until the deficit is reduced.

—In a Hamilton, Frederick and Schneiders poll, 65 percent of persons with incomes below $20,000 were willing to pay $20 per month for a federal long-term care program; 53 percent of persons with incomes between $20,000 and $30,000 were willing to pay $42 per month; and 59 percent of persons earning over $30,000 were willing to pay $58 per month.

—In a Louis Harris poll, 71 percent favored lifting their $48,000 Medicare payroll tax cap to pay for a federal long-term home care program; 73 percent of those earning over $50,000 favored this form of financing.

Over 80% of all Americans favor a federal government program to help pay for long-term care.

—In the Hamilton, Frederick and Schneiders poll (conducted in 12/87), 84% supported a federal program, similar to Social security or Medicare, to pay for long-term care.

—In the Louis Harris poll (conducted 2/88), 87% favored a federal long-term home care program for the elderly.
—In the RL Associates poll (conducted in 7/87), 86% believed it was time for the government to consider a program to cover long-term care.

Over 75% of Americans believe they cannot afford to pay for the cost of long-term care.

—In the RL Associates poll, 75% responded that the cost of nursing home care for one year would either be a major sacrifice or impossible to afford; 74% of respondents with incomes of $30,000 agreed.
—In the Harris poll, 82% responded that they could not afford to pay for the costs of providing long-term care either at home or in a nursing home; 60% of respondents with incomes over $50,000 agreed.

SURVEY AND SAMPLING METHODOLOGIES

The RL Associates poll, "The American Public Views Long-Term Care," was a telephone survey of 1,000 registered voters, conducted between July 1–15, 1987. It has a margin of error of plus or minus 3.2 percent.

The Hamilton, Frederick and Schneiders poll, "Attitudes of Americans over 45 years of age on Long-Term Care," was a telephone survey of 2,001 Americans over the age of 45, conducted between December 4–21, 1987. It has a margin of error of plus or minus 2.3 percent.

The Louis Harris poll was a telephone survey of 1,500 adults conducted between February 18–23, 1988. It has a margin of error of plus or minus 2.6 percent.

The Peter Hart poll, "A Post-Election survey Among Voters Conducted for AFSCME; was a telephone survey of 1, 010 adults who voted in the 1988 presidential election, conducted between November 21–22, 1988. It has a margin of error of plus or minus 3.2 percent.

PREPARED STATEMENT OF PAUL R. WILLGING

Mr. Chairman, members of the Subcommittee on Medicare and long-Term Care, I am Paul Willging, Executive Vice President of the American Health Care Association (AHCA). The more than 10,000 long-term care facilities that make up our Association care for more than one million residents, most of whom are elderly and frail. On behalf of AHCA's members, and the residents for whom our members care, thank you for holding this hearing and for the opportunity to represent them here today.

For quite some time now, the public and the Congress have been giving increasing attention to the need for health care reform and to the question of what direction reform should take. There are some 50 bills—depending on how one counts—to reform the nation's health care system to improve access and control costs. These dozens of entrants into the health care debate offer variations on "play or pay" plans, "single-payer" proposals, and proposals for health insurance tax incentives. Until recently, however, there was something largely absent from this debate. That something was consideration of the greatly growing needs of elderly Americans for long-term care. The puzzle of health care reform cannot be put together adequately and to the satisfaction of most Americans without this missing piece.

The American Health Care Association has applauded the Chairman of this Subcommittee, and those who worked with him, for presenting a plan to reform our country's ailing long-term care financing system. The introduction of "The bong-Term Care Family Security Act" and the introduction last summer of "Secure Choice" by Republican members of this Subcommittee, have done much to bring the long-term care piece back into public efforts to solve the health care puzzle. It is a piece we need to have before us and one that must be made to fit.

To some degree, then, I am "preaching to the choir" today when I speak of the need to address long-term care because the Chairman and members of this Subcommittee certainly are addressing the issue. The "bong-Term Care Family Security Act" and "Secure Choice" are important steps, but there is still much work to be done. AHCA greatly appreciates the willingness of the Chairman and members of this Subcommittee to work with our Association on long-term care reform.

Our society, individually and collectively, has not made adequate provision for financing the costs of long-term care for a growing elderly population with growing needs. Individuals and families are not saving for, or insuring themselves against, the costs of long-term care. The federal/state Medicaid program, never meant for long-term care coverage in the first place, is stretched to the breaking point. Households and governments are going broke.

Absent action to address these problems, our growing elderly population will come to rely much more heavily on Medicaid to pay for their long-term care. Currently, Medicaid accounts for approximately 45 percent of all long-term care payment. If current trends continue unchecked, Medicaid will be called upon to bear some 60 percent of the nation's long-term care costs in the decades to come. *But these current trends cannot continue.* Federal and state budgets—already strained badly by current Medicaid long-term care obligations—cannot bear such costs. Nor would the elderly be well served by an overwhelmed Medicaid program.

In order to meet the nation's growing long-term care needs without both emptying the public purse and driving down the quality of care, our society cannot afford to rely solely on government. Instead we should encourage and enforce an expectation of personal responsibility on the part of those with access to the means to plan for and pay for potential long-term care costs. Government can—must—help in this effort by working to see that individuals have the information and resources they need to take on personal responsibility for meeting their long-term care needs.

PROBLEMS WITH CURRENT FINANCING OF LONG-TERM CARE

Long-Term Care is of Great Concern

America's senior citizens and their families worry about long-term care and long-term care costs—and they are right to worry. The cost of long-term care is far and away the greatest financial burden that the elderly face. Although, obviously of paramount concern to senior citizens, paying for long-term care is of greater and greater concern to younger adults whose parents face the need for long term care.

Long-Term Care Costs are Impoverishing Senior Citizens

Most Americans do not foresee needing long-term care. Most probably do not realize how costly months or years of long-term care can be. Many Americans wrongly assume that government programs or acute care health insurance will cover the costs of any long-term care services they might need. For all these reasons, individuals and families face long-term care costs for which they have not planned and which they cannot afford. Currently, the cost of one year of nursing home care is more than three times the average annual income for an elderly American.

The cost of long-term care can quickly wipe out the savings even of those who have worked saved for a lifetime. The nation's current long-term care policy, however, does not promote personal planning, saving, or the purchase of insurance against the financial risk of long-term care costs. Nor does our nation provide comprehensive social insurance against the financial catastrophe of long-term care costs. Rather, it is only once a long-term care recipient has been impoverished that government assistance is available through Medicaid—a "welfare" program. That is, because of a lack of effective alternatives—public or private—our current means of financing long-term care puts Americans who have most likely been productive and self-sufficient for the whole of their adult lives on the dole.

Medicaid is Impoverishing the Federal and State Governments

Medicaid, the federal/state health insurance program for the poor, now covers about 45 percent of all payments for long-term care services in the United States. Both the federal and state governments provide funding for Medicaid benefits and—in no small part due to growth in Medicaid—both the federal and state governments face dire fiscal straits.

According to Congressional Budget Office (CBO) figures released in January of this year, federal Medicaid spending grew by 28 percent in fiscal year 1991. CBO projects federal Medicaid spending to grow by 30 percent this fiscal year.

CBO analyses show that total Medicaid spending (state and federal) has nearly doubled since just five years ago, from $49.3 billion in FY 1987 to $92.0 billion in FY 1991. CBO projects, if current trends hold, that total Medicaid spending would rise to $222.4 billion in FY 1997.

Medicaid was not designed to be a program for long-term care. However, long term care for the indigent elderly is now the largest single component (40%) of Medicaid spending. The controversy in California over the cost of nursing home reform, the number of court battles over state obligations for adequate Medicaid reimbursement, and last year's protracted battle over Medicaid "provider specific taxes" well illustrate the strain that our current long-term care financing arrangements are putting on government resources. This strain jeopardizes the accessibility and quality of both acute and long-term care for those who must depend on Medicaid. Clearly, if current long-term care needs have stretched the federal and state budgets to their limits, the nation will have to look to sources other than current government programs for additional resources to meet the future long-term care needs of an aging population.

GUIDING PRINCIPLES FOR LONG-TERM CARE FINANCING REFORM

AHCA recognizes the need for steps to make long-term care more accessible and affordable. AHCA also recognizes the serious fiscal constraints facing the federal and state governments and, therefore, the need for individuals and families to take on more of the responsibility for planning for and paying for long-term care. With these needs in mind, AHCA offers the following "guiding principles" for long-term care financing reform.

Continuum of Care

The nation's long-term care financing system must provide access to an appropriate level of care along the entire continuum so that consumer need and efficient use of resources—not availability of benefits—determines care setting.

The long-term care system must focus on individual need, regardless of age, and establish a "level playing field" through payments that vary by appropriate levels of service and individual acuity and not the setting in which care is provided. The efficient use of resources to provide the appropriate level of care should drive the selection process through standardized assessment, all along the continuum from acute settings, to nursing facility care, and to residential or home care.

Private/Public Partnership

The private sector must fulfill the largest possible role in the financing of long-term care.

In order to meet great and growing long-term care financing needs, our society needs to make appropriate use of private sector resources as well as those of the public sector. Private sector resources can and should play a greater role in meeting needs. Federal and state governments should focus on providing a safety net that funds long-term care for those who truly cannot finance their own care.

Federal/State Roles

There must be a federal and state partnership of administration, enforcement, and funding that is designed to achieve consistency and eliminate conflicts.

In order to create a system that is stable and fair to those it serves, the federal government must:

(1) provide the majority of the public funding;
(2) strictly define uniform minimum operating and payment standards; and
(3) strictly enforce states' adherence to those standards.

States must implement the program.

Personal Responsibility and Voluntary Support

Public resources must support—not supplant—personal responsibility and family/community participation in providing and paying for long-term care.

As much as is possible, government resources should be directed to provide long-term care coverage where there would otherwise be none—not replace personal or family efforts.

Government programs should encourage voluntary caregiving and financial support from other sources.

Consumer Participation

Consumers must have the ability to participate in selecting their individual setting of care and choice of providers.

In order for consumers to make an informed choice, they must:

(1) have access to information about the continuum of long-term care, and the choices available to them, and

(2) have or be able to access the resources to pay for the care they choose. The long-term care financing system must provide the opportunity to supplement privately the cost of providing additional services beyond covered benefits and services.

Payment for Quality Care

Our long-term care payment system must encourage quality care.

The nation's long-term care system should encourage and harness market forces as the means to enhance the quality of long-term care. It must provide adequate reimbursement for the manpower and capital needed to provide quality care.

Dedicated Funding Source

Public long-term care funding must be financed through a dedicated, actuarily-sound trust fund that provides both political and fiscal stability.

Funding for long-term care should be established on a firm foundation that assures access and a fair distribution of services to those who need them. A trust fund for this purpose should be supported by a broad-based payroll, estate, value-added, or income tax.

Simplicity

Our long-term care system must maximize the use of public funds for care delivery by seeking administrative simplicity and economy.

The long-term care system should be simple and understandable for beneficiaries and providers. Changes in the current system should be aimed at decreasing burdensome reporting requirements so that scarce funds can be targeted to providing care rather than bureaucratic overhead.

SHORT-TERM STEPS TO HELP WITH LONG-TERM CARE

Optimistically, comprehensive long-term care reform may be quite a ways off. In the meantime, however, there are steps that the Congress can take that would move long-term care financing in the right direction. Based upon the above guiding principles, four strategies would go far, at relatively modest federal expense, to help older Americans and the nation meet the costs of long-term care:

I. Empowering the Consumer
II. Securing the Long-Term Care Safety Net
III. Making the Most of Available Resources
IV. Minimizing Unnecessary Regulation/Administrative Burden

I. Empowering the Consumer

With good information and adequate choices, Americans are quite capable of acting in their own best interests. Unfortunately, current circumstances offer not much of either information or choice regarding long-term care. Elderly Americans are aware neither of the magnitude of long-term care costs nor the limits of government assistance. Many mistakenly think that the Medicare program, which provides health coverage to those over 65 regardless of income level, provides significant long-term care coverage. A national survey of attitudes on long-term care, conducted by the Employee Benefit Research Institute (EBRI) in August 1991, found that 37 percent of those asked believed that Medicare pays for long-term care assistance to the elderly. An additional nine percent did not know whether or not Medicare pays for long-term care.

In order to empower consumers, federal and state governments need to cooperate to provide consumers with access to both the information and resources they need to plan and pay for long-term care. AHCA supports a combination of steps—including public education and tax incentives for long-term care insurance—that will give Americans the information and resources they need to shoulder the responsibility of preparing against the risk of catastrophic long-term care expense. Specifically, AHCA supports the following clarifications to the tax treatment of long-term care insurance:

- treatment of long-term care insurance contracts in the same manner as accident or health insurance contracts;
- treatment of amounts received under long-term care insurance contracts for long-term care services in the same manner as amounts received for personal injuries or sickness;
- treatment of employer plans providing long-term care services in the same manner as accident or health plans;
- treatment of life insurance benefits paid to a terminally ill individual in the same manner as death benefits;
- inclusion of long-term care options as preferred employee benefits in employer programs, including cafeteria plans; and
- codification of the allowance of tax deductions for additions to an insuror's long-term care insurance reserves.

AHCA also supports the establishment of consumer protections and federal minimum standards for long-term care insurance policies.

II. Securing the Long-Term Care Safety Net

The nation's long-term care safety net is strained to the breaking point. A major reason is that the safety net, Medicaid coverage of long-term care, is being made to hold the additional burden of many beneficiaries who have the means to pay for long-term care themselves. It is a common and growing practice for relatively well-off seniors to pay for the advice of an attorney who can tell them how to represent themselves as indigent despite considerable assets.

Worse than the harm that exploitation of the Medicaid program causes taxpayers is the harm that it causes truly needy individuals. The Medicaid program is struggling to meet the health care needs of poor families and the indigent elderly. The use of scarce program resources by those without real need strikes directly at those most in need of help.

In order to ease this unnecessary and unfair burden on the safety net, AHCA supports steps to reserve Medicaid assistance for those who truly need it, including measures to prevent inappropriate Medicaid eligibility through asset divestiture.

III. Making the Most of Available Resources

As currently configured, government long-term care programs present obstacles to the most cost effective placement of beneficiaries. For instance, the Medicare program (which covers skilled nursing home care) requires that beneficiaries spend at least three days in a hospital before they are eligible for program coverage. In many cases, this has the clinically and fiscally perverse result of sending a Medicare beneficiary to a hospital when the appropriate—and much less expensive—level of care is in a skilled nursing facility. AHCA recommends steps to direct those who need long-term care to the settings and services that meet their needs in the most cost effective way.

IV. Minimizing Unnecessary Regulation/Administrative Burden

Too many of the regulations and administrative requirements that nursing facilities must operate under have nothing to do with providing a better quality of care or a higher quality of life for residents. Unnecessary procedures and inappropriate requirements divert resources, energy, and effort away from productive uses. The more resources are tied up in red tape, the fewer resources there are for hiring staff to provide better care and services. In order to minimize bureaucracy, litigation, and other unnecessary burdens, AHCA recommends steps that would free long term care providers of regulations and administrative requirements that unnecessarily divert resources from the care of the elderly and disabled.

CONCLUSION

In order to maintain a high quality of care for the growing number of elderly who will need long-term care services in the years to come, our nation will have to make more efficient use of public sector resources and turn to the private sector for additional resources. Crucial to this effort is encouraging and empowering individuals to take greater responsibility for their potential long-term care needs.

AHCA offers significant steps, but steps readily within reach, for addressing current problems in financing long-term care. A number of these steps, such as decreasing unnecessary regulatory and administrative burdens would save money in both the short and long run. Other steps, such as tax incentives to promote the use of long-term care insurance, might cost the government some money in the short run, but, in the long run, would remove much of the burden from our badly strained long-term care safety net thereby saving on public spending.

In the absence of affordable alternatives to the strategies presented above, the most politically and fiscally feasible way for government to do more to help elderly Americans would be to help them do more to help themselves.

Thank you very much for the opportunity to take part in this hearing.

COMMUNICATIONS

STATEMENT OF THE AMERICAN ASSOCIATION FOR RESPIRATORY CARE

The American Association for Respiratory Care (AARC) is a 33,000-member professional association of respiratory care practitioners. We welcome the opportunity to submit testimony to the Subcommittee on Medicare and Long-Term Care on long-term care for Medicare beneficiaries. Respiratory care practitioners work under medical supervision in the treatment, management, control, life-support, diagnostic evaluation, and care of patients with deficiencies and abnormalities of the cardiopulmonary system.

As your Committee deliberates the structure and form for Medicare long term care benefits, it is imperative that you consider (1) the growing need for respiratory care required by patients and (2) the currently limited role of the respiratory care practitioner in alternate care settings as a result of statutory constraints. This testimony focuses specifically on the mechanical ventilator-dependent patient suffering from chronic respiratory illness and their continuing needs for health care.

Outside the acute care hospital, Medicare coverage policies severely curtail the level and quality of respiratory therapy delivered to a patient. Respiratory therapy is not considered a home health benefit, nor is coverage extensive in a skilled nursing facility. The direct result is that pulmonary patients who could go home, do not go home. Rather they remain in the more costly acute care environment due to a lack of reimbursable services at home. Those fortunate respiratory patients who are sent home find gaps in the services rendered because those providing the care do not necessarily have the education, training, or any expertise in the field of respiratory therapy.

While medical technology in the area of respiratory care has advanced, alternate site Medicare coverage has not kept pace. For example, the current home health care and Part B benefits were constructed over 20 years ago and reflect the state-of-the-art medical practices of that time. During those early years, respiratory care was nearly always delivered in the hospital and, most often, in the intensive care unit. Today the provision of respiratory care has developed far beyond the scope of the iron lung and the oxygen tent. A better medical understanding of a patient's condition and advancement in the treatment regimen, especially in the area of mechanical ventilation, have led to more successful outcomes for the fragile respiratory patient. Many patients with cardiopulmonary lung diseases, who could not have left the hospital ten years ago, can now be routinely stabilized and receive care in a less intensive setting, such as the home or skilled nursing facility. It is not only the financial pressures of the prospective payment system, but the new non-hospital-based treatment available that have paved the way for treating respiratory patients in alternate sites.

The irony of this situation is most strongly illustrated by the ventilator-dependent patient. Many of, these patients can be medically stabilized to the point where they no longer require the services of an acute care hospital. There are, in fact, extreme financial pressures for the hospital to discharge these patients. Many physicians, however, are reluctant to discharge ventilator patients because the necessary respiratory care is not provided or covered in the alternate care setting by qualified respiratory care professionals. Therefore, the patient remains in the hospital.

A recent Gallup survey studied the cost of providing hospital care to chronic ventilator patients. By survey estimates, there are over 11,400 chronic ventilator patients currently in U.S. hospitals costing approximately $789 per patient per day. Gallup calculated that $9 million was being spent daily by hospitals for the care of these chronic ventilator-dependent patients. Once a ventilator patient is medically able to be discharged, it takes an average of 35 days to place the patient in an alternate care site such as the home or skilled nursing facility. That translates to an excess of $27,000 per patient in unnecessary hospital costs. Outdated reimbursement policies which limit the patient's access to respiratory care services outside the hospital are responsible for the discharge delays. We share Congress' concern over the federal deficit and the rapidly escalating cost of the Medicare program. As the Gallup survey clearly indicates, the cost savings to the Medicare program for discharging a ventilator patient into a less acute care setting is particularly compelling.

The AARC strongly supports a House-sponsored bill, H.R. 1120, "The Nursing Home Access to Respiratory Therapy Act, of 1991." H.R. 1120 would permit skilled nursing facilities to receive Medicare reimbursement for the professional services of respiratory therapists either directly or indirectly, which is the standard procedure for other therapies. The bill currently has 65 House co-sponsors as well as the endorsement of the American Health Care Association, the National Association for the Support of Long-Term Care, and the American College of Chest Physicians.

We would also bring to the attention of the Committee the final report of the Pepper Commission, which recommended including respiratory therapy as an extended care benefit. To that end, nearly all of the long-term care bills introduced in Congress over the past 18 months have included respiratory therapy as a long-term care benefit.

Congress is not alone in supporting greater patient access to respiratory care. In 1989, the AARC co-sponsored a consensus conference with the Food and Drug Administration and the Health Resource Services Administration focusing on the problems associated with the introduction of respiratory care equipment into the home. Consensus was that one of the greatest problems occurring today was the increase in the discharge of fragile respiratory patients in need of intensive services into the home. A recommendation of the report was to modify reimbursement policies to allow the home-bound patient access to appropriately trained respiratory therapists when necessary.

It is the AARC's conviction that Medicare should maintain a consistent philosophy on patient care. While in the hospital, the full services of the respiratory care professional are covered without question. When these patients are discharged from the hospital but the need for respiratory equipment and care persists, it is not logical to provide for the equipment, oxygen, and drugs but not allow these patients access to the only personnel who are specifically trained to treat the respiratory patient. We urge the Subcommittee to include respiratory therapy services as a component of any long-term care plan.

STATEMENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS

Our nation can be proud of our achievements in health care. Yet these achievements are diminished by our failure to control health care costs and guarantee all citizens access to basic acute and long-term care services. The extraordinary increase in health care costs is a substantial barrier to access, extending across all age groups and income brackets. There are countless examples of people whose lives and dreams have been shattered by an inability to afford or obtain needed care. Each of us is just as vulnerable. Comprehensive reform of our health care system must become a national priority if we are to reach the goal of assuring access to quality care for all citizens and gain control of escalating health costs.

To date, efforts to address the problems in our health care system have been piecemeal in nature. Year-after-year this "band-aid" approach has added levels of complexity to our already fragmented health care system, resulting in perpetual cost-shifting and increasing administrative costs. The problems caused by piecemeal solutions are quite evident in long-term care, where we have no comprehensive "system" for protecting against long-term care costs. All Americans are at risk of needing long-term care, but neither Medicare nor private insurance has sufficiently pooled this risk, leaving Americans of all ages at risk of losing their life savings and receiving inadequate care.

Many reform proposals focus only on acute care and simply ignore the long-term care needs of American families. These proposals are fundamentally incomplete because they fail to ensure individuals access to a full *continuum* of care throughout their lives. AARP earnestly believes *long-term care* must be an integral part of health care reform. Without long-term care coverage, no one is fully protected from the crippling costs of any serious illness or disability.

Although approximately 85 percent of all Americans have some form of acute care protection, Medicare and private insurance combined currently pay for less than five percent of our citizens' total long-term care expenses. In addition, the diversity of demands on the Medicaid program makes it increasingly difficult for that program to carry out its mandate—to provide basic health care services for low-income individuals at the same time that it provides long-term care services to older Americans.

A reform plan which includes protection against potentially bankrupting long-term care costs—that most families must pay out-of-pocket—could have a significant impact on the public's willingness to pay for reform. A reform plan that does not provide for long-term care coverage simply ignores both the needs of Americans of all ages who suffer from both the debilitating conditions requiring long-term care as well as the burden placed on them and their families for providing and paying for that care. Moreover, demographic trends will dramatically increase the demand for long-term care services early in the next century. We must be prepared to meet that demand.

Our statement will discuss the health cost and access problems that beset our nation, why the health and long-term care crises must be solved simultaneously, and how AARP believes a long-term care program for all Americans should be structured.

THE COST OF LONG-TERM CARE

The escalating cost of health care in America is one of the most significant problems of our current health delivery system. No aspect of our society remains unaffected. The uninsured and underinsured, businesses and federal and state governments, as well as the insured, are adversely affected by rising health costs.

From 1980 to 1989, national health expenditures for nursing homes increased 140 percent. In 1989, out-of-pocket expenditures accounted for 44 percent of expenditures for nursing home care, Medicaid contributed 43 percent, Medicare covered eight percent and private insurance paid for only one percent of the costs. (Note: Prior to 1989, Medicare spending accounted for only one to two percent of nursing home expenditures. For 1989 alone, however, changes made in the Catastrophic Coverage Act contributed to an increase in Medicare's share of the nursing home bill.)

An estimated 81 percent of annual out-of-pocket expenses over $2,000 incurred by elderly persons is spent on long-term care. With average annual nursing home costs of $30,000 and home health care costing from $50 to $200 per day, long-term care out-of-pocket costs are often truly catastrophic.

Significant indirect costs also exact a heavy price from those who need or provide long-term care services. A mother, for instance, who has sacrificed a career to tend to her child may need long-term care due to a disability or illness. Health care statistics do not account for the years of forgone income, pension and Social Security benefits that this mother, and others like her, will experience. These costs need to be taken seriously in the context of meaningful reform.

ACCESS TO LONG-TERM CARE

The only federal program which provides real coverage for nursing home care—Medicaid—forces individuals to deplete their life savings before they can receive benefits. In addition, the absence of meaningful public or private coverage for home and community-based services creates incentives to place individuals in nursing homes when other alternatives would be preferable.

The Medicaid program, which was intended to serve as the "safety net" for our nation's low income population, is severely limited. Moreover, welfare-based programs such as Medicaid typically place unreasonably restrictive income and asset eligibility requirements on individuals and impede access because of administrative barriers in the application process and the stigma attached to it. In addition to constant budgetary constraints, a means-tested program does not receive the broad public and political support granted to social insurance programs like Social Security and Medicare.

THE NEED FOR LONG-TERM CARE

Everyone is at risk for needing long-term care, not just older persons. While an estimated 10.6 million persons of all ages require assistance with one or more ADLs or IADLs, one-third, or 3.5 million of these individuals are under age 65. Of the total disabled population, 84 percent live in the community, with approximately 1.5 million elderly living in nursing homes. It is expected that this figure will increase to 5.3 million by the year 2030.

The need for assistance extends beyond those who need the care to those—family and friends—who provide personal care and financial support. Family members provide the vast majority of long-term care needed by older persons. These caregivers, typically wives and daughters, often provide care every day, with great physical, emotional and financial sacrifice.

For most people, the cost of long-term care is an unmanageable financial burden. Many families are also shocked to find—only too late—that neither Medicare nor private insurance covers long-term care to any great extent. A survey conducted in November, 1989 by the Daniel Yankelovitch Group (DYG) found that fully one-half of the general public and one-third of older Americans erroneously believe that their private insurance or Medicare will cover their long-term care bills, respectively.

Perhaps most important of all is the hidden cost associated with the suffering, deprivation, and isolation for those in our society who get no care or inadequate help. Data from the National Long-Term Care Survey indicate that large numbers of functionally impaired older persons in the community, particularly the severely disabled, have unmet needs for assistance. For example, 77 percent of older people with three or more limitations in their activities of daily living reported they needed more help than they were getting.

Americans of all ages recognize that long-term care protection is a growing necessity. Given demographic trends—with baby boomers aging and mortality rates falling—the longer we wait, the more expensive a solution will be. While many underestimate the costs and the likelihood of their need services (one in three persons will need nursing home care at some point in their lives), surveys have demonstrated that the public is willing to participate in, and pay for, a social insurance approach if the program provides the benefits that are needed most. The 1989 DYG survey, for example, found that Americans are willing to pay increased taxes for a long-term care package that would provide comprehensive coverage for all Americans. Americans want coverage for both nursing home and home care, but their greatest fear is nursing home care costs.

Another DYG survey conducted for AARP in the fall of 1991 and winter of 1992 found: (1) respondents age 50–64 were most concerned about long-term care; (2) respondents had less confidence in the long-term care system than they had in the acute care system; and (3) the nature and comprehensiveness of the benefit package was a major factor in determining willingness to pay.

THE ROLE OF THE PRIVATE SECTOR

The private sector can and should play an important supplementary role in helping to provide protection against the cost of long-term care. Private sector options for financing long-term care include long-term care insurance, home equity conversion plans, and the prospect of long-term care individual medical accounts. Although long-term care insurance offers some promise as a supplement to a federal social insurance program, it is still in its infancy and there are major barriers to its development. While the number of policies sold (now estimated at 2 million, but far fewer remain in place due to lapses) is growing, they cover few of the 51 million Americans aged 55 and over.

Projections from the Brookings-ICF Long-Term Care Financing Model (using assumptions that are favorable to the development of private LTC insurance) indicate that by 2018, under fairly optimistic assumptions, insurance may be affordable to 20–32 percent of those over 65, may finance only 12–19 percent of total nursing home expenditures, and may reduce Medicaid nursing home expenditures by 2–5 percent. The limitations of private long-term care insurance reflected in this data stem principally from barriers that are likely to limit the usefulness of long-term care insurance policies to the public. Such barriers include:

- the prohibitively high cost of policies that provide meaningful protection;
- serious limitations and restrictions in coverage;
- high "lapse," or drop-out rates, with no non-forfeiture protection;
- the lack of adequate inflation protection;
- lack of protection against unreasonable premium increases;
- the lack of meaningful home care benefits, and;
- consumers' lack of knowledge about the need for protection against long-term care expenses.

In addition, people in need often are prohibited from purchasing private long-term care insurance. Few companies will sell insurance to people age 80 or over, or to people with pre-existing (potentially disabling) medical conditions. This practice may be necessary to maintain the financial stability of the insurance plan, but it leaves those most likely to need long-term care without any protection.

AARP RECOMMENDATIONS

These factors—the need for long-term care among persons of all ages, the financial, physical and emotional burden that long-term care places on families, impoverishment and the other shortcomings of the Medicaid program, and the limitations of private sector options—demonstrate the need for a better approach to financing and delivering long-term care. AARP believes that comprehensive health care reform which includes long-term care would significantly reduce many of the health care access problems associated with our current system. To make long-term care coverage affordable and accessible to all Americans, the Association recommends a social insurance approach, similar to the Medicare and Social Security programs. Social insurance would require financial contributions from all members of society and would provide protection to all who need long-term care. Such an approach would spread the burden so that the costs to any one person would be small, while offering protection and appropriate care to all.

Under such a social insurance system, private sector approaches should supplement the public system by covering copayments, deductibles, extra services and services for those not eligible for government program benefits. An analogy for this arrangement already exists with our current Social Security and private pension system: Social Security provides the base or foundation on which private pensions—for those who are fortunate enough to have them—are then based. As stated above, the Association strongly believes that private sector approaches should also include strong federally-mandated consumer protection standards.

AARP'S EFFORTS TOWARDS ACHIEVING COMPREHENSIVE HEALTH CARE REFORM

AARP believes that comprehensive reform of our health care system must become a national priority if we are to achieve the goal of assuring access to quality care for all our citizens and to gain control of escalating health care costs. Broad public consensus about the scope of the problem, and the need to share the risk of health care costs, will be key to Congressional action.

To achieve broad public consensus, continued public education is essential. AARP is making education a priority activity so our members—both under and over age 65—will come to recognize that even though they may have adequate health care coverage today, they could quickly become vulnerable to devastating acute and long-term care costs under our current system.

In this regard, many AARP members are already well aware of our health care problems and are calling for action. In response, the Association's volunteer National Legislative Council recommended to the Board of Directors, and the Board adopted, a *draft* proposal that will be used to inform our members about potential solutions and provide them with the opportunity for input during the next year.

This draft proposal is the culmination of more than two years of hearings, public opinion studies and recommendations from health care experts. It reflects the Association's current best thinking on addressing the growing concern—expressed by Americans young and old—that something must be done. It is, however, a *draft* proposal—that is, it is offered to our members for discussion, debate, suggestions and modifications. The Association will, in the coming year, actively seek reaction to it from our membership.

AARP's draft proposal—known as "Health Care America"—is a comprehensive national health care plan that controls costs and provides high-quality acute and long-term care coverage to everyone who needs it. A public plan ensures access to all Americans, although employers may exercise the option to provide private health insurance coverage to workers and their dependents. Employers who do not provide coverage would pay an eight-percent payroll tax. Global budgets, fee schedules, and care management are at the center of the proposal's strong cost-containment strategy.

Health Care America would provide a single health insurance access card for everyone, known as MediCard. With this card, everyone, regardless of age, income or employment status, would gain access to an improved and expanded Medicare program, or to equivalent or better coverage provided through an employer. Either way, there would be no more denials of coverage for pre-existing conditions, no more people "falling through the cracks," and no more overlapping plans and programs generating wasteful paperwork.

The draft proposal would assure access to a full range of preventive, acute care, prescription drug, and long-term care benefits. There would be no cost-sharing for preventive care services, hospice, or hospital care, and only a 10 percent coinsurance for most other acute care services. For most individuals, it would no longer be necessary to purchase supplemental insurance. The proposal also would incorporate malpractice reforms.

The Association's draft proposal is premised on the belief that long-term care protection is an essential part of comprehensive health care reform. The long-term care component of the draft proposal would provide a full range of home, community-based and institutional care to persons of all ages and incomes, based on care management agencies' determination of a need for assistance with two or more ADLs, need for constant supervision, or assistance with age-appropriate ADLs for children. Home care and community care coverage would be subject to a 20 percent coinsurance rate, with low-income protections for those up to 200 percent of the federal poverty level. Nursing home coverage would be provided on a social insurance basis over the entire length of a person's stay—that is, there would be no *requirement for spend-down of a person's income or assets. A coinsurance roughly equivalent to room and board costs, with sliding scale protection based on income, would apply to the full length of a nursing home stay.* Current Medicare SNF and home health benefits would be retained with some modifications. Strong cost containment and quality standards would be included.

The Association is proposing two options for financing Health Care America:

- A three-percent income tax on modified gross income that would apply to all income, including Social Security, above $15,000 for an individual or $20,000 for a family; *or*
- a five-percent value added tax that would exempt food, housing, and medical care.

In addition, AARP's draft proposal assumes that current state expenditures would be recaptured and proposes other financing sources such as a five-percent surtax on existing corporate income tax, increased estate taxes, and increased alcohol and tobacco taxes.

THE LONG-TERM CARE FAMILY SECURITY ACT

The Association is very pleased about the introduction of the Long-Term Care Family Security Act of 1992, S. 2571. This legislation would take an important step toward helping American families cope with the pressing personal and financial demands of long-term care. We are particularly pleased that the proposal includes cost containment measures, intergenerational coverage for a broad range of home and community-based care for as long as it is needed without regard to income and assets, and federal standards for private long-term care insurance policies.

We are very concerned, however, about the requirement for individuals to "spend-down" in order to receive nursing home protection after the six-month social insurance benefit expires. In our view, the social insurance approach should be expanded to cover an entire nursing home stay. By improving, but not eliminating, the means-testing provision of the current Medicaid-dominated nursing home coverage system, the proposal runs the serious risk both of eligibility levels that would be ratcheted down to lower and lower levels over time and diminished public support—the inevitable result of a means-tested program. Even at the proposed levels, we question whether the public would perceive that the proposal would protect against their greatest fear—the cost of long-term nursing care—and whether those who are expected to pay the most during their lifetime would receive a "fair return" on their contributions.

Findings from a study on long-term care conducted by the Daniel Yankelovich Group (DYG) in the fall of 1989 strongly suggest that the factor which most influences public support for a long-term care benefits package and the willingness to pay for that package is fear of the cost of a long-term nursing home stay. If people do not believe that a long-term care package will address this fear, their willingness to pay for it declines sharply.

Such "up-front" protection would cover a very small percentage of nursing home costs incurred. According to a study by the Agency for Health Care Policy and Research (AHCPR), those using less than six months of nursing home care account for only 2.1 percent of expected discounted lifetime nursing home costs per person. In the aggregate, a six month front-end entitlement with no coinsurance would cover only 13.6 percent of discounted lifetime nursing home costs (Kemper, Spillman, Murtaugh, "A Lifetime Perspective on Proposals for Financing Nursing Home Care," *Inquiry* 28: 333–344 (Winter 1991)). For women, who tend to have longer stays than men, on average, the percentage of costs covered are even lower. Given such relatively low levels of protection, it is not difficult to see why the public may not perceive them as adequate.

Another AHCPR study sheds additional light on the problem. It states: "Our projections also indicate that the likelihood of spending a large amount of time in a nursing home is substantial. .. Of those who enter nursing homes, 55 percent will have total lifetime use of at least one year, and 21 percent will have total lifetime use of five years or more." (Kemper & Murtaugh, "Lifetime Use of Nursing Home Care," *New England Journal of Medicine* 324: No. 9 (February 28, 1991: pp. 595–600))

According to research conducted for AARP by Lewin/ICF, Inc., the AARP draft proposal for nursing home protection—which does not require any asset test or spend-down and which covers a broader range of persons needing care—would cost approximately $10.6 billion more than that provided under S. 2571. We believe the extra protection is worth the additional expense because consumers would be more likely to feel that the program addresses their greatest fears and, therefore, would be more willing to pay for the protections received. In addition, the risk that eligibility for benefits would be eroded over time is much greater under a means-tested, as opposed to a social insurance, program.

We are further concerned that by requiring a spend-down, the nursing home benefit under S. 2571 differentiates drastically between persons incurring $60,000 in expenses because of a 3-month hospital stay and persons incurring $60,000 in expenses because of a 2-year nursing home stay. What is the rationale for treating one person with cancer who needs several months of hospital care differently from the person who is an unfortunate victim of Alzheimer's disease and needs nursing home care? No one can predict who will be stricken with a particular illness. Basic equity argues for similar treatment for the life savings of each of these individuals. The level of protection received should not depend so much on whether a person has an acute or a chronic illness.

We also believe that long-term care insurance provisions of S. 2571 merit further consideration. Under S. 2571, the cost of private long-term care insurance coverage that is implied by the bill would remain unaffordable for the average American family—forcing the vast majority of consumers to spend-down in order to receive meaningful protection. Leaving coverage of the most uncertain, and potentially most costly risk to the private sector—extended stays beyond six months—will do little to make these products more affordable to consumers. In contrast, the AARP draft proposal, by covering the entire length of stay and including generous low-income protections, is expected to significantly lower the cost of private supplemental long-term care insurance policies.

We are also concerned about the requirement that persons must have dependencies in three, as opposed to two, ADLs in order to receive long-term care services. This stricter coverage criteria, for example, would fail to address the needs of approximately 400,000 disabled individuals who need home and community-based care.

In general, we believe that the current Medicare skilled nursing facility (SNF) program was designed to cover the non-custodial, shorter-term nursing home population, and with certain modifications could do so much more effectively. A truly "long-term" care benefit should do just that, protect against longer-term care problems. Retaining Medicaid's means-testing component as a condition for receiving benefits will (1) encourage manipulation through asset transfers and other "shell games;" (2) continue unnecessary administrative costs and stigmas associated with applying for coverage; (3) run the risk of lowering eligibility criteria to lower income or even poverty levels in times of tight budgets; and (4) provide inadequate coverage and protection for those unfortunate individuals who need a significant amount of long-term care. Concerns about not wanting to protect wealthy people's assets are addressed most effectively by a progressive financing structure. In a similar vein, we believe it makes more sense and is far less intrusive to increase taxes on estates and gifts to help finance a long-term care proposal that would resolve people's deepest fears—losing a lifetime of savings because of the need for nursing home care.

CONCLUSION

AARP believes that containing health care costs and guaranteeing all Americans access to affordable, quality acute and long-term care must be a national priority. In discussing this issue with AARP members nationwide, we have found that continued public education will be essential for building consensus on this important issue.

Comprehensive reform of our health care system will only be possible when the American people understand the need for protection and recognize the inherent danger involved in continuing a piecemeal approach to a comprehensive problem. Clearly, the 1992 Presidential and Congressional elections offer had important opportunity to engage in a national debate that can help build a broad consensus not only on the need for action, but also what kind of action.

Long-term care is an integral part of this growing national crisis that touches nearly every American family. Millions of families are vulnerable to financial ruin from the devastating cost of long-term care. Most tragic of all is the deprivation and isolation of those who get inadequate care or no care at all.

The only fair way to provide all Americans with affordable protection from the devastating costs of long-term care is a broad-based social insurance program into which everyone pays and from which all are eligible to benefit. A social insurance program will make paying for long-term care predictable and affordable. By doing so, it will promote dignity and independence for individuals needing long-term care and protection against financial ruin for their families—spouses, friends, children and grandchildren.

AARP stands ready to work with you and your colleagues in achieving the goal of comprehensive and affordable health care for all individuals.

STATEMENT OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES

Access to an array of long-term services is a critical concern for millions of Americans with varying disabilities of all ages, their families and allies. The need for a fair and comprehensive public policy in this area has never been more clear.

Meanwhile without the benefit of such a policy, the federal, state and local governments are attempting to meet the wide range of needs of children and adults with disabilities. This is no easy task. In the past thirty years, and especially since the recently enacted Americans with Disabilities Act, society's views of such individuals, their capabilities and the best ways to encourage their full potential and participation in our nation have changed dramatically. This, in turn, has produced an equally powerful shift in the way in which Americans with disabilities perceive and value themselves as well.

Unfortunately, federal and state policy approaches to providing needed long-term services have not always kept pace with these changing perceptions and expectations. With this in mind, the undersigned members of the Consortium for Citizens with Disabilities' (CCD) Personal Assistance Services and Long-Term Services/Medicaid Task Forces respectfully submit this statement of testimony to the Finance Committee, Subcommittee on Medicare and Long-Term Care in conjunction with the hearing held on May 13, 1992. This statement is intended to supplement views expressed in oral testimony by Jenifer Simpson at the hearing on behalf of the two CCD Task Forces.

RECOMMENDATION: *A fair and comprehensive federal policy on long-term services and supports*[1] *must be developed to foster the increased independence, productivity and integration of individuals with disabilities of all ages into the community, as defined in the Developmental Disabilities Assistance and Bill of Rights Act (as amended by P.L. 101–496, 1990). Such a policy must emphasize that individuals must have the right and possibility to make choices about their lives; make contributions to their family and community through work or other means; and live as fully participating members of society.*

MEETING THE LONG-TERM SERVICES AND SUPPORT NEEDS OF AMERICANS WITH DISABILITIES OF EVERY AGE

> *Jenifer Simpson eloquently explained the needs of her seven year old son Joshua who has cerebral palsy as well as her aspirations for him. Her testimony emphasized that while she is able to meet his needs in a minimal way, she gets no societal support in doing so. His full capability as well as hers is not fostered by the existing system. Her expectations for Joshua as well as her desires for him to live as part of a community, rather than in a segregated institutional setting, must be honored in any federal approach to reforming current long-term services and supports policies.*
>
> *Joshua's needs will not diminish as he grows older and, in particular, when he is no longer eligible for school-related services at age 22, the threat of institutional living may be even more significant. Services for adults with disabilities must be put in place to be ready to meet Joshua's needs and to now meet the needs of thousands of adults who languish at home or in institutional settings.*

There are parallels between the policy issues that must be addressed in designing an effective and equitable system of long-term services and supports for elderly indi-

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[1] NOTE: Terminology Usage· The use of the term "Long-Term care" implies that people with disabilities are dependent and need or want to be taken care of throughout life What the vast majority of individuals with disabilities really need and want is access to long-term supports—not care—to enable them to exercise greater choice and control and thus, make real the promise of the Americans with Disabilities Act in their lives. Thus, we will use the term "long-term services and supports.

viduals with significant disabilities and those who become severely disabled earlier in life. Both of these constituencies will require a coordinated array of health services, income assistance and social supports over an indefinite period of time. Regardless of the age of onset of the disability or its cause, the nature of the individual's needs place a premium on breaking down the traditional barriers between health services, income maintenance and social supports. The new focus instead must be on providing each person with an individualized mix of services and supports that allows him or her to function as independently as possible.

Non-elderly individuals are likely to require an array of services and supports for many years—potentially over their entire lifespan—rather than just during the later years of life. Consequently, the types of services and supports non-elderly individuals will need can be expected to change during different stages of their life. In addition, an individual who experiences a severe disability earlier in life—especially a person who is disabled from birth or soon thereafter—is less likely than an elderly person to have residual life skills which may help to compensate for his or her impairments.

Moreover, services to individuals who are disabled during the developmental period should be aimed at assisting the individual to acquire new and enhanced skills, in contrast to reacquiring lost skills or preventing deterioration in functional capacities. Specialized assistance early in life, including such services as infant stimulation, education, corrective surgery and therapies and vocational preparation, are all vital supports for non-elderly people with severe disabilities. In contrast, individuals who experience severe disabilities, such as mental illness, later in life may have greater need for medical care, assistance with activities of daily living and social/recreational supports.

RECOMMENDATION: *Any attempt to fashion a new set of federal policies which are truly responsive to the needs of both elderly and non-elderly people with severe chronic disabilities must take the above similarities and differences into account.*

THE CURRENT LONG-TERM SERVICES SYSTEM FOR AMERICANS WITH DISABILITIES UNDER AGE 65

> *Ms. Simpson indicated that she is not eligible for Medicaid benefits to cover the cost of the community services and supports her son requires. Joshua would be eligible for Medicaid payments if he were placed in an institution. But since the District of Columbia does not use the Home and Community Based waiver program and did not apply for the option of covering Community Supported Living Arrangement Services under its Title XIX/Medicaid plan, there is no means by which Joshua can qualify for Medicaid reimbursement at present. When he reaches adulthood, even if he becomes eligible for Medicaid on his own, community services are extremely limited and, again, institutional placement might be his only option under Medicaid. This is a clear inequity that needs to be rectified by Congress.*

In the present system, Medicaid is the primary funder of ongoing services to children and adults with disabilities, especially people with mental retardation and other developmental disabilities. Federal-state Medicaid reimbursements on behalf of residents of Intermediate Care Facilities for Persons with Mental Retardation and Related Conditions (ICF/MR) will total nearly $9 billion dollars this fiscal year. While many of these facilities are small, community based residences, the vast majority of ICF/MR funds are still directed toward large congregate facilities. These large congregate facilities cannot and do not promote the goals of independence, productivity and integration. Besides ICF/MR payments the federal Medicaid program expends approximately $3 billion annually on specialized long-term care services for persons with mental retardation and other developmental disabilities, over half of which is used to support Home and Community Based (HCB) waiver services on behalf of this population.

Eight states also are beginning to implement the recently authorized Medicaid Community Supported Living Arrangements (CSLA) option to finance fully integrated community services and supports for people with developmental disabilities.

In addition, tens of thousands of other Americans with disabilities under 65 are needlessly consigned to nursing homes. Unfortunately, the unmet needs of Americans with disabilities living in the community are frequently just as great. According to the World Institute on Disability, 79 percent of people with disabilities who must rely on the assistance of others to complete everyday tasks do not receive adequate assistance on a regular basis and must use informal, catch-as-catch-can supports instead.

One critical question that Congress will need to address as it contemplates possible modifications in existing federal long-term services policies that impact on non-elderly people with severe disabilities is: how should existing Medicaid law (or a successor program of long-term services and supports) be restructured in order to ensure that future policies truly promote the goals of full inclusion, productivity and social integration for all. Clearly, present policies are biased toward institutional living arrangements and segregated, non-productive lives for children and adults with severe, chronic disabilities. The work of the disability community over the past ten years has been aimed at meeting the needs of individuals with disabilities in ways which enhance their humanity and their inclusion in American life.

In fact, many States are trying to assist individuals with disabilities of all ages to cope with the barriers they face everyday; but to do so under present federal policy, states must weave together a patchwork quilt of optional Medicaid services, waivers and state assistance. This is certainly a step in the right direction and one that Congress must support, expand and improve upon with federal policies and programs that are consistent with these efforts. The long-range answer, however, lies not in creating further waivers or exceptions to the law but, rather, in changing the basic focus of the law itself. Any new federal long-term services effort must continue to promote this growing trend toward individual services, choice and self-actualization.

RECOMMENDATION: *A national entitlement program should be created to invest in and fund a comprehensive array of personal assistance, therapies, assistive technology, training, and other vital community support services for all people with disabilities who need them. The basic aim of this program should be to promote full independence, productivity and social integration.*

Any serious attempt at crafting a fair and comprehensive federal long term services entitlement program must eliminate the current federal policy bias that favors paying for institutional care over community support services. In addition, there should be no arbitrary limitation on the quantity of service that any given recipient may receive based on the comparative cost of serving the individual in an institutional setting. For people with disabilities and increasingly for people who are older, this is an inappropriate test. Institutional services do not promote independence, productivity and integration. Whether the facility is a nursing home or a large or small ICF/MR, institutions do not promote the achievement of an individual's full potential or assist him or her to live as part of American society. Experience and research demonstrate that people with disabilities learn and achieve more when community supports are provided. Many examples of individuals and entire programs (like the HCB waiver programs) exist which demonstrate the value of community supports. While some of these programs still must be developed with the nursing facility cost threshold test, this is merely a vestige of outdated public policy. Rather than using institutional cost as the basis of comparison, the test should be whether long-term services and supports are achieving positive individual and social outcomes with whatever resources are expended.

RECOMMENDATION: *Sound, cost effective public policy must allow participants to make real choices by affording them an entitlement to home and community based supports which promote the achievement of their full potential for independence, productivity and integration into the community.*

THE NEED FOR FAIR AND COMPREHENSIVE ELIGIBILITY CRITERIA AND ASSESSMENT

The Need for a Functional and Comprehensive Assessment: In order to effectively address the diverse needs of children and working-age adults, as well as older Americans, a federal long-term services entitlement program must have eligibility requirements that are based on an assessment of functional capabilities and are age-sensitive in scope and nature. This will require a break with currently accepted practice. Traditional approaches to eligibility determination frequently flow from an analysis of the perceived needs of persons who are elderly and from the obsolete view of balancing need for home care against the cost of institutional care.

Often eligibility determinations are based solely on an assessment of an individual's ability to do perform certain activities of daily living (ADLs) independently. This is an appropriate way to determine someone's physical limitations. However, many non-elderly people with disabilities need assistance with "instrumental" activities of daily living (IADLs), such as housework, laundry, making meals, shopping and similar activities. In fact, many individuals with varying disabilities of all ages require a mix of assistance with both activities of daily living and instrumental activities of daily living. However, an assessment limited solely to ADLs reveals little, if anything, of the ways in which the individual's functional limitations and capacities can be addressed through the provision of an array of long-term services and supports. Such a set of criteria or process does not address an individual's real life needs.

There are many individuals with cerebral palsy, for example, who might have ADL limits in only two major areas of life functioning but also need assistance with several other life activities. Eligibility criteria should consider this variable level of intensity. Many persons with cognitive or mental disabilities have few ADL limitations but nonetheless require assistance or supervision to complete other major life functions.

Eligibility standards must be sensitive to these and other factors. Eligibility decisions, therefore, should not occur in a vacuum or be based on a particular category of need to the exclusion of all others.

RECOMMENDATION: *Eligibility determinations should be based on an individualized assessment of the total real life needs of an individual with a disability.*

Eligibility criteria and assessment of this type would lead to a better and more appropriate development of the service constellation needed to meet an individual's needs. Limits or restrictions on levels of service should be individually determined, not based on an arbitrary scale of the relationship between selected functional limitations and need for services.

Age-Appropriate Functional Assessment for Children: The primary needs of children with disabilities, for example, are like those of other youngsters: to be raised by a nurturing and loving family and attend their neighborhood school. The only difference is, of course, that children with disabilities often have additional disability-related needs. Efforts to support children with disabilities must, first and foremost, take into account what it will take to "support" the family to enable a child with disabilities to live at home as part of the family unit and attend the neighborhood school. Application of the test of whether or not a child and his or her family needs assistance should be based on a determination of the child's functional capacities, using instruments and information that are age and disability appropriate.

Age-Appropriate Assessment for Working-Age and Older Americans: Eligibility assessment should be sensitive to the service and support needs of working-age adults with disabilities to work and live in the community., as well as to support older Americans to receive the full range of support and assistance they need to lead self-directing lifestyles in the community. Assessment procedures for federal long term services and supports benefits should encompass an individual with a disability's functional capacities and the full range of community living and personal assistance they need.

Entitlement and Income Eligibility for Long-Term Services: Any income-related tests for a federal long-term services entitlement program should consider not only the income of the individual but the extraordinary expenditures he or she (or his or her family in the case of a minor child) incurs because of a disabling condition. The financial eligibility of adults with disabilities for long-term supports and services should be based on their own incomes and resources, not the incomes and resources of their parents, taking into account any extraordinary expenses the individual incurs which are directly related to a disabling condition.

RECOMMEMDATION: *The eligibility criteria for federally subsidized long-term services and supports should be an entitlement based on broad functional criteria which are assessed in an age-appropriate manner and which consider the full spectrum of an individual's limitations and needs. In addition, adults with disabilities should be determined to be eligible for long-term services and supports on the basis of their own incomes and not the incomes of their parents. Furthermore, cost-sharing requirements should be based on income and resources adjusted for out-of-pocket disability related expenses.*

THE NEED FOR ACCESS TO A BROAD ARRAY OF COMMUNITY LONG-TERM SERVICES AND SUPPORTS

As noted in her testimony, Ms. Simpson believes Joshua will need a complex and comprehensive array of services now and throughout his life. Joshua needs many services including personal assistance to walk, talk, eat, drink, use the bathroom, get dressed or do most anything. He needs therapies, training, assistive technology and other kinds of community supports. Some of this is provided and paid for by his family; some services are provided through health insurance and by the school system at present. He goes without several services and supports.

However, as Joshua grows older his needs and desires will change. He will need many kinds of supports as he grows to adulthood. He will need assistance to live independently. He will continue to need physical therapy, occupational therapy, and speech/language pathology services. He will probably need assessments and services from speech/language pathologists, and will need training and other supports for vocational activities to get and keep a job.

Now, because of the lack of other available services, Ms. Simpson needs respite care to provide her some rest from the constant caregiving duties. While this is a critical need now, it may lessen in importance if Joshua gets necessary services on a regular basis.

People with disabilities need a broad array of services and supports available to them. Many individuals will require simple and specific services in varying levels of intensity. Others may require a complex and interwoven set of services and supports to meet varied and, often, changing needs.

Such support services should be designed and made available to support an individual with a disability whenever and wherever he or she needs them, i.e., at home, in school, on-the-job or elsewhere in the community.

RECOMMENDATION: *A comprehensive set of required reimbursable services and supports under a federal long-term services entitlement program should include:*

Personal assistance services, defined as one or more persons assisting another person with tasks which that individual would typically perform if he or she did not have a disability. This includes assistance with both activities of daily living (ADL) and instrumental activities of daily living (IADL).

Training or assistance in learning to perform or performing everyday activities, including assistance with money management, planning and decision making, home management, use of medications, following instructions, and other adaptive skills necessary to achieve and maintain independence, productivity and integration and to live successfully in his/her home.

Therapies, including communication, audiology, speech/language pathology, occupational, rehabilitation, physical, mental health and other services which are necessary to achieve and maintain the individual's optimal functioning.

Assistive technology services, including assistance with evaluating the needs of an individual in his or her every day environment; purchasing, leasing or obtaining assistive technology devices for use by individuals with disabilities; training the user; and selecting, designing, fitting, customizing, adapting, applying and maintaining, repairing or replacing such devices.

Other community support services: including a broad array of supports such as life skills supports to enable an individual to live independently and participate in social, community or other activities; household services; mobility services in and out of home; security-enhancing services; work-related support services; emergency services; and respite services.

RESPONSIVENESS TO THE CHOICES AND PREFERENCES OF THE INDIVIDUAL WITH A DISABILITY

In order to promote independence, productivity and integration into the community, long-term services and supports should be designed to: (1) be guided and directed by the choices, preferences and desires of the individual; (2) increase the individual's control over his or her life and minimize reliance on others in making decisions and performing everyday activities; (3) increase the independence, productivity and integration of the individual into the community; (4) be provided in or out of the person's home, in any community setting; (5) be based on an individual services and supports plan; and, (6) offer individuals of all ages the opportunity to receive supports needed to permit them to assume greater freedom, responsibility, and choice throughout life.

Joshua and his mother need assistance to negotiate the maze of services and systems which might be available to meet his needs. They need to be in control of what they receive, however, so that Joshua's unique needs and potential are addressed. His needs will change as he grows older and may change from day to day. He needs to be able to get services that are flexible and individually designed.

Individual service coordination is an important aspect of developing any system and of promoting informed consumer choice and control. Families and individuals need assistance to define and develop their service arrays. The system also needs ways of monitoring the effectiveness and appropriateness of the services provided as well as the distribution of available resources. However, any service coordination system should not be used solely to limit and control costs but to assure that appropriate levels and types of services are available to individuals. Service coordination must be performed in full consultation with the individual (and family when appropriate) and any plan for services and supports must be subject to the choice and approval of the consumer. This empowerment is critical to many current "best practice" efforts. For instance, the Medicaid Community Supported Living Arrangements option supports the involvement of the consumer in developing his or her individual support plan; many of the eight states in that program are involving the consumer directly in the assessment of quality as well.

RECOMMENDATION: *Service coordination should be independent of any service providing agencies in order to avoid conflicts of interest and promote consumer choice and control.*

System Design Issues

Any future long-term services legislation should build upon the existing state/local infrastructure that is already in place to serve people with severe, chronic disabilities. Such legislation should include incentives and a process for allowing states to design their own service delivery systems, building on the experience, expertise and resources they have. At the same time, modifications in existing service delivery structures may be necessary to ensure that the provision of future services is consistent with federal goals.

RECOMMENDATION: *Any federal policy change should include explicit option strategies to allow states to alter existing services and supports so that they comply with such new federal policy expectations over a reasonable period of time.*

Consumers of services must be involved in the development, design and implementation of the service system to ensure that the system remains focused on the needs and desires of people with disabilities. Consumers should also be able to rely upon a single point of entry for initial access to the service system.

Quality Assurance

> *As Simpson stated, Joshua's needs are like those of all other children: to be raised by a nurturing and loving family and attend school and other activities in a safe neighborhood. Joshua's needs and the needs of other children must be effectively addressed in order for their families to function and for children to achieve full potential. Any system which tries to meet his needs must provide the assurance that he will be safe; that, even in adulthood, he is protected if that is determined to be necessary; and that any services promote his achievement of positive life goals.*

A federal long-term services entitlement program should support efforts at the state/local level to develop and implement a system of quality assurance that fosters quality and excellence in every aspect of the design, delivery and evaluation of services. Systems must be enabled to take a pro-active approach, anticipate, respond to and solve problems and challenges in a manner that is not intrusive and does not go beyond the need of the individual for support. Individuals with disabilities should be given the support they need to gain, maintain and improve competencies and skills required to exert greater control over their own lives. Such efforts also should provide for enhanced quality assurance support and assistance to people who are at-risk or particularly vulnerable to abuse, neglect or exploitation.

The federal quality assurance role should allow the states and local service providers flexibility in meeting individual needs and involving a broad spectrum of individuals with disabilities, their representatives and advocates to define quality and quality assessment measures. Federal legislation also should call for periodic third-party assessment of individual satisfaction with the services provided.

RECOMMENDATION: *Quality assurance efforts should focus attention on meeting the individual needs and preferences of people with disabilities and, where appropriate, their families. Quality should be defined in terms of outcomes which support independence, productivity and social integration.*

On behalf of the undersigned organizations, we thank the Members and staff of the Committee for this opportunity to outline our views regarding the provision of long-term services and supports for children and adults with disabilities. We look forward to working with the Members of the Committee in crafting long-term services and supports legislation to truly meet the needs of people of all ages with disabilities.

On behalf of:

American Speech-Language-Hearing Association
Autism National Committee
Learning Disabilities Association
Mental Health Law Project
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils
National Association of State Mental Retardation Program Directors
National Head Injury Foundation
National Parent Network on Disabilities
National Recreation and Parks Association
NISH, creating opportunities for people with severe disabilities
The Accreditation Council on Services for People with Disabilities
The Arc (formerly the Association for Retarded Citizens of the US)
The Association for Persons with Severe Handicaps
United Cerebral Palsy Associations, Inc.

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