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HEALTH CARE REFORM: THE LONG-TERM CARE FACTOR

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
U.S. SENATE

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TUESDAY, APRIL 12, 1994

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

The Committee met, pursuant to notice, at 9:35 a.m. in room 216, Hart Senate Office Building, Hon. David Pryor [Chairman of the Committee] presiding.

Present: Senators Pryor, Burns, Riegle, Feingold, Cohen, Bradley, Craig, and Graham.

Staff present: Theresa Forster, Staff Director; Christine Drayton, Chief Clerk; Theresa Sachs, Professional Staff; Lisa Woodruff, Professional Staff; Anne Riley, Professional Staff; Jonathan Adelstein, Professional Staff; Mary Berry Gerwin, Minority Staff Director; Victoria Blatter, Minority Professional Staff; Michael Langan, Legislative Correspondent; Nathan Fretz, Staff Assistant; Jennifer Green, Hearing Clerk; and Andrea Boldon, Press Assistant.

OPENING STATEMENT OF SENATOR DAVID PRYOR, CHAIRMAN

The CHAIRMAN. Ladies and gentlemen, we would like to welcome you this morning to a discussion of health care reform, the long-term care factor.

We are going to be examining this morning the critical role that long-term care plays in health care reform. I would like this morning to have the opportunity to extend a very, very special welcome to the Alzheimer's Association who are joining us here today for this Committee on Aging hearing. The Alzheimer's Association is in town for a public policy conference. If I'm not mistaken, I believe the First Lady addressed you yesterday.

Many of you, I know could speak from personal experience about the need for affordable and appropriate long-term care options. I'm very grateful, we are, that you are spending time with us today as we discuss this issue which affects so many American families regardless of age or income.

You will hear from two of our family witnesses today this issue can affect several generations at one time. We're going to explore some of that this morning.

Before we get into all of that, though, I would like to take a moment of personal time to welcome to our Committee a new member; Senator Don Riegle of the State of Michigan has joined our Committee. This is his first Committee hearing. Senator Riegle, we welcome you to our Committee this morning. We are very indebted to you for joining our clan. I think the crowd feels likewise.

Our good friend, Senator Conrad Burns of Montana, is a stalwart member of the Committee. Senator Cohen is going to come later, our vice chair. He will be here in a few moments; he had another committee meeting as all of us have several committee meetings this morning.

As we debate health care reform, we think it is very important that we not neglect the very, very critical issue of long-term care. We'd like to highlight this morning a few facts and emphasize the importance of this issue that we'll be covering this morning.

It is currently estimated that some 10 million individuals of all ages need long-term care. However, by the year 2040, it is estimated the population 65 and over who will experience long-term disability is going to range somewhere between 15 million and 23 million, an increase of 190 to 345 percent. These estimates are only for the 65 and older population.

Long-term care, as you know it, represents a very substantial portion of our current health care spending, upwards of $70 billion. However, this cost does not include all of the unpaid informal care provided by family members and friends which comprises today in our society the majority of care. Our States have played, and continue to play, a major role in developing, financing, and administering long-term care programs.

As we will hear from some of our witnesses today, long-term care continues to consume an increasing share of the State's Medicaid budget. In our home State of Arkansas, for example, in 1991 alone, Medicaid long-term care spending accounted for more than 25 percent of all Medicaid spending, or about $174 million out of a total of $688 million. It is estimated by the year 2000, without some comprehensive reform, that our State, a small State, will be spending some $50 million in Medicaid and State funds just on home health, personal health care services, and home and community-based waivers.

This is why we expect the States, including Arkansas, and States like Montana or Michigan, to be paying very close attention to the manner in which Congress deals with long-term care and health care reform.

In Arkansas, and in all States, there will be substantial savings of State general funds if President Clinton's plan is enacted. The plan will also give the States the ability to do better and to coordinate the current spectrum of services and to build a cohesive infrastructure for delivering long-term care needs.

Of course the most compelling reason to address long-term care and health care reform is its impact on families. The goal of health care reform is to give all Americans, every American, health care that is always there to respond to the true needs of families and individuals. Universal coverage will ensure that a serious illness such as cancer will not financially devastate a family.

The great untold tragedy of our current health care system is that even people who have generous health care insurance coverage can lose everything to a long-term, chronic illness. The type of care required by an individual with a chronic disease is often not covered by insurance. Nursing home care, for example, is covered by Medicaid only—and you know this—after a person spends a lifetime of savings and is impoverished. That is when nursing home

care is finally covered by Medicaid. That is not acceptable. Other care options such as home care or attendant services may not be readily available even in instances where those services are covered.

This morning, we have some witnesses. One family has lost everything because of an illness requiring long-term care. This can happen to any family in America. It can happen whether a person is old or young, rich or poor, good health, bad health. It should not have to happen. This is why it is vitally important for long-term care to be addressed in any package of health care reform.

We have assembled today some excellent witnesses who are prepared to address all aspects of the long-term care issue. We will describe them in detail for you. We hope that this is a constructive meeting, and we hope that all of us will gain benefit from it and educate ourselves as we carry forward in this great issue of health care reform in 1994.

Now, if I might, I'd like to yield to Senator Burns and then to my friend, Senator Riegle. I see Senators Bradley and Feingold have also arrived.

STATEMENT OF SENATOR CONRAD BURNS

Senator BURNS. Thank you, Mr. Chairman. Thank you for holding this hearing this morning.

I notice we have several other committees meeting this morning, so if we're in and out, I'll have to apologize early for that and I think, in fact, looking at our first witnesses, the Assistant Secretary for Aging will be a very busy man as he takes this subject and other subjects he has to deal with on to the public forum.

I think there is a clear sign right now that the importance of long-term care and the concern with how we deal with it, what happens here in Washington, D.C., I want to say first off that I had a hearing last week in my State that focused on the barriers of accessing home health care, which is just one component of long-term care, but I believe it is a very important one, how long can folks stay at home before they have to go into a managed or skilled care facility.

Of the nine witnesses who presented testimony in Kalispell, Montana, not one sat there and said the system was fine the way it was. Actually, they all came with very constructive, very practical suggestions, ways that the system can be improved and I could have sat there and listened to them all day because they did have some ideas because they are the people that are in the trenches. That's kind of where the rubber hits the road, those people that have to provide the services and can identify those barriers and actually have very, very simple solutions to deal with them. The problem is that Government is very slow in changing policy or we get into a turf war somewhere up and down the line and policy never gets changed at all.

I guess what I'm trying to say is that long-term care is something that we've got to take up here in Washington and really face the music to do something about because our constituents at home are very, very much in tune or keenly in tune with it.

I'm not real sure I know what the answer is. I'll be very interested in hearing our distinguished panel this morning to see what

they would suggest and how we can best confront this problem. We need ever growing health care reform, it's part of that puzzle. I wasn't here to pass the Catastrophic Act in 1988 but I was sure here when we repealed it. I remember those days and that wasn't fun at all. In fact, I think all of my colleagues up and down the line here were here with the exception of my good friend from Wisconsin.

Costs are increasing. No one can deny that, but I don't think it is solely due to the price of services going up. I think we have more elderly than ever. I was astounded at some figures of people over 100 years old now and what is forecast in the future of how that number will grow to live over 100.

I lost my father just a year ago last December. He was 86 years old, farmed all his life in northwest Missouri. The first time he was ever in a hospital is when he died and we were very, very fortunate in that respect. Nonetheless, dad said, I don't mind getting old, but I fear getting too old. I think therein lies probably the biggest problem that we have.

As babyboomers come of age, there will be more demand for long-term care and services for the elderly. We've got to get a handle on it now; otherwise, it will be like trying to nail jello to a tree in order to get a handle on it.

So, Mr. Chairman, I'm truly looking forward to this hearing and to hearing from our witnesses this morning. I hope I can stay the whole duration but then again, we have some other duties to take up.

In particular, I want to thank Ms. Chapman for coming before us. My wife's father died of Alzheimer's and we understand that terrible, terrible disease, so I'll be looking forward to your testimony. He was fortunate enough that he could stay on the ranch in Nebraska and have the love and affection of the family all through that crisis period. We need real life examples.

I only wish that the people from the Administration would listen. If there is one thing I've learned here in Washington, D.C. since I've been here and on these committee hearings, we put the cart before the horse. We should make the Administration people sit here and listen to the real testimony that comes from real people that live in real America outside of this 13-square miles of logic-free environment, and listen to them. We have always been in the experience where we have the Administration—and I don't care whose Administration it is, it doesn't make any difference, they give their testimony and then they jump up and go home. Then we hear the rest of the testimony.

So I would invite the Administration to stay on board with us, listen to some of these people because they tell real life stories about real life people.

Mr. Chairman, thank you for this hearing. I appreciate it. It also points out that you are very interested in this and very dedicated to health care reform, especially in long-term care. I appreciate that.

Thank you very much.

The CHAIRMAN. Thank you very much, Senator Burns.

Employing the early bird rule, I will now yield to Senator Riegle.

STATEMENT OF SENATOR DONALD W. RIEGLE, JR.

Senator RIEGLE. Thank you very much, Chairman Pryor.

I want to say at the outset, I appreciate your personal comment and I want to make a comment of my own for just a moment.

Let me begin by thanking all of those in attendance today. We've got an important part of the national leadership here on long-term care issues. We've got a number of people who speak from very powerful, personal experience and from their knowledge of others. That leadership is invaluable. We have a very precious resource in the room today, including those that are seated here in the audience who have come to participate and who continue to give leadership across the country every day.

Let me also say to you, Mr. Chairman, I remember back nearly three decades ago when you came to the House of Representatives as a newly elected Member and tried, at that time, to force the Congress to pay attention to the issues of aging and of seniors. Back in those days, the House leadership was unwilling to accept that idea from a new Member of Congress from Arkansas. So David Pryor went out and raised private money and actually got ahold of a house trailer, got it set up near the House office building where a staff of volunteers could go to work to start on these very issues that we are here to talk about today. That was nearly 30 years ago. That's leadership. That's seeing things ahead of time. I don't know of anybody in this country who has done more to advance these issues than the man sitting right here to my left, the Chairman of this Committee, Senator David Pryor.

I just want to pay that tribute to him this morning because I remember those days when he was forcing the issue in the form of the work that was being done in that house trailer. So we've come a long way since that period of time, but with the same person giving the leadership.

I want to also thank the Chairman and the Committee for agreeing to hold a hearing in the State of Michigan on Wednesday, May 18th which is not very far ahead of us. We have, in Michigan, every year in the springtime an event called Senior Power Day, at our State capital. This will be the 20th meeting of Senior Power Day. We have invited the First Lady, Hillary Rodham Clinton, to come and speak at that event and we hope that she will be able to do that.

In any event, we will be having a hearing that day where Michigan seniors will be presenting testimony, as we will hear here today as well, on aging issues and very particularly on the needs of long-term care.

There are just two other points I want to make this morning. We have drafted now two pieces of legislation the first is S. 538 which I am co-sponsoring along with Senator Pryor and Senator Daschle. It deals with changing the standards in terms of the purchase of private, long-term health care insurance and provides the kind of reform and change that is clearly needed. That is one way to attack part of this problem.

The real way to get at the full scope of the problem, however, is contained in the general outline of S. 2571 which is the Long-Term Care Family Security Act sponsored by Senator Mitchell in the last Congress. I'm a co-sponsor and there are 11 of us who are. That

is based on the recommendations of the Pepper Commission and is designed to provide access for all chronically-disabled individuals regardless of age or income. I think that bill also moves forward in this great area of national need.

Finally, the President has his proposals on long-term health care reform. We have to make sure that we not only get national health care reform but we get it this year, not some other year in the future where it is going to be too late for a lot of people. Let's get it this year, let's get it in 1994. We've been waiting long enough for it, let's get it this year and let's have long-term health care as part of it. [Applause.]

The CHAIRMAN. Well, you see now why he has gotten on the Aging Committee. He's got a lot of enthusiasm and he will bring a lot of energy to this Committee. We are very proud that Don Riegle is our newest member.

The next Senator in line of appearance is Senator Bill Bradley of New Jersey. Senator Bradley.

STATEMENT OF SENATOR BILL BRADLEY

Senator BRADLEY. Thank you very much, Senator Pryor.

The CHAIRMAN. I believe you have some New Jersey people back there, Senator Bradley.

Senator BRADLEY. I hope so.

Thank you very much for once again turning the spotlight on this very important and emotional issue that I think for too long has been overlooked and that is family caregivers and long-term care.

There are over 2 million severely impaired adults and thousands of disabled children in America living in communities who need help, they need constant care, constant care with the daily functions of life like eating, bathing, dressing. The caregivers who have come here to testify today I think are a moving testament to the strength of families and provide a glaring example of where Federal policy has behaved shortsightedly and fallen short of the needs of its citizens.

The reality is that four out of five Americans with functional disabilities are cared for not in institutions but by family members at home. Family caregiving requires often herculean physical and emotional energy. The loved ones who provide this care have, I think, the toughest job that I've ever seen. They are called on 24 hours a day, 7 days a week, 365 days a year. They face enormous stress, they need special skills and they require physical strength. They earn nothing. They do it out of love, which of course is the best reason to do it.

Caring for loved ones saves thousands of dollars in nursing home costs but all too often the demands of daily care extract an invisible cost. The demands can become too much and under the stress of those demands and other personal and family demands, the bonds of a family's love begin to fray.

If we, as a Nation, are to have an effective long-term care strategy, it will have to build on and support this valuable network of family caregivers. That means that we have to find some way to provide some respite, some time out from the unremitting task of providing for basic human needs.

In New Jersey, we've had a program pursuant to a bill that I introduced and we got passed of respite care for a number of years, since 1988. There have been over 12,000 families in New Jersey since then that have received respite services in our State. Because of the success of that respite program, I've introduced the Family Caregivers Act which would provide for eligible families up to $2,400 a year to pay for respite services. It could be used for 1 afternoon a week, 1 day a week, a 2-week break as a vacation, any way you want to use it, but to give the individual providing the care some real break, some rest.

From my perspective, the need for these programs was only reemphasized during our recent congressional break when I visited with any number of family caregivers. In particular, I remember one meeting in Bergen County in New Jersey where 15 sat around a living room and told their stories, many of which will be similar I think to the ones we will hear today.

From those stories, I really heard two main concerns. The first was, access to affordable care that fit the needs of the individual and the family situation. I was shocked to hear that in New Jersey it can cost a family close to $40,000 per year to provide 24-hour care service in the home. You can be fairly frugal, save a lot of money and in a very short time, have all those savings gone.

If a family applies for home and community-based assistance in New Jersey, they may have to wait up to 6 months for existing services. The different eligibility criteria and service limitations of various Federal, State, and local programs make it difficult for families to receive the continuum of care that fits their needs.

Therefore, Mr. Chairman, what I think we need is to encourage the development of better and stronger State infrastructures that will be able to weave together the funding and delivery of home and community-based care into a continuum of care network.

The second and perhaps most disturbing concern that was raised by New Jersey caregivers was that it took months, literally months to discover what home and community-based services were available for the elderly and the disabled. They didn't know where to go for help. They couldn't find out where to go for help. Finally, when they did discover what services were out there, they faced the same 6-month to 8-month wait before they could get the services.

How frustrating this must be. If you have a loved one with Alzheimer's and you need to get them placed, you need to get care, you can't wait 6 months. One woman told the story of her father who developed Alzheimer's; she was unable to get help and so she left him at home for 7 hours a day. She said, so far it goes okay because he hasn't figured out how to turn on the stove yet.

These are the worries of family caregivers. I believe they need our support, the minimum we can do while we're waiting for the Administration and the National Health Bill which I hope will include some respite care, is to make sure that family caregivers have access to the information that they so desperately need to do what only they can do best, which is provide that loving care.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Bradley.

Now, our very distinguished Vice Chairman of the Aging Committee is with us, Senator Cohen of Maine. Senator Cohen.

STATEMENT OF SENATOR WILLIAM S. COHEN

Senator COHEN. Thank you very much, Mr. Chairman, and ladies and gentlemen.

One of our colleagues just arrived. He said you mean we're still in the opening statements. That was sort of a hint to me to I think even shorten up my own remarks. I have a fairly lengthy statement which I'm going to submit for the record and not delay you too much longer from really hearing from the people you came to hear and not from us to tell you our thoughts. I think we have occasion to do that on almost every day by virtue of speeches on the Senate floor and other types of forum.

Let me just say that for too long, long-term care has been considered a sort of stepchild of the health care debate. It's an afterthought, it comes at the very end of all the discussion and debate. I think that President Clinton deserves credit, I think he deserves a great deal of credit for introducing a health care proposal, controversial as it is, but nonetheless the first time that there has been a long-term care proposal included as a part of that. So he deserves credit for that.

There are other proposals that also have various formulations of long-term care—the Chafee proposal, the so-called HEART proposal—also have some changes in tax codes and other types of incentives in order to encourage individuals to start acquiring long-term care coverage.

Last year, we had a hearing in Maine and we had the great privilege of having Dr. Fernando Torres-Gil appear at that hearing. I think he will tell you that there were between 500 and 600 people who attended that hearing, certainly some indication they were seniors and caregivers, and health care providers and policymakers, some indication that this is not a fringe issue, this is central, this is key to the question as to whether or not we're going to have a health care proposal that is comprehensive in nature, that deals with a growing problem and one that has, for too long, been ignored.

I'd point out, however, there is going to be great controversy as to whether we can at this time afford to create a new, open-ended entitlement program. I'm not sure that there is the political support or the public funding that would be necessary to sustain such a program. I think that new and unrestrained, non-means tested programs are not likely to receive a majority of support, but I believe that we can formulate a proposal that will start to deal with this in a very positive and constructive fashion.

One thing that we need to do, we've got to eliminate the current bias toward nursing home care. There are alternatives for people who can remain in their homes, who want to be in their homes, who are not allowed to do so under the current financing mechanism. That needs to be changed. There are always going to be nursing homes needed for the kind of long-term care for those who are in desperate need of that level of service, but not everybody is in need of that level of service, so we have to change the laws which are currently on the books in order to take that into account.

Mr. Chairman, let me conclude—I'll put my statement in the record—by saying this is an issue that no longer can be deferred and I think we're going to see both Republicans and Democrats

joining in a fashion to come up with a program that will make sense for our citizens. Thank you.

[The prepared statement Senator Cohen follows:]

STATEMENT OF SENATOR WILLIAM S. COHEN, RANKING MINORITY MEMBER, APRIL 12, 1994

Thank you, Mr. Chairman, for holding this hearing on the importance of addressing the long term care needs of our Nation's elderly and disabled in comprehensive health care reform.

The American public has cried out for health care reform and the Administration and many Members of Congress—both Republicans and Democrats—have heeded the call with proposals on how to solve the serious problems of our current health care system.

As Shakespeare described in Henry V, "Now sits expectation in the air." The public is now waiting and watching to see what form health care reform will take.

While we spend the next few months debating the merits of such issues as managed competition, health care alliances, the amount of regulation necessary, and who should pay for each proposal, we must keep in mind that the ultimate measure of reform for each American will be, "What will health care reform mean for me?"

For many older Americans, individuals with disabilities, and their families, the most personal way that health care reform could touch their lives would be by making affordable, appropriate long term care services more available.

As we will hear from our witnesses today, our current long term care system is fragmented, inequitable, and insufficient to meet the needs of today's disabled population and the expanding needs of tomorrow's aging population.

For far too long, the question of how we provide and pay for long term care has been simply an after-thought, or stepchild, of health care reform discussions. Despite the fact that long term care is the number one major catastrophic expense for our nation's elderly, we still do not have, either in the public or private sectors, satisfactory ways to help families anticipate and pay for their long term care needs. Instead, families are too often left on their own to juggle round-the-clock caregiving needs with their own jobs, or are forced to institutionalize their elderly parents or disabled children when they desperately want to keep them at home, simply because there is no other affordable care available to them.

Fortunately, long-term care is beginning to emerge as a vital element of the health care debate. Last September, for example, a conference I held in Augusta, Maine, on long-term care, was attended by over 500 senior citizens, caregivers, health care providers, and policy makers. We were very fortunate to have Dr. Fernando Torres-Gil, Assistant Secretary of Aging, who will testify later this morning, as our opening speaker at the conference. I am sure he will agree that the enthusiasm and deep involvement of the participants in that session last fall sent the clear message that making long-term care services more affordable and available is not a fringe issue—but rather a key test—of health care reform for millions of Americans.

There is a variety of long-term care proposals now on the table for the Congress' consideration. For example, the Administration has included a comprehensive long-term care benefit as part of its Health Security Act, and the Senate Republican Task Force's health care plan, the "HEART" proposal, provides tax incentives for the purchase of long term care insurance.

Correcting the serious flaws of our current long-term care delivery system will not be easy. In earlier days, when federal budget deficits did not loom so large over our economy, the solution would have been relatively simple: just create a new open-ended entitlement program.

Today, however, we can no longer afford to construct new, unrestrained non-means-tested programs. Such an approach is not only fiscally irresponsible, but also impedes the creation of a private long term care insurance market and fails to encourage individuals who are financially able to plan and save for their own future long term care needs.

I believe there are several steps we can and should take that would provide meaningful relief to families facing exorbitant long-term care costs both now and in the future. For example:

For those without the resources to finance their own care, we can improve our public "safety net" to better protect those at low-income levels against the catastrophic expense of long term care services.

We can also eliminate the current bias in our system toward nursing home care. Far too often, elderly or disabled individuals are forced to enter nursing homes pre-

maturely simply because this is the only care that is covered under Medicaid. While there will always be those who require institutionalized care, for many others home and community-based care can be a less expensive alternative, saving millions of dollars for the overall system.

We can provide tax and other incentives for individuals to purchase long term care insurance, and should place strong consumer protections on these policies to ensure the availability of high quality, affordable insurance. Encouraging the creation of a strong private long-term care market now will ease the financial burden on the Federal Government for years to come, as our population ages and more and more elderly persons need long term care services.

Finally, we should explore ways to better integrate long term care with the rest of the health care system, so that we create a more balanced and integrated delivery system that will meet people's needs over the years.

Mr. Chairman, it would be tragic indeed if we allow the opportunity of health care reform to pass us by without addressing the desperate need for affordable long term care. For many of our most vulnerable citizens, this is the health care crisis facing our Nation, and now is the time for us to act.

The CHAIRMAN. Senator Cohen, thank you. Thank you very much.

Let me also state we have a very good relationship on this Committee, Republicans and Democrats. We have never had a vote of anything like that I'm aware of where we split on party lines. We try to look at issues and look at them objectively and put partisanship aside because we know that these are issues that affect every American in our country. We just wanted those of you who may not have attended any of the hearings before to take cognizance of that fact.

Our next member, who is a very loyal member of this Committee, is Senator Russ Feingold from Wisconsin. Senator Feingold.

You've got some constituents out there, I believe.

STATEMENT OF SENATOR RUSSELL D. FEINGOLD

Senator FEINGOLD. Thank you, Mr. Chairman.

I too want to thank you for holding this hearing. I can't think of a better way to come back from this 2-week recess than to begin on this issue of long-term care. There is no more pertinent an issue that this Committee can examine right now than long-term care, and in particular, how long-term care fits in with the health care proposals that we're going to be looking at this year. Not in future years, but this year.

This is the first issue that I've ever made a proposal on during my campaign for the U.S. Senate. We had the opportunity to have a wonderful hearing on this issue in Wisconsin in November thanks to the good auspices of the Chairman of this Committee which really highlighted the benefit of community-based and home-based, long-term care, in part based on the Wisconsin experience, but also some more general examples from around the country.

I have had the opportunity to spend more time on this particular issue, I don't mean health care in general, but long-term care, more time on this issue than any other issue other than deficit reduction since I have come here to the U.S. Senate.

Let me take this opportunity also to thank the members of the Alzheimer's Association who took the time to attend this meeting in pretty good numbers. There are many familiar faces in the audience and it is especially nice for me to see some of those who helped create our Wisconsin Alzheimer's Program. I was very honored to have the chance to be the author of that program and this

year is the 10th anniversary of our home-based, community-based Alzheimer's Disease Program for Respite in Wisconsin.

There are many different groups that provide skilled advocacy for long-term care, but no group brings more personal credibility and force to long-term care than the members of the Alzheimer's Association and those of us entrusted in ensuring that long-term care is included in the health care package owe them a tremendous debt.

The Chair, the ranking member, as well as the Committee staff, are to be congratulated for an excellent set of witnesses. I appreciate the testimony in advance and we'll have some questions. I want to especially thank Dr. Torres-Gil and Dr. Stone for taking the time to appear before us.

In many ways, the survey results show how much States have already done in providing home and community options and long-term care thanks, in part, to inaction at the Federal level. I look forward to asking some questions about the President's proposed new home and community long-term care benefits.

Even though I support making some changes to his proposal, I want to stress that the President's new home and community-based, long-term care benefit achieves more of what long-term care reform advocates have wanted for many, many years than any other proposal to date. The President's plan is not open-ended, it is not an entitlement, and we cannot afford not to do it. We must do it in order to save money.

That is our experience in Wisconsin, that if you don't do this, you will break the bank on health care reform and that is I think the most critical point in addition to the good caregiving aspects of it. In fact, the other health care reform proposals not only fail to offer the kind of home and community-based flexible benefit that is needed, most of them do not include long-term care at all. It's my understanding that one of the plans in the Cooper bill actually backtracks on long-term care, shifting all of the Medicaid long-term care costs onto the States.

In the heat of the debate, it's easy to get caught up in the detail of the program and to miss the big picture. The big picture here is that we absolutely must have significant, consumer-oriented, home- and community-based long-term care reform as a part of our overall health care package and the President's proposal achieves that. If we don't do that, I'm not prepared to really call it health care reform. It needs to include long-term care reform.

I thank the Chair and I look forward to the testimony of the witnesses.

The CHAIRMAN. Thanks very much, Senator Feingold.

Now, fresh from a field hearing in his home State of Florida, the Honorable Bob Graham. Bob, we welcome you back.

STATEMENT OF SENATOR BOB GRAHAM

Senator GRAHAM. Thank you, Mr. Chairman and thank you for holding this hearing today.

I have a full statement that I would like to submit for the record.

The CHAIRMAN. Without objection, your statement will be placed in the record.

Senator GRAHAM. Just to make a few comments, it seems to me that the issue of long-term care challenges us to redefine and rethink some old concepts. One of those is the difference between sickness and wellness. While we call our system a health care system, it is essentially a sickness system. Enormous benefits are available after you become ill, relatively few in order to maintain a high level of wellness. I believe that is one of the goals of a long-term care program, to assure that people have the early assistance so that they can maintain a high state of well-being.

Second is the conflict between institutional and community-based care, a conflict which I do not believe needs to exist. What we should be thinking about is a continuity of care with the level of care that which is appropriate to the ability of the individual to function in an independent and self-sufficient way, and the provision of services that relate to the gradual effects of the aging process.

Today, we spend over 70 percent of all funds on persons' health care beyond the age of 65 in an institutional setting. That is not to say that the total dollars spent are inappropriate but that we need to begin to refocus on the totality of the aging process and how to provide effective services throughout. We know that the vast majority of older person would prefer to receive services in their homes, in their communities, and we need to make that possible.

Finally, the distinction between medical and social services, the fact is that many of the things that have the greatest medical benefit are today often defined as social services, things such as respite care for the caregiver, home care that allows a person to be able to continue to function in their home. We need to eliminate those artificial and I think defeating distinctions.

I have some concerns as we approach this as a Federal issue. First, as has been referred to previously, particularly by my good friend from Wisconsin, that long-term care needs to be an integral part and not an affectation in a national health care reform effort.

Second, it needs to be accepted as a program of equal dignity in terms of Federal responsibility. It would be a very serious error if we were to segment long-term care and say that it had a lower status in terms of Federal financial involvement.

Third, that we not make the hurdles for participation in long-term care too high or we will result in people reaching a level of disability before they can receive the benefits of long-term care and therefore defeating many of the objectives of early intervention and the maintenance of wellness.

As Senator Feingold said, we have the benefit, as we approach Federal legislation, of drawing on a number of States. I am very proud of the efforts that Florida has made over a number of years through our Community Care for the Elderly Program. Just as Wisconsin and other States, I think it offers a laboratory of real life experience in terms of how to structure an effective long-term care program.

So Mr. Chairman I am very pleased that you are holding this hearing today and look forward to hearing from the witnesses who will enlighten us on this important subject.

[The prepared statement of Senator Graham follows:]

STATEMENT OF SENATOR BOB GRAHAM

Good morning and welcome to today's hearing, "Health Care Reform: The Long-Term Care Factor". I commend Senator Pryor for convening this hearing, giving us the opportunity to discuss the role of long-term care in health care reform.

In addition, I would like to thank the witnesses who will share their experiences with us this morning and our panelists who will offer their insight and expertise.

Long-term care is an integral component of the growing health crisis which will touch almost all Americans. Families are increasingly vulnerable to financial ruin and emotional strain from the devastating cost and burden of long-term care.

As you will hear today's testimony, long-term care needs fail to discriminate in the difficult choices they inflict upon needy individuals and their families. Too often, unanticipated costs and the burden of caregiving financially and emotionally devastate persons with chronic care needs and their families, leaving them without dignity, sometimes ruining years of financial planning efforts.

Long-term care comprises a range of services involving rehabilitative, medical, social and housing components. Care may be provided in the home through home health care, assisted living or delivered meals; in community-based facilities, such as adult care and senior centers; or, in an institutional setting that is also the person's residence, for example, a nursing home or Adult Congregate Living Facility (ACLF).

According to a poll in the citizens in my State of Florida, 86% said they desired care at home. Even when 14-hour care is needed, a 1991 survey by the American Association of Retired Persons found that half of the respondents still preferred home care over nursing home care. Despite this, approximately 70% of all spending on long term care continues to go for institutional care.

Clearly, it is in the interests of all concerned—patient, family, community, taxpayers—to build a system that helps people to remain at home if they prefer and are able to do so. This does not have to occur at the expense of nursing home programs. Instead, it should be achieved by reducing the need for institutional care by increasing the access, availability and quality of home and community based care.

Much of this could be achieved through emphasis on preventive health care, greater use of rehabilitative and social services to maintain and sustain independent living, and recognition of the importance of informal caregivers and seeking to help relieve them from time to time by providing respite care, alternative care arrangements such as adult care centers and other services.

I was pleased to find that the Clinton proposal would create a program for home and community-based care. The program, which would be available to individuals of all ages and incomes, is the first step toward addressing the long-term care needs of the disabled, the elderly, and their caregivers.

Last year, our nation spent an estimated $108 billion on long-term care—over $70 billion of this total amount was government spending. According to recent estimates, long term care expenditures will increase to $250 billion nationally by 2020. The need for action is clear and the cost of inaction is high. For all concerned, our nation must establish a coordinated and coherent policy for long-term care that will undoubtedly require making difficult choices among competing priorities.

I thank the witnesses for their participation. I look forward to a productive discussion.

The CHAIRMAN. Senator Graham, thank you. We can see evidence by the number of Senators who are in the hearing this morning, I must say in and out, once again there are a lot of committees going on at this time that this is an intense issue, the issue of long-term care, as we go forward with this debate on health care reform.

Our next and I think our final presenter this morning is our good friend, Senator Larry Craig from Idaho. Senator Craig.

STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Ladies and gentlemen, I was that person who came into the room and walked up to the Chairman and said, are we still in opening statements? So then, having said it, I have to respond appropriately by asking unanimous consent that my statement be entered into the record.

The CHAIRMAN. Without objection.

Senator CRAIG. And say to the Committee and to all of you, I agree with much of what has been said on the issue.

Let me conclude my comments with the concluding paragraph of my statement. I believe this to be most important as we finalize the debate and our decisions on health care reform and that is what we will be doing here in the next several months.

We must be extremely careful that we do not make promises we cannot keep. It is not feasible for the Federal Government to become the sole provider of extensive, long-term health care coverage. Rather than promising what we wish we could provide, we must work toward sensible, effective reform that empowers the individual, does not complicate it or tie their hands.

I think by concentrating on consumer-oriented programs, we work toward meeting individual needs, recognizing it is not a sole provider we play but a partnership in facilitating.

With that, Mr. Chairman, I look forward to hearing the comments of those who are here to testify.

[The prepared statement of Senator Craig follows:]

STATEMENT OF SENATOR LARRY E. CRAIG

Mr. Chairman, I want to thank you for conducting this hearing today on long-term care. There has been a great deal of discussion and debate regarding health care reform, and I am pleased that long-term care has become a focus in this debate. Families with loved ones suffering from serious disabilities deal with this issue every day, and they can certainly provide us valuable insight by sharing their experiences. I appreciate the opportunity to highlight this important issue and look forward to hearing from the diverse panel of witnesses.

While most of us are familiar with nursing homes and skilled nursing facilities as providers of long-term care, delivery is not restricted to these conventional methods. There are many other ways long-term care is being delivered today. This includes residential care facilities, in-home nursing, and family-provided care in the home. All of these components of delivering care are important in meeting the needs of the individual. The delivery of care, whether in a nursing home or patient's home, should be chosen by the patient and their family in order to meet the needs and desires of the individual requiring care.

Due to the varying degrees of disabilities and health care accessibility, any reform proposal must allow flexibility in providing long-term health care. However, the burden of providing care should not fall solely on the Federal Government, preventing a lively, competent, private sector from making practical contributions. By adopting programs that allow refundable tax credits and medical savings accounts to be used for various health care options, consumers can make decisions to meet their individual needs. In short, we need to focus on education and empowering people.

As the health care debate progresses and we begin to finalize decisions, we must be careful not to make promises we cannot fulfill. It is not feasible that the Federal Government become the sole provider of extensive, long-term health care coverage. Rather than promising what we wish we could provide, we must work toward sensible, effective reforms. By concentrating on consumer-oriented programs that meet the needs of the individual, I am confident we can make great steps toward solving the problems of long-term health care delivery and ease the minds of those who need long-term care and their families.

I am interested in hearing our witnesses' thoughts on these ideas and any other insights they can provide on this problem today.

The CHAIRMAN. Senator Craig, thank you. I thank all of our colleagues for their very good testimony this morning.

We're going to move to panel one: Dr. Fernando Torres-Gil, Assistant Secretary for Aging in the Administration on Aging, Department of Health and Human Services. We deeply appreciate your attendance this morning.

He is accompanied by Dr. Robyn Stone, the Deputy Assistant Secretary for Family, Community and Long Term Care Policy, Department of Health and Human Services.

Dr. Stone, we are very proud that you are here with us.

Also seated to Dr. Torres-Gil's right is an old friend, a good friend of this Committee, a former member of its staff, a very distinguished member Mr. Bill Benson who is today the Deputy Assistant for Aging in the Administration on Aging. Bill, we appreciate your being here with us and accompanying our distinguished panel this morning.

Dr. Torres-Gil, I'm going to attempt to try to see if there is a way for your statement to maybe consist of not more than 10 minutes and then we will have questions for you and then we will move to our next panel. We certainly appreciate you coming.

STATEMENT OF HON. FERNANDO TORRES-GIL, ASSISTANT SECRETARY FOR AGING, ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY DR. ROBYN STONE, DEPUTY ASSISTANT SECRETARY, FAMILY, COMMUNITY, AND LONG-TERM CARE POLICY, DEPARTMENT OF HEALTH AND HUMAN SERVICES, AND WILLIAM BENSON, DEPUTY ASSISTANT SECRETARY FOR AGING, ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Assistant Secretary TORRES-GIL. Thank you very much, Senator Pryor.

It is indeed a pleasure to be here before your Committee and I will keep my comments to a short 10 minutes. We certainly want to hear both from the members of your distinguished Committee and certainly from the witnesses. I will submit my testimony for the record and summarize my comments. Let me thank all the members of the Committee.

Senator Burns, I certainly understand and agree with the importance of going beyond the Beltway. One of the first trips I took when I was confirmed was to Montana and I learned very quickly the importance of rural issues and transportation. That has been very much with us since that time.

I might also add, Senator Riegle, we certainly agree with you about the distinguished leadership of Senator Pryor. As I mentioned to you, a year ago, Senator Pryor, when I first came before you, I teach gerontology and social policy and aging and as part of our history books on aging, Senator Pryor's involvement, especially in the early Congressional investigations that led up to the formation of this Committee is part of that story.

This is not to say you're history, Senator. You are the future and part of what we are going to be doing, but you are now well known in terms of what has gone on in the past, and so we thank all of you for what you have done.

I do have some good colleagues, as you mentioned, such as Dr. Robyn Stone, who can address the detailed specifics of the President's Health Security Act and its long-term care provisions. I might add, Senator Feingold, when I was here a year ago, we didn't have that proposal fleshed out in any detail at that time. I hope you and the other members will feel that we tried to strike a bal-

ance in terms of the approach and the proposal itself. We can go into that in greater detail if you wish. Of course also with me is Bill Benson, who handles program operations at the Administration on Aging.

I would like, as part of my testimony, to address some of the issues and some of the steps we are taking because when I was here last time, you asked and we committed ourselves to making long-term care one of our several priorities in the work of the Administration on Aging.

Let me state a few points which you will hear in great detail from the witnesses. Clearly long-term care is desperately needed, but it is also in need of reform. In many respects, it is the next frontier in terms of health care and domestic concerns. For too many of America's families and individuals with disabilities, they face difficult choices, whether it is expensive care in the home, which as Senator Bradley pointed out can be as much as $40,000; whether it is impoverishing one's self to become eligible for Medicaid or whether one must rely on informal caregivers who too often have to face the emotional, financial and physical costs of balancing out jobs and family needs as well as caregiving. Certainly what we might call a long-term care system today is fragmented, complicated, and not evenly available for all who need it.

I might also add, however, that the demographic imperative will absolutely require that we address long-term care sooner than later. With the doubling of the older population, a tripling of the group 85 and over, and with growing numbers of persons with disabilities, we know that this is now the time to begin to build that infrastructure. We certainly hope the Congress will choose to include the President's long-term care provisions in the final health care bill. That is certainly your decision and we stand ready to provide you with whatever information you may need in that respect.

Certainly we hope that we will over time have a continuum of home and community-based services which provides choices for families and individuals to stay in the home, to be in the community, or where necessary, to afford good and quality nursing home care. The President's proposal certainly focuses on the home and community-based side.

The President's proposal, and Robyn can get into it in detail if you wish, includes four or five critical features: a new State capitated home and community-based program that allows States, for the very first time, to develop their own tailored system of home and community-based services; we do rely on the use of ADLs as well as focusing on those with severe disabilities who are cognitively disabled or mentally retarded, or are developmentally disabled to focus on those who truly need it immediately.

We look at private insurance and reform of the private insurance market because we feel the private sector continues to play a role, and should have a role, but we want to ensure that it is done in a way that provides quality, consistent, and affordable private insurance.

We also have focused greatly on the needs of persons with disabilities and, as one person with a disability, I certainly look towards the tax credit which will allow many of us who wish to work to continue to do so and receive a tax credit. We have also provided

some liberalization of the Medicaid Nursing Home Program. We are going to phase-in this system over 5 to 7 years. Certainly one issue is the cost. We don't have the money immediately but we want to provide approximately $56 billion over the first 5 years.

We also want to phase in a system so that we can learn from it and we can build on the best innovations at the State level. We can ensure, hopefully, as Senator Graham pointed out, that it is based more on the social model, as opposed to a medical model, but that it blends in the best of both of those systems.

That is a quick, overall summary of the President's plan. If I can, for the next few minutes, I'd like to lay out what we are doing in the Administration on Aging to complement what the President is proposing and the work that we are doing in the Department of Health and Human Services in the area of long-term care.

Last year, when I came on board, we made the issue of long-term care one of our priorities in AOA. Since that time, we have been focusing on four objectives. Those objectives and our long-term care agenda build on one of the ready infrastructures that, should the Congress decide to have long-term care, can be quickly utilized. That is the aging network, the 57 State offices or units on aging, the 670 area agencies on aging, the over 27,000 service providers who are already providing community-based services, and over 225 tribal organizations.

This aging network draws on much of our funds from the Administration on Aging and the Older Americans Act as well as other sources. The President's long-term care plan draws on the many State innovations. It draws on the lessons that we have learned in providing community-based services; it draws on our involvement with the consumer; and the President's plan requires that any long-term care plans draw on the ombudsman and elder rights protection programs of the Older Americans Act.

The four objectives include building strategic partnerships, and that is certainly important in what we are doing in AOA and in the President's plan, because the fact is there are many players now providing different forms of home and community-based care. We certainly look toward the private sector and rely on their expertise and their concern about elder care; we're going to look to the use of volunteers; and we have a priority area in our discretionary funding program to provide volunteer service credits. We now also have a Business and Aging Leadership Roundtable that reflects the private sector's experience in addressing the long-term care needs of their employees and retirees.

One of the purposes for elevating my position to Assistant Secretary, which the Secretary, the President and you wished to occur, is to ensure that AOA was able to work closely with the Health Care Financing Administration, the Public Health Service, and the Social Security Administration. We are doing so and certainly long-term care lends itself well to that.

We are also working very closely to enhance the capability of our aging network, and we are providing additional funds for them to do so and to be equal partners in whatever expansion we might have.

We intend to work with Congress to help improve the regulatory and legislative climate, and we certainly hope that we have long-

term care in the final health care reform package. We will work closely with you in its implementation.

We will promote and protect consumer interests and choices in any long-term care plan and certainly in the President's plan, and we are doing so in AOA by incorporating features in terms of quality assurance and ensuring the protection of individuals who will receive those services.

I might add, for Senator Bradley who was here earlier, he mentioned the case of how an individual trying to find services. As part of our focus on the consumer, we have a very successful National Elder Care Locator Program, which is an 800-number established by my predecessor which has, at this point, over 3,000 callers a month who use that service. I'm happy to report that we will be continuing it.

In conclusion, our last objective is to build the capacity of AOA and the aging network to work with Congress on whatever proposals you might develop. The results of the survey that I detail in my written testimony, provide, I believe, striking evidence that the aging network is already a major player in providing home and community-based services.

You have in the testimony a variety of data. For example, 16 of our State units on aging already have program and policy responsibility for the disabled and 9 State units provide waiver programs for the disabled; 41 percent of our State units on aging utilize the Medicaid home and community-based waiver to bring in additional dollars. Almost all of our State units on aging use a variety of funds—general revenue, social services block grant, Medicaid dollars, as well as the Older Americans Act. So they are ready, they have the experience, and we will be helping them by providing enhanced technical assistance and capacity to ensure that there is more of an evenness in terms of capability and quality.

I might finish by saying there are other priorities in the Administration on Aging in addition to our important programs. We have a priority focusing on older women as caregivers; they are an important part of providing the informal long-term care services. Nutrition and malnutrition, is a priority because we know that having food and good nutritional habits is an important way to stay healthier.

Lastly, we're going to be preparing a blueprint for looking ahead at the aging of our society. Certainly one of the great needs for our aging baby boomers will be having a system of home and community-based long-term care services.

I thank you, members of the Committee and Senator Pryor, for this opportunity to provide this information, and we certainly support your efforts to enhance visibility of this very important topic.

[The prepared statement of Assistant Secretary Torres-Gil follows:]

TESTIMONY OF FERNANDO M. TORRES-GIL, ASSISTANT SECRETARY FOR AGING, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman, members of the Committee. It is a pleasure to be here with you today. It has been almost a year since I last presented testimony before your Committee. At that time, I testified on the subject of the aging network and linking older Americans to home and community based care. Today, I am please to be re-

porting to you on the tremendous progress of the Administration on Aging's (AoA) home and community-based long-term care agenda since that time.

The need for reform of the long-term care system has finally arrived as a national issue in the consciousness of the American people. No longer is it just an issue for the professionals in the fields of gerontology, social work, health and government. Now, more than ever before, the American people are involved with a better understanding of the stakes involved.

We all know that the existing system of home and community-based care falls short of meeting the needs of the many people who need help. The current system is complex and fragmented. Public and private programs are, for the most part, uncoordinated. It is difficult for elderly and disabled persons who need such services to navigate the system. It makes it very difficult to coordinate such a system and use resources efficiently.

The ideal system of long-term care is a continuum of services which includes home and community-based services as well as institutional care, housing alternatives such as assisted living, transportation and other social services. The system should feature a single entry point where local organizations coordinate care and control resources, basing eligibility and access to services on people's needs.

As you know from my previous testimony, shortly after assuming the office of Assistant Secretary for Aging, and in response to Secretary Shalala's request, I designated long-term care as one of AoA's four priorities. A Long-Term Care Work Group composed largely of volunteer AoA staff representing virtually every unit in AoA, spent many long hours deliberating and developing our agenda. I personally want to express my appreciation to the AoA Long-Term Care Work Group for their commitment to this effort.

The AoA home and community based long-term care agenda is a comprehensive series of plans and activities for the continued development of consumer-driven home and community-based systems of care for persons who need services. It includes plans to work with other agencies and organizations that are interested in promoting home and community-based care. We view it as an ongoing multi-year effort.

Its objectives support the President's health care reform plan and it provides us with a road map to do things that need to be done even in the absence of national legislation. There are four major objectives which I would like to briefly review:

Build strategic partnerships between public and private sector organizations at the national, State and local levels to expand home and community-based systems.

Promote maximum flexibility in the development of comprehensive systems consistent with the traditional advocacy role of AoA and the aging network.

Promote and protect consumer interests and choices in the provision of Home and Community-Based Care (HCBC).

Build the capacity of AoA and aging network staff in the field of Home and Community-Based Services (HCBS) programs.

Under each of these four broad objectives, a whole series of major steps and activities are taking place or will take place over the next two to three years. These activities have required significant decisions by AoA to commit staff and resources and my job has been made easier by the excellent staff work that has gone into this process. I would like to discuss some of the important work and accomplishments achieved to date in the implementation of the AoA home and community-based long-term care agenda. I have selected a few examples:

OBJECTIVE 1—BUILDING STRATEGIC PARTNERSHIPS

Rationale

In an era of diminishing resources, it is essential to collaborate with others if resources are to be maximized and efficiency achieved in the delivery of human services. There are many players involved in the financing, organization and delivery of home and community-based systems of service. They include Federal, State and local governments, private non-profit organizations and the business community.

Work Underway

The Private Sector Management Committee is being revitalized and renamed the Business and Aging Leadership Roundtable. A Planning Committee meeting for a new roundtable was held on April 5. The first meeting of the roundtable is being convened May 27 to coincide with Older Americans Month. We are also strengthening our efforts to increase the supply of human resources for home and community-based care on a number of fronts:

A Volunteer Services Credit priority area will be included in the 1994 Discretionary Fund Program (DFP) announcement. New models will be developed and ef-

fective existing models will be replicated. The basic service credit concept is to give volunteers a unit of credit for each service hour performed, regardless of the type of service, in the expectation that accrued credits will be redeemed for services by the volunteers at some future time of need. A primary focus will be on home and community-based services that help at-risk elders to continue to live in their homes;

We met on March 29 with the Corporation for National and Community Service to discuss possible joint initiatives;

A meeting was held on March 22 with Generations United to discuss intergenerational programming in relationship to HCBC; and

The National Eldercare Institute on Employment and Volunteerism is convening a Roundtable on Senior Volunteerism today to discuss the future of volunteerism and aging.

We are cultivating a number of joint ventures with other Federal agencies both within the Department of Health and Human Services (HHS) and across the Government:

We are working with the Office of the Assistant Secretary for Planning and Evaluation, HHS, on a study of assisted living as well as an evaluation of the elderly nutrition program;

We are working with a number of HHS agencies on the health care planning group to coordinate activities within the Department on health care/long-term care;

AoA and the National Institute of Aging (NIA) are planning to convene a conference next month on self-help for the elderly;

We have met with officials of the Federal Transit Administration at the Department of Transportation (DoT) to strengthen transportation systems for the elderly, and we are participating in a newly revitalized HHS–DoT Coordinating Council.

Today we are meeting with Housing and Urban Development (HUD) officials to re-establish a working relationship, which has been dormant for far too long, with the important housing and supportive-services programs which HUD administers.

We are also reaching out to other organizations and groups which share our concerns and interests in long term care. We have a particular interest in strengthening our ties to the disability community. We have some meetings planned in the near future which will focus on identifying common concerns and issues. We also expect to fund some projects through the FY 1994 DFP for development of model projects for coordinated service delivery.

OBJECTIVE 2—IMPROVING THE REGULATORY AND LEGISLATIVE CLIMATE FOR CHANGE

Rationale

We recognize that the complex array of programs, each with their separate eligibility requirements, makes it difficult to coordinate programs and resources and provide needed services to those in need.

Work Underway

We will shortly begin to develop legislative amendments for the next reauthorization of the OAA. We are also determined to share with Congress as much information as we have regarding programs for home and community-based care. Just a few days ago we provided a briefing to staff of this Committee on the AoA survey of home and community-based care. Later, in my testimony I will speak more about what we learned as a result of the survey.

OBJECTIVE 3—PROMOTING AND PROTECTING CONSUMER INTERESTS AND CHOICES

Rationale

Home and community-based care is the choice most people and families want. To achieve a comprehensive, high quality and responsive system we must have effective models which promote consumer participation in the design and delivery of services. Individual service providers, Area Agencies on Aging (AAA) and State Units on Aging (SUA) are already developing such models. AoA can play a vital role by facilitating on a national level the development of a cohesive strategy for involving, protecting, and advocating on behalf of consumers.

Work Underway

We are working with the Cherokee Nation to replicate the PACE (Program of All Inclusive Care for the Elderly) model in a rural, reservation setting. We are also exploring the use of the long-term care ombudsman model to monitor the quality of home and community based services:

We are monitoring the Institute of Medicine evaluation of the long-term care ombudsman program. AoA staff will be discussing results to date at the Ombudsman Resource Center Annual Training Conference in San Antonio, TX, April 23–27.

We will be meeting with the five housing ombudsman demonstration projects this fall.

The National Center for Elder Abuse is providing technical assistance to State Units on Aging in the prevention of elder abuse, neglect, and exploitation.

The National Long Term Care Ombudsman Resource Center is providing technical assistance to State Units on Aging to strengthen advocacy for residents of long-term care facilities.

We will continue to fund the National Eldercare Locator Program to assist consumers to locate needed home and community-based long-term care.

OBJECTIVE 4—BUILDING CAPACITY OF AOA AND AGING NETWORK STAFF IN HCBS PROGRAMS

Rationale

If the aging network is to continue playing an influential role in the development of home and community-based systems of care, it must further develop its expertise and knowledge. We have taken a number of important steps to achieve this objective and I would like to discuss two of them.

Work Underway

Promote Knowledge Sharing

We are going to establish a capacity-building, mentoring program in which a system will be set up to use the expertise and knowledge of State and Area Agency on Aging staff who have demonstrated leadership in creating innovative systems in their States to provide peer consultation to States which have a commitment to improve their systems. This will be done through a multi-year cooperative agreement. And, in January we conducted a very successful Health Care University for the aging network in which the latest information about health care reform and survey data was provided.

AoA National Data Base on HCBC

I would like to discuss a few of the highlights from the data acquired through the AoA survey of State HCBS program. Materials are available which provide a fuller picture of our analysis to date. I also want to emphasize that we are continuing to analyze and refine the data and will publish additional analyses. The survey was a major initiative designed to establish a data base on State infrastructure for HCBS. It has increased our understanding and knowledge of what's happening at the State and, to some extent, the local level. The focus and scope included:

The impaired elderly receiving home and community services

State administered programs

Period of analysis—FY 1992

Subjects included: Governance/policy making; services and service expenditures; access/care coordination mechanisms; contracting methods; and review of State general revenue programs.

The survey was designed to achieve certain goals which would describe the State HCBS infrastructure for the impaired elderly; review the aging network's involvement in HCBS infrastructure; review State readiness for LTC reform; establish AoA priorities for support and advocacy; encourage data base development on State-administered HCBS for the elderly and disabled, and support long term care reform efforts both at the State and national levels.

State Level Policy Making Mechanisms in Place

47 States have some type of policy-making mechanism in place;

163 separate mechanisms were identified over a broad range from policy making councils to interagency agreements to regular interagency meetings;

22 States have a formal long term care council/task force and,

17 percent of the policy mechanisms focus on the elderly only.

HCBS Resources/Expenditures

The survey focused on the major publicly funded programs such as Medicaid (State plan and waiver), Social Services Block Grant, (SSBG), the Older Americans Act (OAA) and State general revenue programs plus match outlays. Medicaid includes estimates for the elderly portion.

We estimate total U.S. HCBS FY 1992 expenditures for the elderly by major public programs at $6.45 billion.

Two States account for 56% of the total—NY—$2.8 billion and CA—$777 million.

The remaining States spent $2.86 billion in HCBS expenditures for the elderly.

We found that State General Revenue Programs are a significant source of support for HCBS

There were a total of 153 State funded programs reported.

Total outlays were $702 million which is 11% of the total U.S. expenditure, and 24% if New York and California are excluded. (New York and California have disproportionately high expenditures—NY $2.8 billion with $2.5 Medicaid Personal Care, and California $777 million with Title XIX State Plan of $342 million, and SSBG, $376 million) (Funding Sources: Medicaid State Plan, Medicaid Waiver, SSBG, Older Americans Act and State General Revenue).

Nationally a large majority of these State-funded programs are administered by State Agencies on Aging—73%.

A wide variety of services are being funded by State general revenue programs including: Home delivered meals, personal care, transportation, home health aide, homemaker/chore, adult day care, respite care, and access-related services.

Other frequently provided services include case management, home health nursing, home repair/modifications and phone reassurance/companion.

The average funding level (153 State funded programs) was $4.6 million.

81 programs had annual expenditures of less than 2 million.

Service Access / Coordination of Care

Access and care coordination is a key policy issue as reported by 29 States. There is notable movement by States to adopt a single entry point concept—16 have done so and 3 additional States have adopted concept as a strategy to implement. Of the 16 which have adopted single entry point—13 are Statewide in scope frequently using common funding sources (waiver, State funds, etc.). Local administration is mixed.

State General Revenue Funds Programs Eligibility Criteria

We find that States are targeting their programs to an impaired population. 80% of the 153 programs use some form of functional eligibility criteria. Many programs link eligibility to Activities of Daily Living (ADL)/Instrumental Activities of Daily Living (IADL).

States are using different approaches for financial eligibility including Medicaid/SSI eligibility, cost sharing and State-defined thresholds.

Role of the aging network in State-Administered HCBS—A Profile of SUAs

The role of the aging network in the administration of home and community-based care programs is quite significant;

31 SUAs are part of a broader human service agency;

SUA responsibilities go well beyond the OAA: Waiver programs for disabled—at least 9 SUAs; policy/program management responsibility for disabled—16 SUAs; adult protective services—22 SUAs; and State General Revenue programs—48 SUAs.

Many SUAs have administrative responsibilities for Federal programs: 6% administer Medicaid State plans; 41% administer Medicaid waivers; 22% administer SSBG; and 98% administer at least one State General Revenue program.

Our analysis of the data from the AoA survey to date provides new insights about the impressive efforts States are making to develop comprehensive systems of long-term care for home and community-based services for the elderly and the disabled. I am particularly impressed with the role of many State and Area Agencies. Our survey and studies have provided much insight into how the States are progressing to reform their systems and are preparing to take on the tasks of long-term care reform as proposed by the Administration.

As I noted in my opening comments, the AoA home and community-based long-term care agenda, which we will be pursuing, supports Federal and State efforts at reform, strengthens the capacity of States to plan and implement improvements in their systems, and will assist States that are not as far advanced to develop new approaches and systems of care. I think it's fair to say from my testimony that the aging network is working on a broad, comprehensive front on long-term care reform, at the Federal, State and local levels.

Thank you for inviting me to share with you our ideas, programs and information on this vital topic of concern.

The CHAIRMAN. Thank you for your very fine statement. All of your statement will be placed in the record and we very much appreciate it.

We're going to use the 5-minute rule in questioning. We hope all of our members of the Committee will help cooperate in this be-

cause we have a very, very large panel of witnesses which will follow this particular panel.

I'll open with a couple of questions, if I might. Under the Clinton Health Administration Reform Plan, it looks to me like there is going to be a broad new home and community-based care benefits package for disabled individuals of all ages, not necessarily just the elderly. Even without the expansion of publicly provided services, we know that our current long-term care work force is very inadequate. We wonder how we're going to address this concern about an inadequate work force, not only in terms of inadequate numbers but inadequate training and skills.

Perhaps Robyn Stone or yourself or Mr. Benson, or anyone who would like to talk about this work force out there to provide these health care services?

Assistant Secretary TORRES-GIL. Certainly, Senator Pryor, you have raised one of the critical implementation issues, if I can use that bureaucratic term, of who will provide the actual jobs. We know there is tremendous diversity and variation in terms of the compensation, rewards, status, and training and quality monitoring of the many, many men and women who provide some of the hands-on work.

Let me ask Dr. Stone if she would like to address that issue or Mr. Benson.

Dr. STONE. Yes, Mr. Chairman, I think I can address that. First of all, I think it is important to recognize that we estimate that the long-term care provisions of the Health Security Act may create as many as 1 million new jobs in the home care industry. We see this as a very, very important piece in terms of the economic contribution of the Health Security Act to the economy in general. I think that is the first point to be made.

The issue has to do with one, we're talking about tremendous amounts of new infusion of dollars into the system. Where dollars are, providers go. We saw that with the nursing home industry and I believe that we will see a home care industry that has already been growing, explode over the next decade.

I should also say that it will not only be in the home care industry, we are also talking about the possibility of tremendous growth in assisted living because these services can be provided in any kind of residential setting other than an institution. We expect that this will be an incentive for States to start using other kinds of residential care alternatives.

With respect to the points around are we going to be able to provide an adequate and trained work force, there are some pieces in the Health Security Act that begin to get to this and that is recognition in graduate medical education training that we need to take a look at the paraprofessional work force, not just physicians and nurses, but also pay attention to the frontline workers, the home health aides, the nursing home aides, the people who really do provide personal care and attendant services as well as other kinds of nonskilled services.

So there is a recognition in the bill that we need to begin putting dollars into training these types of workers, and also to explore a number of alternatives with career ladders, other incentives, not monetary incentives for the workers so that they will have the mo-

tivation to continue working so that we can cut down on turnover rates and so that we can provide an adequate work force.

You might want to speak a little bit about some of the AOA efforts in that area.

Mr. BENSON. Thanks, Dr. Stone.

Senator Pryor, just very quickly, we recognize that the work force issues are so compelling and so large that we really have to move forward on all fronts to address them. So, in addition to the things that Dr. Stone has mentioned, we are beginning discussions with the Department of Labor to look at a lot of work force issues that we might collaborate on. The Assistant Secretary will be meeting shortly with Eli Siegel from the National Corporation for Community Services to talk about their endeavors and how they may address some of the work force issues in long-term care. We've used our discretionary funds to fund some demonstration projects ranging from apprenticeships for homecare workers and ways of looking at quality assurance with the work force we have today as well as in the future.

The CHAIRMAN. Thank you, Mr. Benson.

My time is about up so I won't ask another question but when my time does reoccur, I'd like to ask a few questions about the States' role. We have two former Governors here today and I think we would be interested in hearing what the States have to do.

Mr. BENSON. And we do work for a former Governor.

The CHAIRMAN. You do work for a former Governor, that's right.

I believe Senator Burns is next. Senator Burns.

Senator BURNS. Thank you, Mr. Chairman.

I thank you for your testimony this morning. I noticed in your testimony, Mr. Torres-Gil, you are seeking to put together joint ventures across government between government agencies and government lines, you say with other Federal agencies both within Health and Human Services and across other government agencies. I think probably it was alluded to that you're starting to work even on the training of new professionals in the field.

Have you taken a step outside of that and said, what about joint ventures with the private sector?

Assistant Secretary TORRES-GIL. In terms of the private sector, as you can see from the testimony, we are now having some active discussions with the group we formed called the Business and Aging Leadership Roundtable. We have, I think, a good history of working with the private sector. For several years now, we've had our Eldercare Services Program to work with employers and employees, because of the rapidly growing number of individuals who have to take time off to take care of an older relative or younger disabled person. We have worked closely with them to help them and to promote an awareness of this issue.

There is much more we can do, and I certainly hope at least through the Administration on Aging that businesses, large and small, employers large and small, would at least know that with AOA and the work we are doing, we want to incorporate their concerns. We are just beginning to do so and to come up with ideas of how much more we can go beyond the Business Roundtable, the elder care projects that we have been doing.

I'd like to also ask Bill Benson to address that and he can add some more specifics.

Mr. BENSON. Senator Burns, Assistant Secretary Torres-Gil will be chairing a meeting of the Business and Aging Roundtable in May at which a number of the leading corporations that are really struggling with the issue of providing either services or access to services for their workers, for their dependents, for their retirees—to long-term care services of one kind of or another. IBM, AT&T, and a variety of other companies from different sectors of the economy will be coming together in Washington, D.C., to spend several hours in May to begin a process of figuring how we can collaborate with the business community to build on some of the fine efforts they are doing, as well as their need to look to Government to help them relieve some of the tremendous burdens they are facing in this area.

Senator BURNS. At my hearing in Montana, we sort of turned up the thing of training people. In order to really put home health care—this was basically dealt with in the home because I'm more familiar with that because of my wife's father and of course with my parents. I like to use real life examples, if I could.

Have we explored the situation of not only training these paramedicals and getting some people out there that know what they are doing but how we reimburse those people? In other words, right now we have different levels of reimbursement and they are all sort of performing the same service, but they are being reimbursed at different levels?

Assistant Secretary TORRES-GIL. I think that both services are being reimbursed at different levels and from different pots of money so it becomes quite complicated, especially with eligibility criteria and means testing in some and no means testing in others. I'd like to ask Dr. Stone to speak to this. We address it in part, sir, in the President's long-term care bill. Robyn.

Dr. STONE. I just wanted to speak to that point. I think one of the most important contributions of the Clinton proposal is its flexibility in terms of what kinds of providers can be used. For example, it is not necessarily the case that you need a Medicaid-certified home health aide to go into a home to provide personal care, homemaker chore, and those kinds of services. It's a very expensive mechanism and there are opportunities in the Clinton proposal for States to use a whole variety of providers, including, by the way, independent providers as well as paying family caregivers.

We believe that this gives an opportunity to really pay attention to the needs of the beneficiaries and to try to address them appropriately with workers. On the other hand, we also recognize that the frontline workers, for example, personal care workers and homemaker workers, are the poorest paid and generally tend to have very low benefits, if any benefits at all. We are hoping that the Health Security Act, number one, will ensure that all of these workers are covered for health insurance which is critical.

In addition, we will be begin to raise the esteem and the level at which these folks are being looked at and the reimbursement mechanisms then will begin to address their needs as well.

Senator BURNS. I'm not going to let you get off the hook here because when you said a million new jobs, we've batted around a lot

of numbers here in this place and number one, I want to ask you this because I've got to go. Where are those jobs now and will these be government jobs or private sector jobs? Who pays?

Dr. STONE. The new jobs are jobs that currently do not exist because we are talking about a tremendous expansion of home and community-based services. In that sense, if you look at what kind of home and community-based care is provided now, generally, there are a number of States that have substantial programs. Aside from that, we really are talking about a very paltry program out there for home and community-based care. So we are talking about tremendous expansion in home and community-based services.

Senator BURNS. You're talking about a tremendous expansion in Government, aren't you?

Dr. STONE. No, these are not Government jobs. For the most part, these will be jobs in the public sector. States may contract with the private sector, they may contract with nonprofits. The opportunities are there in the private sector for the expansion of these types of jobs. As I said, there are opportunities as well for the expansion in assisted living which is, for the most part, a proprietary industry.

Senator BURNS. Thank you.

The CHAIRMAN. Thank you, Senator Burns.

Senator Feingold.

Senator FEINGOLD. Thank you, Mr. Chairman.

Just following up on the last question, I would just comment that in Wisconsin, where we have a community options program that services thousands of people, it is run by just a few people in the State Government, a handful, and is administered primarily through the counties with substantially State funding and through a great deal of private effort. So I certainly would lend credence to Dr. Stone's remarks.

I'd ask any of you about a major population needing long-term care services that we have had experience with in Wisconsin is individuals with severe and long-term mental illnesses. In Wisconsin, we include this population in our State-funded home and community benefit and they make up about 10 percent of the population using the overall services of the Community Options Program and they use about 8 or 9 percent of the budget.

In addition to helping fund community support programs, the program has also provided assistance for paid roommates or neighbors, supporting housing, respite care and other long-term support services.

Some advocates for the mentally ill have suggested that the eligibility requirements for the new long-term care benefit might not be appropriate for many with severe and long-term mental illnesses. They cite, for example, the requirement in the proposal that an individual meet the eligibility threshold for those with a cognitive or mental impairment for at least 100 days.

How would some with a severe and long-term mental illness become eligible for the new benefit, especially if that illness were episodic?

Dr. STONE. Let me say at the outset, this is a program that is targeted to persons of all ages with the most severe disabilities. We recognize right up front that not every disabled person in the coun-

try will be eligible for this program, including persons who are chronically mentally ill. We frankly have heard concerns expressed from a variety of other groups as well, why didn't we use a 2+ ADL limitation rather than a 3+ ADL limitation. You can hear these problems from all of the groups. I'm very sympathetic to it. However, this is a prudent proposal that tries to keep the costs down and that is really targeting formal dollars, formal services to those most in need.

Having said that, we believe that a substantial population of chronically, mentally ill could be eligible for this program through the four criteria that we have set forth. That is, there are a number of chronically, mentally ill folks who would be eligible through the 3+ ADL limitation because it is a very broad definition. It includes supervision and queuing. That means not just that they can't dress or bathe or do other activities, but that they need supervision or they need some kind of queuing in order to motivate. We believe that this is an area where some chronically ill folks would qualify. In addition, there are severe mental impairment eligibility criteria which is an avenue for the chronically mentally ill.

As I said at the outset, with respect to concerns about the chronically mentally ill, we've heard those concerns from all groups of people with disabilities. The fact is we had to make some choices and we believed it was most prudent to target to the most severely disabled where families were most at risk and were breaking down. We recognize that there are some issues for all of the disabled population around this program.

Assistant Secretary TORRES-GIL. I might just add, Senator, we had to make choices and try to afford what we can start off with, but this is also on top of any other dollars that may be available at the State or Federal level for those who are developmentally disabled, frail, or chronically ill. This is in addition to what else might already be available. We certainly hope it will complement the dollars that are available.

Senator FEINGOLD. I appreciate your comment. I believe that there is a potential here, under one of the two approaches for somebody who is severely mentally ill to benefit but I think there may be room for yet another basis for eligibility.

We are real concerned in Wisconsin that our successful community support program, a State program which has also benefitted from some Federal dollars, could no longer function effectively and it has been effective much like our community options program, cost effective as well as effective for the individual. So I hope there will be openness in terms of some adjustment in that area, with an eye to the cost, with an eye to a net positive result.

Another question has to do with the co-payments in the President's proposal. The co-payments for services in the long-term care program are kept at 25 percent, but there is no overall cap on the cost to consumers. For some disabled individuals, this could result in substantial cost. Has the Administration discussed possible overall cost limits for consumer co-payments?

Dr. STONE. We have certainly explored putting a cap on and at this point, the belief is that we have entertained putting on an overall cap, for the most part, we are talking about the majority of these folks. A large majority of them will be at the 150 percent

poverty and under level and that the 10 to 25 percent picks up another major chunk, so there is really only a small minority of folks who are over that threshold to pay over 25 percent co-payment and that the out-of-pocket costs that they would be responsible for would not be exorbitant.

On the other hand, we are open to working with Congress in terms of helping to provide technical assistance around the possibilities of putting an overall cap on and seeing what the expenditures outcomes would be for doing that.

Senator FEINGOLD. My time is up for now but let me just say that my questions are in the spirit of fine tuning and improving what is a very courageous and very good proposal. We're just trying to get down to some of the specifics.

Mr. Chairman, thank you.

The CHAIRMAN. Thank you, Senator Feingold.

Senator Graham.

Senator GRAHAM. My questions are both in the same spirit as Senator Feingold's and also in the same general areas.

I'm concerned about the eligibility requirements from the perspective of particularly the aging individual who is beginning to encounter the first losses of functioning and therefore is in need of some support. The concern has been expressed that if the hurdles, the thresholds for participation in the program are such that a person has to degenerate to a relatively advanced stage of disability before any services are available, that will aggravate both human suffering and the extended cost of providing services.

I wonder if you could give us some of both the philosophy as well as the economics that led to the standards of eligibility that are in the President's proposal?

Assistant Secretary TORRES-GIL. Let me address at least the philosophical approach and ask Dr. Stone to address some of the specifics.

As we mentioned, we are mindful that not everyone that wants or needs or should have access will be immediately eligible for it. I think we estimate that approximately 3.1 million persons will be eligible, two-thirds older persons, and the remaining persons with disabilities, the younger disabled.

Again, because we are mindful of the costs and we wanted to make sure the balance sheet was set and well laid out, we realize that there are other ways to take care of those who may not quite fit the eligibility criteria. For example, States are going to save quite a bit of money in their Medicaid budget with this new program. In addition, the Older Americans Act, as you may know, provides many of those social and supportive services for people that have some level of frailty but may not quite be eligible.

With the President's proposal, should it be adopted, it should free up more money for those individuals under the Older Americans Act. It also may free up dollars from the Social Services Block Grant Title XX of the Social Security Act which provides much in-home support services. So with the President's plan, we capture many of those who most need it, and it helps to free up dollars in the other existing pools of funds. Again, these are all tough choices, Senator Graham, and we are just trying to make the best use of

the limited dollars and target first those who most need it. I think that is the philosophical approach.

Robyn.

Dr. STONE. Let me just give you the sort of dilemma that we faced. We are talking about a capped program. That means that there is a fixed budget and the State needs to operate within that budget. The State has two choices. We could either have a targeted set of eligibility criteria for those most in need or we could have a much broader set of criteria that would allow folks with lesser disabilities into the program.

The problem is if you do that, you end up basically giving everybody a $1.99 benefit. That is not what we wanted to do. If you expand your eligibility pool, given the fact that you have a capped program, and you don't have anywhere to go, you have to work within that capped program, you can only do one or two things. You can cut back on the people that you serve or you can cut back on your services. We believe the way our budget is estimated, it is a generous budget that is based on the cost of serving this number of severely disabled people at the level that they need service.

If we went to a broader set of disability criteria, we do not believe that we would be able to serve all of those people well.

One other point that I would make, and I think there is a lot of rhetoric around how much home care services helps to prevent the degeneration from one ADL to three or more ADLs. The fact of the matter is that we have not found a tremendous amount of empirical evidence to support that kind of prevention. So we do not believe that is an argument for opening up this program to lesser disabled folks.

Senator GRAHAM. You say you have not found evidence that indicates that early intervention, while the person has lost some independence but has not reached a level of three ADLs, that early intervention delays or reduces the likelihood of moving toward those higher levels of disabilities?

Dr. STONE. Yes. There is no strong empirical evidence to indicate that there is a strong relationship between home care, for example, and the prevention of further deterioration in function. What we do find is that there is a tremendous amount of positive well-being and comfort and family support that is provided through home care, also allowing these folks to remain in the community where they want to be rather than going into an institution.

Senator GRAHAM. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Graham.

Let me dwell just a moment on the issue I raised before I yielded. Tell me what roles the State governments have to play in long-term health care with the establishment of qualifications, quality of care, et cetera? Give us a little update on that.

Assistant Secretary TORRES-GIL. I think it is important to note that the States are the key players in this proposal. We know that is where many of the innovations originated. Their leadership has been due to the absence of Federal focus or leadership in this area. That is where the innovation is and that is where the flexibility should be.

In the President's plan, we leave it up to the States to decide how they will structure or implement this new long-term care pro-

gram, whether through an existing agency or several agencies, or a whole new structure. We require them to develop a State plan which will go through an advisory group at the State level and then to the Department where the Secretary of Health and Human Services will decide whether or not it meets our criteria in terms of quality issues, in terms of implementation. So we are allowing the States tremendous flexibility.

The only two things we require in the benefits package is assessment and a care plan. The State must also include personal assistance services in their State plan. Beyond that, the States decide whatever it is that allows an individual to stay in the home.

That is the broad framework within which we are looking at the States' role.

Robyn.

Dr. STONE. I know there have been some issues around the degree of State flexibility. We certainly worked long and hard to try to figure out the best way to approach this. Frankly, we used a number of States as models for this particular set of provisions, including the State of Wisconsin which has a very successful capped program with a flexible set of benefits for persons of all ages.

There is a Federal framework that is established and that is there is a uniform protocol, eligibility protocol, a uniform screen that must be used by all States. This will be developed by the Secretary of Health and Human Services and to that extent, we're talking about uniformity in terms of who gets into the program.

In addition, every State must conduct a screening, there must be an assessment for every person who is screened into the program, and there must be an individualized care plan that is developed. So in that sense, we are talking about some uniformity across States.

The third thing which Fernando spoke to is that a State must make available personal assistance services. That does not mean everybody is going to get personal assistance services, but they must be made available. There has to be two flavors of PAS. They must be agency-directed and they also must be client-directed services.

The CHAIRMAN. What is PAS?

Dr. STONE. Personal assistance services.

The CHAIRMAN. Is that going to be a new term?

Dr. STONE. That is already a new term.

The CHAIRMAN. You used the term awhile ago ADL.

Dr. STONE. Activity of daily living—eating, bathing, dressing, toileting, getting in and out of bed, that kind of thing.

The CHAIRMAN. I just want the audience to know that many times I don't understand these things and maybe some of you don't. A little translation every now and then is helpful.

Dr. STONE. The major focus of this and the whole question around quality is we have some tension between personal choice and personal autonomy and ensuring the safety and protection of care recipients and also workers. The issues really go both ways. You have to maintain some level of oversight over the worker as well.

This plan builds in a tremendous amount of consumer involvement, much more than we see, for example, in the Medicaid pro-

gram. We have a State advisory board that has to have at least 50-percent representation from consumers. They work with the State from the outset in the development of the State plan, in development of the structure, what kinds of guidelines are going to be established, what types of minimum standards are going to be set for agency providers and for their workers.

In this bill the Federal Government does not prescribe quality standards but the States must have minimum standards established in their State plan in order to meet approval. We believe strongly that this consumer involvement from the very beginning through implementation and evaluation will be a major safety check, if you will, for abuse and neglect.

In addition, we require that the States work with the AOA Ombudsman Program and other advocates for people with disabilities; that they establish minimum standards for the assessors and also for the folks who are going to be providing care through an agency, and they have to have these standards set in their State plan. So there is a level of Federal monitoring but it is not a heavy-handed regulatory approach. It is really trying to say we need to involve the consumer and in essence, give the consumer a range of choices and then have the consumer really work with the family, the workers, and the agency to ensure that we don't have a lot of abuse and safety problems.

The CHAIRMAN. When we hear this health plan and reform measure discussed, many times, we don't hear the role of the States and I think it is very apparent that there is going to be a significant role for the States, and also a significant role for the consumer. We don't hear a great deal about that aspect of this particular plan.

I'll yield to Senator Feingold.

Senator FEINGOLD. I want to just begin this portion by reiterating something I said in the introduction which is there is a misunderstanding, I hope it is not an intentional effort, to try to call this new program an entitlement. It is not.

Dr. STONE. No.

Senator FEINGOLD. It is a set amount of dollars and there will be an effort made by those who want to take it out of the President's plan to call it an entitlement. We're talking about a certain amount of dollars going to the States which they will have certain rules about how they can use it but I might point out that our community options program in Wisconsin is also not an entitlement. When money is gone, money is gone.

With that comment in mind and your response to the last question, the new benefit requires that States must specify the home and community based services that will be available under the plan or category of individuals' disabilities and must specify the limits applicable to those services.

In Wisconsin, we've been wary of a specific list of services. Rather than trying to make the needs of consumers fit the services we choose to offer, the community options program allows case managers and consumers to design a plan of care that meets the consumers needs and preferences. We think this approach not only provides maximum flexibility, which you were talking about, it also avoids the real problem of a program for consumers becoming a program for providers.

Would the Administration accept language that would allow States like Wisconsin to use an approach for the block grant like we do now for the benefit they receive under the new benefit or would we be tied to a set list of benefits?

Dr. STONE. You definitely would not be tied to a set list of benefits. As I said earlier, we have one requirement which is that the State has to have personal assistance services available, both agency-directed and client-directed which you already have in Wisconsin so you would not have any problem with that.

Again, there has been some misunderstanding of this as well. That does not mean everybody will receive personal assistance services. It means that has to be available and the reason for that was we believe this was the core service that most folks who would qualify for this program would need. Outside of that, a State can provide anything from home modifications, which Wisconsin does provide, to respite care, to home health services, a whole array of things as well as opting for cash payments.

So there are clients who would prefer to get the money and actually go out and hire their own person. States have the option to implement a cash payment program and they also have the option to pay family caregivers which is currently very difficult to do in a number of States. I know that Michigan and Wisconsin, for example, use paid caregivers as an option but that is not true across the board.

Senator FEINGOLD. There are couple of items that are explicitly excluded, that the money can't be used for, I believe rent or something like that?

Dr. STONE. It cannot be used for rent and board, although if there is the cash option, folks could use that for rent and board in an assisted living setting.

Senator FEINGOLD. Another problem that is increasing for the State-funded home and community benefit in Wisconsin is increasing pressure from institutional providers to allow them to tap into that source of funding. For example, there have been efforts to raise the bed limit we set for community facilities providing services under the program and it's a continuing problem.

The institutional providers already receive about 85 percent of our long-term care dollars and their political presence is usually a little more potent than the unorganized consumers or future consumers of home-based long-term care, at least in many settings, maybe not today.

What steps would you recommend to ensure that the new long-term care benefits not be channeled to institutions effectively disguised as community facilities?

Assistant Secretary TORRES-GIL. Let me just say that we recognize that there is a healthy tension of sorts between the existing institutional infrastructure we have and I think we all agree, including many nursing home operators, to really expand the home and community-base side. We certainly ultimately—in that ideal continuum I referenced at the beginning—see a continuing role for nursing homes.

The President's home and community-based long-term care program, however, was developed to be separate and freestanding to ensure that it had a chance to evolve and grow and not be captured

or be a part of any other institutionalized source of funding. We are very sensitive to and cognizant that unless the home and community-based side develops as a community-based service, hopefully a socially-oriented social service model, it won't be there to give us that balance. So that is separate, although in the President's plan, we will have a major demonstration project, I believe, by the year 2000 that will look at the possibility of ultimately integrating acute and home and community-based services.

Robyn.

Dr. STONE. There is actually explicit language that indicates that these dollars cannot be used in an institutional setting. It is also the case that some nursing homes may turn a wing or a unit into an assisted living unit and then would be eligible for receipt of these services as a residential care setting.

We are expecting that we will see some shifting out of institutions into the home and community-based care program which is in essence, one of the things that we would like to see happen.

Senator FEINGOLD. I appreciate the recognition that there needs to be a time for the home community base to take hold and I want it clear that my remarks do not suggest that I don't think nursing homes are needed in cases and it is part of the long-term care continuum but we needed to make that distinction in Wisconsin in order for the Community Options Program to flourish and develop. I think it is going to be essential here given the tendency of people to even think when they hear the word or phrase long-term care. They think of nursing homes and we need to reform that.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Graham.

Senator GRAHAM. You mentioned that the eligibility standards in the President's program would result in approximately 3.1 million persons being eligible, two-thirds of whom were elderly. If you were to have adopted the eligibility standards that are applicable in the Wisconsin program and had applied that on a nationwide basis, do you have an estimate of how many people would have been eligible?

Dr. STONE. Partly no, because I think Wisconsin has sort of a triage system and I am not sure that we could use the same exact criteria. The fact of the matter is that we could end up with as many as 10 million folks who would be eligible at any one point in time if you expanded the criteria to the kinds of criteria that Wisconsin is using. It would dramatically increase the size of the population and really dilute the services I think that could be provided given that we have established a cap that we believe is fairly prudent.

Senator GRAHAM. Would Wisconsin standards be typical of the kinds of standards States have adopted in those States which have a long-term care program?

Dr. STONE. I don't want to speak for Wisconsin—Donna McDowell would probably have my head. Let me say that I think in reality what has happened to many of the State programs is, as they have felt significant fiscal constraints, many of them have ratcheted down on their eligibility criteria and so you are looking at a lot of States that have very similar criteria currently to what we have in the Health Security Act. Maine is a good example of

a home care program that has ratcheted down its eligibility criteria and is targeting to people with severe disabilities. So I think that is more the tendency.

There is a recognition clearly that the dollars are not ever-flowing and that somehow we have to get control over that and try to serve people most in need. Remember also that other Medicaid and other programs for long-term care remain untouched. That is to say to the extent that States are now participating in the Medicaid Waiver Program, personal care option, the Older Americans Act, Social Services Block Grants, they will continue to do so. We expect that there will be a shift of some of these folks into the new program in which case, they are going to save on Medicaid dollars, can plow that back into their other programs to serve people with lesser disabilities.

Senator GRAHAM. I'd like to explore that point. Currently, most of the States' expenditures for long-care as well as for nursing home care is through the Medicaid Program. What will be the effect on both long-term care and nursing home care of the folding of Medicaid into the larger national health care program that the President has recommended?

Assistant Secretary TORRES-GIL. If I understand your question, Medicaid is not folded into the new program. The Medicaid long-term care nursing home benefit and Medicaid waiver services are not folded into other parts of the President's plan; they remain the same. There are no changes. Is that correct, Robyn?

Dr. STONE. Yes. On the acute care side, Medicaid is folded in, on the long-term care side, it remains as current law.

Senator GRAHAM. In my State, approximately two-thirds to 70 percent of our Medicaid expenditures are in institutional settings for long-term care, so I raised the question of just how much money is in fact going to be released by folding in the acute care into a larger system since 70 percent more or less of our State's expenditures are going to be in the area that will not be altered, we're still going to be committed to a large amount of our Medicaid.

Dr. STONE. I can't speak to the exact savings on the acute care side. We can certainly get back to you on that. On the long-term care side, again I think the notion is that this is a Federal-State program with a much more generous match rate than currently exists in Medicaid, a 28 percent point higher match rate than the State currently gets. So a State can serve current Medicaid recipients who meet our eligibility criteria in the new program and draw down three or four times more dollars than they are currently drawing down on that person in the Medicaid program. This is where we see savings coming from on the State side with respect to the new program.

Senator GRAHAM. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Graham.

Senator Cohen.

Senator COHEN. I'm told this hearing on long-term care is turning into a long-term hearing. You've already had two rounds and I checked with my staff and they said every question that I wanted to ask has already been asked and answered, so I will follow the dictum that was laid down by a former colleague of mine, Senator

Edmund Muskie who said, if you can't improve upon silence, don't. [Laughter.]

That was advice he routinely ignored himself but I've decided to accept it and therefore, let me thank the witnesses for coming forward and hopefully we can expedite moving to the next panel. I appreciate all that has been presented and we will look over the record.

The CHAIRMAN. Thank you, Senator Cohen.

We very much appreciate this panel. I will add to what Senator Cohen said by just saying that the committee is honored that you would appear before us today and give us this testimony.

We are going to keep open the record for 10 days. I have, for example, another three or four questions that I will not belabor you with at this moment, one of which is how we are going to deal with the myriad of programs that we have out there administering long-term care, how we are going to try to consolidate those under the President's proposal. We will ask those to be placed in the record and your responses we hope will be timely. We deeply appreciate this.

Thank you very much.

Assistant Secretary TORRES-GIL. We thank you and we thank the audience for their patience.

[Subsequent to the hearing, the following information was received for the record:]

QUESTIONS FOR FERNANDO TORRES-GIL

From Senator Pryor:

1. I recognize that the long-term care provisions in the Health Security Act provide for a great deal of State flexibility, and I understand that it is important to let States decide what package of services best meets the needs of their citizens. However, this raises the question of quality, consistency, and equitable access to services. With such a substantial new investment of Federal dollars in long-term care, how will we make sure we get our money's worth while still allowing States some measure of flexibility?

2. When the Health Care Task Force did its research on the long-term care component of the health care reform plan, did you notice substantial differences in need, and in the way services are used, between the elderly and non-elderly population with disabilities? Do you think we can reasonably expect to fashion a single system which will meet the diverse needs of the different groups?

3. Many of the consumers who use home and community-based care services are a very vulnerable population, particularly the older population. They are older, frail, and often dependent on their services to help them stay in their homes. As we contemplate expanding home and community-based care services, are there any recommendations that you have for assuring quality of care for this population?

DEPARTMENT OF HEALTH & HUMAN SERVICES,
Washington, DC.

Hon. DAVID PRYOR,
U.S. Senate,
Washington, DC.

DEAR SENATOR PRYOR: Thank you for the opportunity to provide additional information regarding questions raised by the Special Committee on Aging relative to the long-term care provisions of the Health Security Act.

Your first question asks how can we permit maximum State flexibility yet assure quality, consistency, equitable access to services and at the same time, ensure cost effectiveness under the Health Security Act. The Act calls for a phase-in period during which States are required, using the State's methodology or one provided by the Federal government, to earmark funds for eligible individuals. State developed methodologies must specify the groups among which the State's allocation will be divided, estimate the number of severely disabled individuals in each group and the

average cost of home and community care in each group. At least 60 percent of the budget must be allocated across severely disabled individuals.

States that use the Federal methodology must specify the principal stakeholder groups which correspond with the groups already identified by most States. The principal stakeholders would be the elderly, who would receive 42 percent; the mentally retarded/developmentally disabled, who would receive six percent; and others such as children and the working disabled, who would receive 12 percent of the allocation. The preceding percentages are based on 60 percent of the amount estimated to be expended nationally for each of these groups. By using a percentage of our national estimate, States have flexibility to address State specific situations while still guaranteeing a minimal level of equity for everyone.

States who develop their own methodology would have to provide a rationale as to why the Federal methodology is inappropriate. State flexibility would be enhanced by permitting States to set a more restrictive functional criteria than the Federal criteria. States would be prohibited from using income (and other financial resources), age, geography, category of disability, or residential setting (other than an institutional setting) to limit eligibility and allocate resources.

Relative to cost-effectiveness, the Health Security Act allows States to set limits so that program recipients could not force States to provide services in the person's home if it were less expensive to provide the services in another residential setting. This is not an entitlement program for individuals for specific services. Federal and State governments and providers are only required to provide services within the limit of the State's budget.

Your second question asks whether a *single* long-term care system will meet the diverse needs of the different groups. The Health Security Act does not require a single system; therefore, States have considerable flexibility to design community-based systems which respond to the diverse needs of the eligible population. States can use separate agency protocols which address individual and separate needs. States will be able to pattern services to meet the unique circumstances of individual States and communities.

The third question seeks our recommendations for assuring quality home and community-based care for the frail and dependent population. State plans should require quality assurance systems that protect consumer rights, such as: (1) free choice in selecting a qualified provider; (2) consumer participation in the care planning process; (3) privacy with respect to care; (4) minimum standards for providers of care; and other such safeguards. The State plan should also specify the process for evaluating the effectiveness of eligibility determinations, service delivery systems and investigation of consumer complaints and neglect. Conflict of interest concerns must be addressed.

I hope this information will clarify the issues you have raised regarding Health Security Act provisions. Please contact me if I may be of further assistance.

Sincerely,

FERNANDO M. TORRES-GIL,
Assistant Secretary for Aging.

The CHAIRMAN. Now we are going to call our next panel. We have a large number of panelists on this next and final panel: Jane Ross, Associate Director, Income Security Issues, U.S. General Accounting Office; Ms. Hazel Chapman and Angela Chapman, aged 13, residents of Virginia Beach, VA. Mr. Chapman has late stage Alzheimer's Disease and is being cared for at home. We're going to hear what the caregivers have to say about this. We also have Shirley Reed, a resident of Washington, D.C., a primary caregiver for her father, who is paralyzed as the result of a stroke; Diane Rowland is Senior Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on the Future of Medicaid; Gail Shearer is Manager, Policy Analysis, Consumers Union, Washington, D.C.; James Firman is President and CEO, United Seniors Health Cooperative, Washington, D.C.; and Mark Meiners is Director, National Program Office, Robert Wood Johnson Foundation Partnership for Long-Term Care Insurance located at the University of Maryland.

I've been around here a long time but I don't think I've ever seen more witnesses seated at one table at any one given time. We thought we could do this because we want to make sure that everyone gets a chance for their say and we don't want this to be very formalized. We want free and open discussion to come forth.

We're going to ask our representative from the General Accounting Office, Jane Ross, if she will speak first this morning. I want to ask, do you think it's possible to summarize your statement into about 5 minutes or maybe a few minutes? Then we are going to ask our panelists to hold their statements to 5 minutes each. You may take a little more time because you have done a tremendous amount of research in preparation for this hearing this morning.

Jane, we appreciate your coming before us.

STATEMENT OF JANE L. ROSS, ASSOCIATE DIRECTOR, INCOME SECURITY ISSUES, U.S. GENERAL ACCOUNTING OFFICE

Ms. ROSS. I'd like to have my full statement entered in the record and I'm sure I can do it in less than 5 minutes.

The CHAIRMAN. Surely.

Ms. ROSS. I'm pleased to be here to discuss some of the problems with the current long-term care programs and to suggest some principles that might guide you as you work to reform this system. My testimony is based on ongoing work requested by your Committee.

The long-term care system we have today is a patchwork of programs that individuals find hard to access. Despite billions of dollars in expenditures, the system often fails to meet diverse needs of disabled individuals. Many people believe that access to more appropriate services could be improved even at current funding levels.

In my remarks, I will discuss the long-term care system as we know it today. There are at least three areas that underpin the need for reform. First, demographic trends that make rising demand for long-term care inevitable, across all ages, not just for the elderly. Second, spending will escalate steeply whether or not reform occurs and third, despite the high costs, disabled persons are increasingly dissatisfied with the available services and their ability to access those services.

You've already heard a good deal about the demographic growth and the cost of the program, so let me go right to the section on dissatisfaction. Despite the tremendous cost that is associated with the long-term care system, and it's about $108 billion just this year, considerable dissatisfaction exists, especially among the persons needing care. At the core of their frustration lies the belief that services are difficult to access and are not matched well with the diverse needs and preferences of disabled individuals.

Individuals seeking services often have to contend with fragmented service delivery systems that force them to negotiate for services from a variety of agencies with different rules and requirements. In addition to dealing with their functional limitations, they also have to deal with the maze of government programs.

The current long-term care system has been patched together from multiple funding streams both Federal and State. Literally dozens of categorical funding streams provide long-term care to specific populations. At the State level, there is significant vari-

ation in the way these funding streams are managed. Typically there is no single long-term care system or agency.

In one State we studied, 10 State and 3 Federal agencies were responsible for administering and funding long-term care. Moreover, the types of long-term care services provided are different for elderly and younger-aged groups and also among the States. This variation in the depth and comprehensiveness of these networks is the subject we are exploring now in our current work for your committee.

Some Federal and State programs were initially designed to meet acute health care needs, not long-term care needs. Two of the major sources of Federal funding, Medicare and Medicaid, are primarily acute care programs. As a result, many disabled persons may be eligible only to receive institutional or medical services when other less intensive and even less expensive nonmedical services may be more appropriate.

Because Medicaid benefits for home and community-based services are limited, institutional care may be the only option available for many individuals, including the frail elderly and sources with severe mental retardation.

Today, some States are trying to better match services to needs by focusing more on the individual. The importance of this focus is underscored by the variation within the diverse group of disabled persons as well as the fact that an individual's needs may vary over the course of his or her lifetime. Some States have expanded home and community-based long-term care options such as personal assistance services through their Medicaid State plans or through Medicaid waivers. In addition, several States are now using their own funds to provide home and community-based programs. This allows them greater flexibility in whom they serve and what service they are providing.

The Administration has proposed changes to the long-term care system and other proposals are before you as well. Based on our work to date, we'd like to suggest two principles to consider in your deliberations. These are—greater tailoring of services to the needs of the individual and greater flexibility in funding. We believe that reform initiatives that reflect these principles will bring about program changes that can better serve individuals even at existing funding levels.

As I stated earlier, some States and other countries already are working to provide services better tailored to individual needs. These systems begin with an assessment of the individual needs of the disabled person rather than pigeonholing a person into existing programs. They attempt to develop a customized set of services unique to the individual's needs and preferences.

Second, more flexibility in funding could help alleviate the tendency to provide medical and institutional services. Much of the support persons with severe disabilities need is not complex medical care but assistance with every day activities that could be provided in their own homes and communities.

The millions of Americans with severe disabilities today comprises a dynamic and diverse group of all ages with varying care needs and levels of information assistance and support. The chal-

lenge of reform will be to better meet their needs while assuring maximum value for long-term care dollars.

This concludes my statement. I'd be happy to answer any questions.

[The prepared statement of Ms. Ross follows:]

LONG-TERM CARE—DEMOGRAPHY, DOLLARS, AND DISSATISFACTION DRIVE REFORM

Statement of Jane L. Ross, Associate Director, Income Security Issues, Health, Education, and Human Services Division

SUMMARY

The current long-term care system has been patched together from multiple funding streams, both federal and state. Individuals seeking services often have to contend with a fragmented service delivery system that forces them to negotiate for services from a variety of agencies. Each federal program has its own unique rules governing eligibility and prescribing specific services under certain conditions. The maze of long-term care services varies from state to state. It also differs for elderly and younger age groups, with different networks for different groups. Moreover, existing programs tend to deliver "one size fits all" services. The bulk of federal funding—Medicare and Medicaid—pays for services that are often institutional and medical in nature and may not be appropriate for, nor preferred by, many individuals. As a result, disabled persons may only be eligible to receive institutional or medical services when other, less intensive and even less expensive nonmedical services may be more appropriate.

Approximately 11 million Americans of all ages are chronically disabled and depend on others for assistance in the basic tasks of daily living. Unprecedented growth in the elderly population is projected for the 21st century, and the population age 85 and over—those most in need for long-term care services—is expected to outpace the rate of growth for all aged. The population of younger disabled persons has been increasing and is expected to grow, although the exact size is difficult to predict.

Today family and friends, mostly women, provide the overwhelming majority of care for disabled persons informally on a nonpaid basis. Even so, long-term care expenditures are high. In 1993, long-term care expenditures nationwide were estimated at approximately $108 billion, of which about $70 billion was government spending. Expenditures for long-term care are projected to more than double in the next 25 years. The future demand for paid services may grow at an even faster rate because informal caregiving will de difficult to sustain as more women join the work force and geographic dispersion of families continues.

Despite the expense associated with the long-term care system, considerable dissatisfaction exists, especially among persons needing care. At the core of their frustration lies a belief that services are often difficult to access and not matched well with the diverse needs and preferences of disabled individuals.

Current government spending of about $70 billion is expected to rise, yet the long-term care system is fragmented, does not meet current demand, and is not well matched to the diverse needs of individuals. GAO suggests two principles to consider in long-term care delibeerations—greater tailoring of services to the needs of the individual and greater flexibility in funding. Reform initiatives that reflect these principles will bring about program changes that can better serve individuals even at existing funding levels.

Mr. Chairman and Members of the Committee: I am pleased to be here to discuss problems with current long-term care programs and services and to suggest some principles that might guide reform efforts. As you know, there is a growing sense on many fronts that long-term care needs to be reformed. The long-term care system we have today has evolved over time as a patchwork of multiple programs that individuals find difficult to access. Despite billions of dollars in expenditures, the system often fails to meet the diverse needs of disabled individuals, and many believe that access to more appropriate services could be improved even at current funding levels.

In my remarks, which are based on work we are doing for your Committee, I will discuss the long-term care system as we know it today and focus on three areas that underpin the need for reform. First, demographic trends make rising demand for long-term care inevitable across all ages, not just for the elderly. Second, spending will escalate steeply whether or not reform occurs. Third, despite high costs, dis-

abled persons are increasingly dissatisfied with available services and their ability to access those services.

Demand for long-term care increasing among all age groups

Today, approximately 11 million Americans of all ages are chronically disabled and depend on others for assistance in the basic tasks of daily living such as eating, bathing, and other activities that most of us take for granted. In this highly diverse population are people with both physical and cognitive disabilities, including the frail elderly, quadriplegics and paraplegics, persons with developmental disabilities, persons with severe mental illness, and children with chronic conditions. Of the 11 million Americans with disabilities, about 3 million are considered to be severely disabled.

The number of elderly and non-elderly persons needing long-term care is expected to increase substantially in the future. Unprecedented growth in the elderly population is projected for the 21st century, and the populations age 85 and over—those most in need of long-term care services—is expected to outpace the rate of growth for all aged. Although most elderly persons are healthy, approximately 7.1 million of them need long-term care, and 1.5 million of these elderly, many of them age 85 or over, are currently in nursing homes.

Less is known about the present and future prevalence of disability among persons under age 65. According to the Pepper Commission, the number of non-elderly persons needing long-term care is about 4 million. However, depending on the definition of disability used, others have estimated higher numbers.

Experts believe that the population of younger disabled persons will continue to grow although the exact size is difficult to predict. Many attribute the growing numbers of younger disabled persons to factors such as longer life spans for persons born with severely disabling genetic conditions and increased survival among groups such as low birth-weight babies and victims of violence and automobile accidents.

High costs burden public and private payers

Long-term care expenditures nationwide were recently estimated by the Administration to be approximately $108 billion in 1993, about 65 percent paid by federal and state governments and about 35 percent paid out-of-pocket by private individuals. In 1993, total federal and state Medicaid expenditures for long-term care equalled $42 billion—$26.1 billion for nursing homes, $9.2 billion for intermediate care facilities for the mentally retarded, and $6.7 billion for home care. States are particularly concerned about their rising Medicaid expenditures, largely for nursing homes. About 70 percent of total public and private long-term care dollars are currently spent for institutional care.

All families worry about the catastrophic costs they could face if a family member should need long-term care. Families also worry about the human costs associated with caring for a disabled family member. Today family and friends, mostly women, provide the overwhelming majority of care for disabled persons informally on a nonpaid basis. A very small but growing number purchase long-term care insurance to prevent financial loss.

Assuming the continuation of current spending patterns for nursing home and home health care, expenditures for long-term care are projected to more than double in the next 25 years. The future demand for paid services may grow at an even faster rate because informal caregiving will be difficult to sustain as more women join the work force and geographic dispersion of families continues.

Dissatisfaction with current system, desire for more options

Despite the expense associated with the long-term care system, considerable dissatisfaction exists, especially among persons needing care. At the core of their frustration lies a belief that services are often difficult to access and not matched well with the diverse needs and preferences of disabled individuals.

Disabled persons face maze of long-term care services

Individuals seeking services often have their difficulties compounded by a fragmented service delivery system that forces them to negotiate for services from a variety of agencies. For example, a person paralyzed in an automobile accident, newly released from the hospital, might need many services, including meals, transportation, personal assistance, and homemaking. To negotiate services, an individual may need to contend with the myriad of federal and state long-term care programs that provide services, sometimes with different eligibility requirements. In fact, some states use case managers to help individuals find their way through the maze.

The current long-term care system has been patched together from multiple funding streams, both federal and state. Literally dozens of categorical funding streams provide long-term care to specific populations such as chronically ill children, per-

sons with AIDS, persons with developmental disabilities, persons with mental illness, and the frail elderly.[1] At the federal level, Medicaid is the largest program providing support for long-term care services. Other federal programs include Medicare, the Social Services Block Grant, the Older Americans Act, and the Rehabilitation Act. Each federal program has its own unique rules governing eligibility and prescribing specific services under certain conditions. In addition, a number of state and local governments allocate significant funds to long-term care services.

At the state level, there is significant variation in the way these funding streams are managed. Typically, there is no single long-term care system at the state level. Rather, long-term care programs can be found in a variety of configurations. In one state we studied, 10 state and 3 federal agencies were responsible for administering or funding long-term care. State agencies are frequently organized along disability population lines. For example, states may have different departments dealing with the elderly, children and families, those with developmental disabilities, those with mental illness, and others.

Moreover, the long-term care infrastructure is different for elderly and younger age groups. For example, the Older Americans Act put in place a network for the elderly that includes more than 50 state units on aging and over 600 Area Agencies on Aging. This network has been charged with administering certain long-term care programs for persons over age 60. For persons with severe disabilities under age 60, other networks exist, primarily at the state level. The variation in the depth and comprehensiveness of these networks is a subject we are exploring in our current work for this Committee.[2]

Services available often do not match individual's needs

Many existing programs tend to deliver "one size fits all" services. The bulk of federal funding—Medicare and Medicaid—pays for services that are often institutional and medical in nature and may not be appropriate for, nor preferred by, many individuals.

Many federal programs were initially designed to meet acute health care, not long-term care, needs. As a result, disabled persons may only be eligible to receive institutional or medical services when other, less intensive and even less expensive nonmedical services may be more appropriate. Because Medicaid benefits for home and community based services are limited, institutional care may be the only option available for many individuals, including the frail elderly and persons with severe mental retardation. Similarly, when respite care needed for the family of a person with Alzheimer's or a person with traumatic brain injury is not available, the risk of institutionalization for that person is greater. These sorts of adverse outcomes follow from mismatches between needs and programs.

Some states are trying to better match services to needs by focusing more on the individual. The importance of this focus on the individual is underscored by the variation within the diverse groups of disabled persons, as well as the fact that an individual's needs may vary over the course of a lifetime. For example, persons with cognitive disabilities—limits in their ability to reason—differ from those with physical disabilities in the types of supports they need. At the same time, not all persons with the same impairment need the same type and level of assistance. And a single individual, such as a person with AIDS, can have varying care needs over time as he or she experiences different episodes of acute and chronic illness.

Some states have made apparent progress in tailoring services to individual's needs. These states offer considerably more long-term care options, such as personal assistance services, through their Medicaid state plans or through Medicaid waivers, than do others. Such waivers permit states to provide home and community based services to severely disabled persons who would otherwise have been institutionalized. In addition, several states' home and community based programs, funded with state dollars, allow them a considerably greater amount of flexibility in whom they serve and what services are provided. Not all states, however, opt to provide home and community based services through Medicaid waivers or state funds to all groups of the severely disabled.

Principles for long-term care reform: Greater focus on the individual and more flexible funding streams

The Administration has proposed changes to the long-term care system, and other proposals are before you as well. Current government spending of about $70 billion is expected to rise, yet the system is fragmented, does not meet current demand,

[1] For a list of major federal programs supporting long-term care services for the elderly and disabled, see attachment I.

[2] For more information about our issued reports and current work, see attachment II.

and is not well matched to the diverse needs of disabled individuals. Based on our work, we would like to suggest two principles to consider in your deliberations—greater tailoring of services to the needs of the individual and greater flexibility in funding. We believe that reform initiatives that reflect these principles will bring about program changes that can better serve individuals even at existing funding levels.

Some states and other countries already have initiatives to provide services better tailored to individual need. These states and other countries are developing new, flexible delivery systems that they believe may be more appropriate for and preferred by disabled persons. For all disabled persons, whether elderly or not, their systems often begin with an assessment of the individual needs of the disabled person rather than pigeonholing disabled persons into existing programs. They then attempt to develop a customized set of services unique to the individual's needs and preferences. Because we have so much to learn about delivering services to the disabled, state and local governments should be encouraged to try new approaches, to evaluate results, and to share their successes.

More flexibility in funding could also help alleviate the tendency to provide medical services when nonmedical services are needed instead. Much of the support persons with severe disabilities need is not complex medical care, but assistance with everyday activities that could be provided in their own homes or communities. To control utilization, however, funding has often been restricted to medical services and institutional care. Many believe that more home and community based services tailored to individual needs can provide better care even at current funding levels.

The millions of Americans with severe disabilities today comprise a dynamic and diverse group of all ages, with varying care needs and levels of informal assistance and support. The challenge of reform will be to better meet their diverse needs while assuring maximum value for long-term care dollars.

Mr. Chairman, this concludes my statement. I will be glad to answer any questions you or the Members of the Committee may have.

ATTACHMENT I.—MAJOR FEDERAL PROGRAMS SUPPORTING LONG-TERM CARE SERVICES FOR THE ELDERLY AND DISABLED

[In millions [1]]

Program	Objectives	Fiscal year 1993 Federal spending: Total and long-term care only	Administration	Long-term care services
Medicare/Title XVIII of the Social Security Act.	To pay for acute medical care for the aged and selected disabled.	Total: $138,810 Long-term care: $15,800 (estimated)	Federal: HCFA/HHS [2] State: None	Home health visits, limited skilled nursing facility care.
Medicaid/Title XIX of the Social Security Act.	To pay for medical assistance for certain low-income persons.	Total: $77,367 Long-term care: $24,700 (estimated)	Federal: HCFA/HHS State: State Medicaid Agency	Nursing home care, home and community-based health and social services, facilities for the mentally retarded, chronic care hospitals.
Social Services Block Grant/Title XX of the Social Security Act.	To assist families and individuals in maintaining self-sufficiency and independence.	Total: $2,805 Long-term care: (not available)	Federal: Office of Human Development Services/HHS State: State Social Services or Human Resources Agency; other state agencies may administer part of Title XX funds for certain groups; for example, State Agency on Aging	Services provided at the states' discretion, may include long-term care.

ATTACHMENT I.—MAJOR FEDERAL PROGRAMS SUPPORTING LONG-TERM CARE SERVICES FOR THE ELDERLY AND DISABLED—Continued

[In millions [1]]

Program	Objectives	Fiscal year 1993 Federal spending: Total and long-term care only	Administration	Long-term care services
Rehabilitation Act	To promote and support vocational rehabilitation and independent living services for the disabled.	Total: $2,186 Long-term care: $54	Federal: Office of Special Education and Rehabilitative Services/ Department of Education State: State Vocational Rehabilitation Agencies	Rehabilitation services, attendant and personal care, centers for independent living.
Older Americans Act ...	Foster the development of a comprehensive and coordinated services system to serve the elderly.	Total: $1,377 Long-term care: $765	Federal Administration on Aging/Office of Human Development/HHS State: State Agency on Aging	Nutrition services, home and community-based social services, protective services, and long-term care ombudsman.

[1] Data represent total Fiscal Year 1993 obligations as reported in the *Budget of the United States Government, Appendix, Fiscal Year 1995*, except for estimates of Medicare and Medicaid long-term care spending. These figures are estimates for 1993 from the Assistant Secretary for Planning and Evaluation, HHS. Under the Medicaid program, states contributed an estimated $19.0 billion in support of long-term care in addition to the federal share of $24.7 billion.

[2] Health Care Financing Administration, Department of Health and Human Services.

ATTACHMENT II

Related Products

Reports on long-term care

Administration on Aging: Autonomy Has Increased but Harmonization of Mission and Resources Is Still Needed (June 11, 1991, GAO/T–PEMD–92–9).

Administration on Aging: More Federal Action Needed to Promote Service Coordination for the Elderly (Report, GAO/HRD–91–45, April 23, 1991).

Board and Care Homes: Elderly at Risk from Mishandled Medications (Testimony, Feb. 7, 1992, GAO/T–HRD–92–45).

Health Care Reform: Supplemental and Long-Term Care Insurance (Testimony, 11/9/93. GAO/T–HRD–94–58).

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (Report, 1/31/94, GAO/HEHS–94–60).

Long-Term Care: Projected Needs of the Aging Baby Boom Generation (Report, June 14, 1991, GAO/HRD–91–86).

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (Report, 3/4/94, GAO/HEHS–94–64).

Long-Term Care Case Management: State Experiences and Implications for Federal Policy (Report, 4/6/93, GAO/HRD–93–52).

Long-Term Care Insurance: Actions Needed to Reduce Risks to Consumers (Testimony, 6/23/92, GAO/T–HRD–92–44). Reports on same topic (3/27/92, GAO/HRD–92–66 and 12/26/91, GAO/HRD–92–14). Testimonies on same topic (5/20/92, GAO/T–HRD–92–31 and 4/11/91, GAO/T–HRD–91–14).

Long-Term Care Insurance: Better Controls Needed in Sales to People With Limited Financial Resources (Report, 3/27/92, GAO/HRD–92–66).

Long-Term Care Insurance: High Percentage of Policyholders Drop Policies (Report, 8/25/93. GAO/HRD–93–129).

Long-Term Care Insurance: Tax Preferences Reduce Costs More for Those in Higher Tax Brackets (Report, 6/22/93, GAO/GGD–93–110).

Long-Term Care Insurance Partnerships (Letter, 9/25/92, GAO/HRD–92–44R).

Long-Term Care Reform: Rethinking Service Delivery, Accountability, and Cost Control (Discussion Paper, 7/13–14/93, GAO/HRD–93–1–SP).

Massachusetts Long-Term Care (Letter, 5/17/93, GAO/HRD–93–22R).

Services for the Elderly: Longstanding Transportation Problems Need More Federal Attention (Report, 8/29/91, GAO/HRD–91–117).

VA Health Care: Potential for Offsetting Long-Term Care Costs Through Estate Recovery (Report, 7/27/93, GAO/HRD–93–68).

Current long-term care work

Diverse Long-Term Care Populations and Needs: Implications for Reform
Geriatric Assessment
International Long-Term Care Reform
Long-Term Care Programs and Innovations in Services: Implications for Reform
Older Americans Act: Funding Formula Could Better Reflect State Needs
Public and Private Financing for Long-Term Care: Current Responsibilities and Implications for Reform
Service Quality in Home and Community-Based Services
State Medicaid Home and Community-Based Service Programs: Accomplishments and Implications for Reform
State Survey of Home and Community-Based Services' Lessons Learned

[Subsequent to the hearing, the following information was received for the record:]

QUESTIONS FOR JANE ROSS

From Senator Pryor:

1. You have had a chance to look at service delivery models for a wide variety of different disability groups. Were there any particularly good models that you observed that would be useful to us as we contemplate how we will set up a new home and community-based care program?
2. Based on what you have observed, do you have any recommendations with respect to how services can be better coordinated for people with disabilities as they move through different stages of life?
3. In terms of the proposed Clinton plan or any other national long-term care reform effort, what should the Federal role be?
4. In our past experiences with home and community-based services, can we say that these services do indeed save money overall and on an individual basis?

From Senator Feingold:

1. Your statement on the need for greater tailoring of services to the needs and preferences of the individual and greater flexibility in funding were right on the mark. I think the point that increased flexibility results in greater customer satisfaction was well made. For many units of government, from the federal level on down, this new, flexible approach to providing services will require a different way of thinking about how services are provided. It also means we will have to rethink our old definitions of things like quality assurance. This doesn't mean we neglect reasonable safety requirements where needed, but it will mean paying more attention to what consumers want and less to what might be easy to measure or document. A good definition of quality is meeting the expectations of the consumer. What are your thoughts on how and what we should regulate under a new, consumer-oriented system?

U.S. GENERAL ACCOUNTING OFFICE,
Washington, DC, June 27, 1994.

Hon. DAVID PRYOR,
Chairman, Special Committee on Aging, U.S. Senate, Washington, DC.

DEAR MR. CHAIRMAN: You asked that I respond to five written questions arising from my testimony at the Committee's recent hearing on "Health Care Reform: The Long Term Care Factor." I am pleased to provide my responses, for the record, as a follow up to issues addressed in my testimony, Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform (GAO/T–HEHS–94–140, Apr. 12, 1994).

Questions from Senator Pryor:

Question. You have had a chance to look at service delivery models for a variety of different disability groups. Were there any particularly good models that you observed that would be useful to us as we contemplate how we will set up a new home and community-based care program?

Answer. We have not comprehensively evaluated service delivery models for different groups in our long-term care work. However, what we have found so far in our work suggests that most, if not all, service models are moving toward an increase in emphasis on home and community-based services. These models are generally designed to promote flexible and individualized support, the involvement of family and friends in providing care, decentralized program implementation at the local level, and cost control.

As we learn more about different disability groups, we are beginning to identify diverse needs and views about long-term care, including rejection by some of the term "long-term care" itself. We are continuing our work by focusing on different service arrangements that exist to provide long-term care not only for elderly persons but also for children with chronic conditions, persons with developmental disabilities, persons with physical disabilities, persons with AIDS, and persons with mental illness.

We are examining potential similarities and differences among established service models for various populations as well as some of the most current thinking on how these models are evolving. It is important to note that individuals with the same disability may need very different types of long-term care support depending upon their circumstances. Diverse needs among long-term care populations as well as within these populations suggest that no one service model will best meet all needs. Nonetheless the general design features I mentioned appear to be either in place or developing in many long-term care service models.

Question. Based on what you have observed, do you have any recommendations with respect to how services can be better coordinated for people with disabilities as they move through different stages of life?

Answer. We do not have specific recommendations in this area because we have not examined it in any detail. Based on prior work we have done on long-term care coordination, it would probably be sensible to begin by examining what transition problems clients may be having in accessing services and tracing those problems to lack of coordination between programs involved in the transitions. Because long-term care services are organized in very different ways from one state to another, these problems and their solutions are likely to vary greatly. The starting point in each case, however, is to establish what aspects of service fragmentation are causing clients problems and then focus on the causes identified to prevent these problems from occurring.

Question. In terms of the proposed Clinton plan or any other national long-term care reform effort, what should the federal role be?

Answer. The role of the federal government in a reformed long-term care system could include encouraging innovation, disseminating information, and monitoring the design and administration of programs.

Encouraging innovation and avoiding adverse outcomes will be an essential part of long-term care reform as new approaches continue to develop for customizing services to meet different individual needs. Because there is no single way to best address needs while using funds most efficiently, states and communities often have very different approaches to long-term care. In this environment, the federal government could play a valuable role by increasing its capacity to distinguish developments in programs that are positive from those that are negative. This could enable the federal government to be a resource for supporting innovation and helping states correct approaches that are not leading to positive outcomes.

The federal government could also play a key role in disseminating information to states and communities on what works well. Interactive information dissemination and technical assistance would be particularly useful. One way to do this is through the organization and sponsorship of peer assistance programs in which state and local government officials and researchers may provide technical assistance to programs around the country. This can be done through telephone consultation, travel to specific program sites, and electronic information exchange.

In addition, the federal government could do much to achieve better outcomes by working with states to monitor the design and administration of programs. Indeed, the federal government can learn from the leading states because they have been the originators of long-term care innovation. The federal government, in partnership with the states, should be monitoring implementation to detect problems, to help strengthen uneven service capacities, and to encourage development of new accountability measures. This can include gathering comparative information across the states and providing these data to individual states to help them improve their programs.

We believe that the federal government's monitoring role in program implementation should be recognized explicitly in legislation. Because our knowledge of optimal implementation of long-term care programs is limited, monitoring by the federal government is essential to help better understand how to achieve client satisfaction and cost efficiency. With such information, the federal government will be able to continually refine guidance as needed on which methods of service delivery work best under which circumstances and how to avoid adverse outcomes. The federal government needs to be flexible in its approach to long-term care rather than locking in current service delivery models that may evolve in the future.

We discussed the federal role in the administration's long-term care proposal in our testimony before the Subcommittee on Aging of the Senate Committee on Labor and Human Resources, Long-Term Care Reform: Program Eligibility, States' Service Capacity, and Federal Role in Reform Need More Consideration (GAO/T–HEHS–94–144, Apr. 14, 1994).

Question. In our past experience with home and community-based services, can we say that these services do indeed save money overall and on an individual basis?

Answer. Research has shown that home and community-based services can often be less costly than nursing home care on an individual basis. A "guarantee" of savings at the level of the individual has been built into most Medicaid waiver projects, which generally require that they not spend more to support persons in the home than would be spent to support them in a nursing home. However, these services have not been shown to reduce overall spending for long-term care through a reduction in the use of nursing home or hospital services. Several demonstration projects of the early 1980s found that home and community-based services often did not substitute for nursing home care and instead served beneficiaries who might not necessarily have entered a nursing home. While these services do not generally replace nursing home care, neither do they replace the primary role played by family caregivers in delivering long-term care. Home and community-based care has generally been found to be a complement to, not a substitute for, other forms of both formal and informal long-term care.

Recent evidence from some State Medicaid programs suggests that these services can contribute positively to an overall long-term care cost control strategy. Expansions of home and community care in some states have been undertaken not just with the goal of better meeting the population's needs but also with the goals of controlling program growth and expenditures. State officials argue that the expansion of home and community care has allowed them to more stringently control the supply of costly nursing home beds and enhanced their ability to control increases in long-term care expenditures. The availability of a wide range of long-term care service options may allow program managers to operate more efficiently by providing them the flexibility to select the least costly alternative to meet an individual's needs.

Questions from Senator Feingold:

Question. Your statement on the need for a greater tailoring of services to the needs and preferences of the individual and greater flexibility in funding were right on the mark. I think the point that increased flexibility results in greater customer satisfaction was well made. For many units of government, from the Federal level on down, this new, flexible approach to providing services will require a different way of thinking about how services are provided. It also means we will have to rethink our old definition of things like quality assurance. This doesn't mean we neglect reasonable safety requirements where needed, but it will mean paying more attention to what customers want and less to what might be easy to measure or document. A good definition of quality is meeting the expectations of the consumer. What are your thoughts on how and what we should regulate under a new, consumer-oriented system?

Answer. Tailoring services to meet individual needs in homes and communities will require new ways of thinking about quality and assuring quality services. As you suggest, consumers and their families have an important role to play in helping policy makers and program officials think about the best ways to achieve quality, some of which may require regulation and some of which will require other methods. More consumer, family, and citizen involvement in defining and assessing service quality appears to be one of the key elements many state programs use to achieve quality services. We may need some broad guidelines or principles included in regulation to ensure that this participation is continuously built into long-term care planning and implementation. One of these principles is that consumers need to have choices in how they live. Another is that programs need to recognize vulnerability among some individuals who receive long-term care. These individuals include those who may be unable to fully speak for themselves or others who may fear loss of services if they voice dissatisfaction. GAO will continue to look at quality assurance issues in its long-term care work.

Please contact me on (202) 512–7215 if I may be of additional assistance.

Sincerely yours,

JANE L. ROSS,
Associate Director,
Income Security Issues.

The CHAIRMAN. Thank you very much.

We're going to allow all of our witnesses to make their statement and then we will have questions following.

Ms. Chapman, Angela, we welcome you here today. Have you been to Washington, D.C. before? Have you ever attended a hearing like this? Sometimes you have to sit and wait a long time and we do apologize to you. I've been watching you out there; you got kind of sleepy a time or two and I've kind of gotten sleepy myself. [Laughter.]

Ms. Chapman, thank you. You may proceed.

STATEMENT OF HAZEL CHAPMAN, VIRGINIA BEACH, VA ACCOMPANIED BY ANGELA CHAPMAN, DAUGHTER

Ms. CHAPMAN. Thank you.

Mr. Chairman and members of the Committee, I am grateful to you for inviting me here to tell my story. Let me begin by saying that I never thought I would be here talking about Alzheimer's disease and long-term care. I always thought these were things that affected old people. Now I know that they affect people of any age. I am only 45, Angela is only 13. This disease has made a huge impact on our lives.

My husband, Tom, is 53 years old and he suffers from Alzheimer's Disease. He was diagnosed 3 years ago and the disease has progressed to the point that he is incapable of doing anything on his own. He can't dress himself or go to the bathroom by himself; he shadows me all day long because he is afraid to be alone. When he eats, he often does not know that food is supposed to go into his mouth, sometimes he puts it in his ear.

Tom's disease, bad as it is, is only part of our problem. Because he is not old enough, my husband doesn't qualify for most of the services that are available in our community which has an age limit of 60. He is not eligible for home and community services provided by the Older Americans Act. Also, he can't get Social Security retirement or other regular pension benefits and he isn't eligible for Medicare. He is in a "no man's land."

Our family is living on a small amount of money from Social Security disability and an $85 a month Government retirement fund. With that, we have to buy health insurance which costs $122 a month, pay for housing, food, and anything else we need. I can no longer meet the mortgage payments on our house, so we've put it up for sale. We have to be moving next month.

Thank God for the Alzheimer's Association Chapter. They help out by offering us 2 days a week of day care. This allows me to get some break from taking care of Tom around-the-clock and lets me attend to other needs. Unfortunately, it is not enough. I am having a lot of difficulty juggling caregiving for Tom and raising my daughter, Angela. I need to get a job but I can't possibly be away from home right now. I have to stay home to care for my husband and help my daughter to grow up.

I have heard about President Clinton's health care plan and especially about the long-term care program he has proposed. As far as I can tell, it is exactly what we need. If I had help at home, for example, it would allow me time to be a better mother and I could go back to work. I am now at the point that I am forced to place Tom in a nursing home. I am told that it will cost $2,900 a month,

money we simply do not have. I have started the process of applying for Medicaid which I hope will pay the cost but it seems it would be much cheaper and better for everyone if there were some services at home to help our family and other families like us.

I know there is a lot of concern here in Washington about the cost of President Clinton's plan. I understand that but how can we put a price tag on the value of the family and then say we can't afford it? Our family is being torn apart by Alzheimer's Disease and there no help for us. Our little health insurance policy pays for treating my husband's high blood pressure but it is of no use for his Alzheimer's Disease. It doesn't seem right that we can turn our backs on people because the ailment doesn't fall in the right category.

The devastation of Alzheimer's Disease knows no boundaries. As our elected leaders, you can't cure my suffering over the loss of my husband, you can't bring my daughter, Angela's daddy back to her so that she can be a normal teenager, you can't ease the mental anguish my husband goes through as his mind gradually erodes, but you can help ease the financial strain on my family. You can help provide some of the support and services our family needs to keep going and you can help our family stay together and Tom out of an institution.

I don't envy your task as you struggle with the best ways of fixing our health care system. I hope you will have enough strength and courage to stand up to the special interests that say it can't and shouldn't be changed. I hope you can keep all of us in mind when you are told you can't afford to include long-term care. I don't see any way that we cannot afford to include it.

May God be with you and thank you for listening to my story.

I would beg your further indulgence while my daughter, Angela makes a brief statement.

The CHAIRMAN. Yes.

ANGELA CHAPMAN. I used to be daddy's girl and anything I wanted, my dad did for me. Before his disease, he used to help me and now it's the other way around. Mentally, my father is younger than me and I have to help feed him, put on his shoes and dress him. When my mom needs to run an errand, I have to stay and watch my father. He gets into trouble if there isn't someone watching at all times.

I missed the way it used to be. When he was working, I was able to go skating and bowling and now I can't do these things because we don't have the money and we can't leave him in the house alone. I am embarrassed to bring friends to my house because they won't understand. It's not that my father says bad things, he just acts strange. I have one good friend whose grandmother has Alzheimer's and she understands what I'm going through but most of my friends wouldn't understand.

I go to my friend's house after school to get away from it all. I'm afraid of being too close to my dad because when he dies, it will be too hard. People say I am growing up too fast. I'm becoming kind of a midget adult, I can't have fun like I used.

Sometimes I can't even go to school because I get so stressed out about everything that's happening to my dad and my family.

I suppose it would be easy if he were in a nursing home, at least then I could start to have a more normal life, but I really don't want him to go. I'm scared about my future, my mom is scared because we don't have enough money, I'm scared that I might get this disease some day. Both my uncles, my dad's brothers, have Alzheimer's.

If there was one thing I could ask you for, it would be to change things so that my dad could get some help. He can't get any services now because he's too young. If someone could come to our home to help care for my dad, it would make things easier for me and my mom. What I really want is my dad back.

The CHAIRMAN. Thank you.

Your dad is 53, is that correct? He's a very young man. We'll come back for a question or two later.

Shirley Reed is a caregiver for her father and you live in Washington, D.C., I believe, Ms. Reed, is that correct?

Ms. REED. Yes, I do.

The CHAIRMAN. We appreciate you coming and telling your story. You may proceed.

STATEMENT OF SHIRLEY REED, CAREGIVER, WASHINGTON, DC

Ms. REED. Mr. Chairman, my name is Shirley Reed and I thank God for being here and I thank you all for the opportunity to speak today on behalf of families like mine who need a little help to be able to continue caring for our loved ones at home.

I am 60 years old, a retired Federal Government employee after 38 years of service, most of it with Food and Drug Administration. I live in southeast Washington, DC.

On August 23, 1992, my father, Clarence Springs, had a stroke which left him paralyzed from the neck down. He was in D.C. General Hospital for a short time and in October, he went to the Rehabilitation Hospital until January 1993, after which I brought him home to live with me.

My mother passed in December of the same year my father had the stroke, December 9, 1992. I knew it was her desire for him not to go into a nursing home, so I brought him home with me.

When my father was first released from the hospital, he was given 4 hours of home health care a day under Medicare. They gave me a Saturday and Sunday for only 2 weeks. I was frightened as I didn't know exactly what I would have to do. That time was reduced after 6 or 7 months to 2 hours and in all fairness, I must say that they are there sometimes for about 1 hour and 45 minutes. It was explained to me just this morning by one of the home health aides that sometimes when they have three patients to care for, they will have more time to spend with my father. He takes a little more time because they have to stop and take care of his wants when his head itches or his nose or his face, which he can't do anything for himself.

When they have four patients, within an 8-hour time frame, they have less time to spend with my father and they only have enough time or they need enough time to bathe and then shave him. Every Saturday and Sunday, I have someone come in the evening to bathe my father. We were fortunate this past Saturday for someone

to come in, spend the night, dress and bathe my father and the church van picked him up for church service. I've been in the same church since the age of 8 which is 52 years. I get good support from the church family and good neighbors and friends.

There is a need for help with my father and he needs my attention all day and then it depends upon his feeling at night. If he wakes up, his head will itch, his nose will itch, his face will itch. In fact, this morning, before I left to come here, there was certain care that had to be done; he has a G-tube and he requires feedings at 7, 11, 3 and 7 and as I was feeding him, I had to stop because he told me that he felt that he was laying on the peg, so that meant that you turn him a little more, you brush his hair, you lift his head from the pillow, you have to clean his eyes and then also his nose.

I get up each morning most times around 6 a.m. My time can run 4 o'clock, it can even run 2 o'clock in the morning. At that time he has his medication. Thank God he is not on blood pressure medicine but the spasm medicine, is taken at 6 a.m., 12, 6 p.m. and 12 p.m. He has the Pericolace for his bowels. He also has a bowel training program that is done every other day. Actually, I try to get someone to do that. I can do most things but that really gets next to me. The feeding tube requires attention, as I said before, four times a day.

What I'm really upset about with Medicare is his therapy, the therapist was able at one time to have him up, sitting on the side of the bed and Medicare, if you don't progress within a certain time frame, they stop it and it's really disgusting because an 83-year-old man can't jump back just like someone who is playing basketball. It irritates me to no end that they just don't consider they are dealing with human beings. I think the system needs to be changed.

Because of his constant care, running errands outside of the home is quite difficult for me but I'm glad of our close family relationship. I have three daughters here—JoAnne was actually there last night—and I thought daddy didn't wake up but she told me he did three times but I guess I just didn't hear him. So they have themselves on a schedule where they come certain times—Sunday and Tuesday belongs to Dana, Wednesday and Friday belongs to Donna, JoAnne will come during the day. She is a probation officer for D.C. Superior Court and she is off every other Monday. She will come Monday during the day and then the next Monday her schedule is at night. They all hold full-time jobs during the day.

Someone asked me yesterday was I waiting to put my father in a nursing home? I don't intend to put him in one. I hear too much about nursing homes and I said as long as God gives me strength, he will be with me. It's difficult to pay $7 or $8 a hour for someone to come in to help for 8 hours but I'm glad that with the years of service I had with the Federal Government, we are not poverty-stricken, we can use help, I need rest, but I'll take it when I can get it.

I thank you for the opportunity to speak with you today.

[The prepared statement Ms. Reed follows:]

THE LONG-TERM CARE CAMPAIGN

(Statement of Shirley Reed, Washington, DC)

My name is Shirley Reed. Thank you for the opportunity to speak to you today on behalf of families like mine, who need a little help to be able to continuing caring for our loved ones at home. I am a 60-year-old retired D.C. government employee who lives in Southeast Washington, D.C. In August of 1992, my father, Clarence Springs, had a stroke which left him paralyzed from the neck down. He was in the D.C. General Hospital and the National Rehabilitation Hospital until January 25, 1993, after which I brought him home to live with me.

When my father was first released from the hospital he was given four hours of home health care a day under Medicare, but that was reduced after six or seven months to two hours, five days a week. There is a one-half hour travel time for the aide after which there is only enough time for the aide to bathe, wash his hair, and perhaps shave my father. I get in-home support services from the Veterans Administration three hours, twice weekly. Sometimes, I pay a friend out-of-pocket to help me on weekends and some evenings.

I need help because my father needs attention all hours of the day and night. He calls to me in the night if he is coughing or he may have itching and he cannot help himself. I might be able to sleep for an hour or two and then be up with him for an hour and then sleep for another few hours before he might call again.

I rise early each day, about 6 a.m. to provide his medication and feed. He is on a feeding tube now and that requires attention four times a day and other food as required. Since Medicare stopped paying for his physical therapy about a year ago, I must also exercise him twice daily. And, although I try to minimize the lifting and turning that I do because of previous problems with my back, he must be turned and cared for 2–3 times a day.

Because of his need for constant care, running errands outside of my home is difficult. I have three adult daughters who live in the Washington area and they help as often as they can, but there are still times when I must care for him all day and then all night by myself. On those days, which are the hardest times for me, it is very difficult just to get the rest I need. All three of my daughters hold full-time jobs during the day. I have four other adult children who live outside of the area and visit when they can to help.

I don't want to put Dad in a nursing home. He doesn't need that. I can't afford to pay someone $7–8 an hour to help me. If I could just get some one to help me out on a regular basis so that I can get the rest I need, I would be able to keep Dad home a lot longer.

Again, thank you for the opportunity to speak here today.

The CHAIRMAN. Thank you, Ms. Reed, a very, very moving statement. We will have a question or two in a moment.

Diane Rowland is the Senior Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on the Future of Medicaid. Thank you for coming.

STATEMENT OF DIANE ROWLAND, EXECUTIVE DIRECTOR, KAISER COMMISSION ON THE FUTURE OF MEDICAID

Ms. ROWLAND. Thank you, Mr. Chairman and members of the Committee.

I am pleased to be here today to testify before the Committee on the need for long-term care reform but it would be hard to make a statement more dramatic than the two we have just listened to. I think it's important, however, to remember that the need for long-term care, which is a devastating emotional and financial burden, occurs for millions of families and millions of Americans. We believe that there are around 11 million adults and 2 million children today with ongoing disabilities related to chronic diseases and conditions. Roughly half of our disabled population is over age 65 but the remainder, as we've heard today, are under age 65. Most people with disabilities, as we've heard demonstrated so aptly, live in the community and receive assistance from family and friends,

but about 2 million more have lost the option to live in the community and are now in nursing homes and other institutions.

Our long-term care population needs a broad range of medical, social, personal care and support services over an extended period of time. There are no logical boundaries in this continuum of services, although we as policymakers and researchers often try to draw them. Families know that the needs cross all lines and will defy any benefit package we try to construct.

There is also no standard definition today of exactly who needs long-term care. It is easy to hear the cases and know that they need it but it's hard to put into legislative language the kinds of criteria that would enable all these families to be able to use services.

I only urge you to remember that merely looking at activities of daily living and physical limitations leave outside of the net many people with cognitive problems who are equally in need of assistance and help, especially the caregivers of these individuals.

The burden today of providing care rests largely on the shoulders of family and friends. There are limited services available in the community. The President's proposal speaks of trying to expand these services. Nursing homes, while available, have constrained bed supply and are not the personal or preferred choice of most individuals. Therefore, in the current system, we require families to provide enormous amounts of informal, unpaid care. When they try to supplement that with paid care, the costs can be overwhelming. In a year, nursing home care can cost over $30,000 a year and we've heard that home care equivalent amounts can be $30,000 or $40,000 for around-the-clock, daily care. Paying for long-term care falls to families.

Unlike medical expenses, long-term care is generally not covered by private insurance and is not included in Medicare. Medicaid is only available when families impoverish themselves to receive assistance. It is this lack of protection that erodes family savings and leads to the call for reform.

I ask you in looking at the reform of long-term health care to remember that most of the population in need of long-term care and their families are not themselves well off. Among persons with disabilities, between the ages of 16 and 64, the poverty rate is 28 percent and compared to poverty rate of about 9 percent for nondisabled individuals in that age group.

For the elderly, 40 percent of the severely disabled are poor in contrast to about 12 percent of the nondisabled elderly. It is therefore, essential that health care reform include provisions to make long-term care affordable to Americans. It is a priority for most of the public to include long-term care in the benefit package.

In a survey that we did just last year asking Americans to rate the importance of different benefits to be included in the health care reform benefit package, 27 percent of adults listed long-term care, including both nursing home care and home care as essential components of any health reform package. Another 41 percent ranked long-term care as a very important benefit.

I look forward to working with this committee to help make that desire of the American people a reality.

Thank you for your time.

I thank you for the opportunity to speak with you today.
[The prepared statement Ms. Rowland follows:]

STATEMENT OF DIANE ROWLAND, SC.D., SENIOR VICE PRESIDENT, HENRY J. KAISER FOUNDATION AND KAISER COMMISSION ON THE FUTURE ON MEDICAID

Thank you Mr. Chairman and members of the Committee for this opportunity to testify on the need for long-term care reform. I am Diane Rowland, Senior Vice President of the Henry J. Kaiser Family Foundation and Executive Director of the Kaiser Commission on the Future of Medicaid. I am also an Associate Professor of Health Policy and Management in the School of Hygiene and Public Health of the Johns Hopkins University.

I am pleased to be here today to describe the problems faced by individuals and families in need of long-term care and to underscore the importance of reforming the way we provide assistance to those in need of long-term care services. My testimony provides an overview of the population in need of long-term care, the gaps in the current delivery and financing of services, and the choices and challenges to be addressed in the reform of the long-term care system.

THE NEED FOR LONG-TERM CARE

Long-term care encompasses a wide range of medical and social services and personal and supportive care that millions of disabled Americans need to cope with ongoing disabilities related to chronic diseases or conditions. Poor health and disability often combine to require both substantial medical care and assistance with basic activities of daily living for the population in need of long-term care.

The long-term care population is diverse and defies simple characterizations. People of all ages with varying types and levels of disability have long-term care needs. the long-term care population is comprised of people with severe and chronic physical and mental impairments; developmental disabilities associated with conditions such as mental retardation, epilepsy, and severe and prolonged mental illness.

Although elderly Americans are the population group most commonly associated with the need for long-term care services, many younger Americans also require comparable levels of assistance with their disabilities. Estimates vary depending on the precise definition of disability. About 11.3 million Americans over age 21 have long-term care needs that limit their ability to live independently, as shown in Figure 1 (Center for Vulnerable Populations, 1992). Of these, 5.5 million, or just over half, are elderly. An additional 2 million children have disabilities that limit their functioning (National Governors' Association, 1990).

Most of the disabled population lives in the community and relies on family and friends for support and assistance. However, people with disabilities who are very old or have serious mental problems often require institutional care. In 1990, about 2.0 million persons were in institutions. including nursing homes, mental hospitals, and facilities for persons with mental retardation (LaPlante, 1992). The vast majority (90 percent) of the nursing home population is age 65 or older. People in institutions generally have more severe disabilities and have more continuous care needs. they often have few other available choices as care in the community for severely disabling conditions is often unavailable or beyond family means.

Part of the problem in assessing the size of the long-term care population stems from the lack of consensus on how to define who needs long-term care. The most common measure used to describe the level of physical disability in the population is limitations in the ability to perform activities of daily living (ADLs). ADLs generally include getting in and out of bed, walking, dressing, bathing, using the toilet, and eating. Persons who over an extended time are unable to perform these activities or require help from another person to perform them compose most of the long-term care population. Individuals with ADL limitations also often have medical problems related to underlying chronic conditions and many have both physical and cognitive deficits.

Dementias, such as Alzheimer's disease, are often a cause for the need for long-term care, particularly among the elderly population. Cognitive impairment is an important contributor to the need for assistance that leads to long-term care, but is not always captured in the ADL definition that relates more directly to physical activity levels. The disabled population with cognitive impairment generally needs more supervision and less direct assistance than those with physical impairments as measured by ADL limitations. Over half (54 percent) of the 1.6 million severely disabled elderly people living in the community suffer from severe cognitive impairment, as shown in Figure 2. Half a million of these severely disabled elderly people have severe cognitive limitations, but are not physically restricted. Three-fifths of

the 1.5 million elderly nursing home residents also have some degree of cognitive impairment.

LONG-TERM CARE SERVICES

The concept of long-term care combines medical, social, personal care, and supportive services needed over an extended period of time. Long-term care needs are neither short-term nor simple. The diverse service needs of the long-term care population reflect the tremendous variations in the factors contributing to the need for long-term care. Poor health, chronic illness and conditions, and frailty must be addressed differently in different individuals depending on age, mental status, and available assistance from family and other informal support groups. As shown in Figure 3, some services are more medical in nature and include rehabilitation services and monitoring medications, while others are related to personal care needs such as eating and bathing. Other long-term care services, such as housekeeping and transportation services, are designed to facilitate the ability of an individual with disabilities to remain independent in the community.

In many cases, it is difficult to establish when long-term care needs begin because the transition from acute to long-term care services is often unclear. For some, the need for long-term care follows a medical problem, such as a stroke, hip fracture or head trauma. For others, particularly among the elderly, limitations result from a gradual decline in functional status over time. In addition, acute medical needs often overlap with long-term care needs. Use of medical services, such as physician and hospital care, is higher among the long-term care population than the general population.

Need for assistance varies tremendously depending on conditions and the availability of family and other sources of support. The majority of those with long-term care needs reside in the community, either with family or in more formal assisted or congregate living arrangements. Survey results reveal that most people with disabilities prefer to remain in the community. Among the elderly, the group most at risk of institutionalization, fear of losing independence and being placed in a nursing home is a major concern.

However, for some, remaining at home is not an option. Today, 2 million Americans are cared for in institutional settings. Nursing homes and residential facilities for the mentally ill and developmentally disabled population remain a central part of the long-term care delivery system. They are a major part of long-term care spending because institutional care provides a comprehensive range of services for individuals with disabilities beyond the scope of care that can reasonably be provided at home with assistance from family and friends or from home care agencies.

Although institutions have historically been the major paid source of care for people with disabilities, use of home and community-based services has grown substantially over the past decade. In 1987, about 41 percent of people with 3 or more limitations in ADLs used formal or paid home care services (Altman and Walden, 1993). Home and community-based services include skilled services provided by health care professionals such as physicians, nurses, and therapists, as well as unskilled services, such as homemaking assistance. In addition, other programs operating outside the home, such as adult day care, provide services in a congregate setting.

Despite the recent growth in formal community-based care, the majority of disabled individuals being cared for in the community still rely on the informal, unpaid help of a spouse, child, or friends. Seventy percent of the elderly with severe disabilities receive no paid assistance and rely solely on informal care provided by family and friends, as shown in Figure 4. A quarter (27 percent) use a combination of formal, paid services and informal care. Only three percent of elderly people with severe disabilities relies entirely on paid help for assistance.

The burden of caregiving falls disproportionately on women, primarily wives and daughters, who comprise nearly three-quarters of the 2.2 million caregivers. For most, caregiving is a long-term personal and financial commitment. Eighty percent of current caregivers have been providing care for a year or longer. The physical, financial and emotional toll on caregivers can be a heavy burden. Many caregivers are themselves suffering from health problems often made more severe by the physical activities of providing assistance to a severely disabled person. Caregivers must struggle to balance other family obligations and work responsibilities with caregiving. Most caregivers are of modest means. Nine out of ten caregivers have incomes below 400 percent of the federal poverty. Nearly one-third are poor or near-poor with incomes below 125 percent of poverty. Thus, providing care can be both an emotional and financial burden with little ability to obtain paid help to alleviate the burden.

PAYMENT FOR LONG-TERM CARE

One of the most serious problems individuals and families face when they themselves, a child, parent, or other family member needs long-term care is the tremendous cost and the lack of financial assistance to help meet those costs. A year of institutional care can exceed $30,000 and community level in-home services can be comparably expensive for severely disabled people who require substantial care on a daily basis.

In 1990, $60 billion was spent on long-term care services in institutions and in the community, as shown in Figure 5 (Levit et al. 1991). The bulk of these expenditures were paid directly by disabled individuals and their families. Unlike medical care expenses, long-term care services are not covered for most people by private insurance policies or Medicare. Long-term care remains a family responsibility for which many families pay dearly to provide the assistance needed for the severe disability of a family member.

The only real hope of assistance with long-term care today is to qualify for the Medicaid program which provides assistance with health and long-term care to low-income individuals. When personal resources are depleted or if the disabled individual is destitute to begin with, the welfare-based Medicaid program will provide financial support. Medicaid is thus the major source of public financing for long-term care services.

In 1990, Medicaid provided long-term care assistance to 1.6 million elderly people and 3.7 million nonelderly disabled persons living in the community and in institutions, as shown in Figure 6 (Rowland, et al. 1992). Individuals with long-term care needs account for a disproportionate share of Medicaid spending. Representing 21 percent of Medicaid beneficiaries, the long-term care population accounts for 68 percent of program expenditures. On a per capita basis, Medicaid spending is much higher among the institutionalized population compared to those in the community.

Medicaid long-term care expenditures are overwhelmingly devoted to nursing home care. In 1990, Medicaid paid $26 billion for nursing home and community-based care, representing almost half of total spending on long-term care services. Of Medicaid long-term care spending, 92 percent went towards nursing home care. Although states may and do offer home and community-based services under their Medicaid programs, many have been reluctant to expand substantially in this area because of limitations on federal matching funds for community-based services and fears that costs will increase rapidly.

Other sources of public financing for long-term care services are extremely limited. Although Medicare provides coverage of acute care services for elderly and disabled beneficiaries, it does not provide long-term personal care for persons in the community or in nursing homes. As a result, Medicare covers less than 5 percent of nursing home expenses. Medicare covers a greater share of home health care, but this is restricted to coverage following an acute medical episode and does not address the needs of individuals with ongoing chronic problems or with needs related to personal care services.

Other public programs, such as the Social Services Block Grant and Administration on Aging programs provide long-term care benefits, but these programs are relatively small and limited in funds. Although private long-term care insurance has emerged over the last decade and 2 million Americans have policies, they are not affordable for most elderly people or available to those with disabilities or at-risk for disability.

Despite the recent growth in the private long-term care insurance market, there are numerous factors that limit its ability to provide substantial assistance in meeting the long-term care needs of the population now and in the future. For the population that is already elderly, these policies are unaffordable. Among the leading policies sold, the average annual premium for a high quality long-term care insurance policy in 1992 was $2,228 at age 65 and $7,202 at age 79 (Health Insurance Association of America, 1994).

Because the cost of these policies is so high, it is unlikely that many elderly people will be able to purchase private long-term care insurance. Work by the Brookings Institution shows that even under an optimistic scenario, less than 20 percent of elderly people would have private long-term care insurance in 2018 and most of these would be elderly people with higher incomes (Weiner and Illston, 1994). Thus, most elderly people with disabilities would continue to face substantial out-of-pocket costs.

Barriers also exist in marketing these policies to younger people. Working age adults are unlikely to purchase these policies and employers have been slow to offer or contribute to this benefit. In 1992, only 350,000 policies had been sold through 506 employers (Health Insurance Association of America, 1994).

In essence, paying for long-term care is today a personal and family affair and not part of either the social insurance protection provided by Medicare or the private insurance protection for medical care that most of us have though our employer-based coverage. It is this lack of protection for what is often an expense that erodes savings and family finances over time and in some cases hits suddenly as a catastrophic burden that leads families to rank long-term care coverages as an essential gap to fill.

THE IMPORTANCE OF LONG-TERM CARE REFORM

Lack of assistance with the cost of long-term care is a fear of most families and an unfortunate reality for those families with someone who is severely disabled. The absence of a long-term care financing system, other than the means-tested Medicaid program, results in tremendous financial burdens for individuals with disabilities and their families, especially for low and moderate income families.

People with long-term care needs are much more likely to be financially strapped than other people. Among persons with disabilities between age 16 and 64, the poverty rate is 28 percent compared to 9 percent for those without disability (Center for Vulnerable Populations, 1992). Among the elderly population with severe disabilities, 40 percent are poor compared to 12 percent of the general elderly population, as shown in Figure 7 (Rowland, 1989). An additional 43 percent of elderly people with disabilities are near-poor. Thus, a striking 83 percent of elderly people with severe disabilities have incomes below 200 percent of poverty. Meeting basic living expenses, long-term care needs and medical expenses can result in extremely difficult financial and personal choices for individuals and their families.

The rapid growth in the costs of long-term care and gaps in available services have heightened the need for long-term care reform. The situation is projected to intensify as the size of the elderly population grows, especially with the rapid increase in those over age 85. This projected growth in the elderly population and the associated increase in the need for long-term care services creates additional pressure to reform a system that does not work very well.

Currently, the need for long-term care services exceeds the system's capacity and the problem will only be worse in the future. To try to limit long-term care costs, states have focused on holding down the number of nursing home beds, limiting reimbursement to nursing homes, and limiting the services offered in the community. In addition to constrained capacity, current delivery and financing arrangements have insufficient coordination between acute and long-term care. This can result in individuals receiving more intensive services than needed or having care provided in a setting that is not the most appropriate or cost-effective.

The stresses in the long-term care system will increase with the growth in the elderly population. According to projections from the Brookings Institution, between 1993 to 2018 the number of elderly users of nursing homes is expected to increase from 2.2 to 3.6 million and users of home care from 5.2 million to 7.4 million (Weiner and Illston, 1994). With this dramatic growth in the number of people who will need long-term care services, expenditures are projected to more than double over the next twenty-five years putting tremendous pressure on current public financing programs.

CHOICES AND CHALLENGES IN LONG-TERM CARE REFORM

As health reform options are debated in the Congress and among the American public, one of the key issues will be whether coverage should be extended to include long-term care services and if so, how such a benefit should be structured, delivered, and financed. The President's plan provides a starting point in the debate by providing for a new home and community-based services program for people with disabilities of all ages, setting standards and providing incentives for the purchase of private long-term care insurance, and improving access to nursing home services under Medicaid.

Improving coverage for long-term care is an important component of health reform for the American people. In a 1993 national survey sponsored by the Henry J. Kaiser Family Foundation and the Commonwealth Fund, adults were asked to rate the importance of including various benefits as part of a uniform benefit package under health reform. Over a quarter (27 percent) of the surveyed adults viewed inclusion of nursing home care and home care as essential and 41 percent rated these services as very important to include in the basic benefit package (Kaiser/Commonwealth Survey, 1993). It is interesting to note that 37 percent of those between age 18 and 49 rated this coverage as essential compared to 29 percent of those between age 50 and 64 and 26 percent of those over age 65. Long-term care reform is not an issue solely for the elderly—it is a concern that affects us and our families.

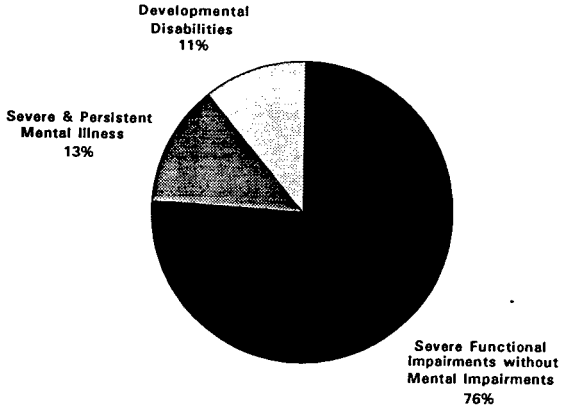
However, despite the support for long-term care, fashioning a solution will not be easy. There is a limited base of public assistance today for long-term care services through the means-tested Medicaid program, but most reform options will require a substantial expansion of coverage beyond that provided by Medicaid. Major choices must be made regarding the appropriate public versus private mix of services and financing. Currently, there is only limited private insurance available for long-term care. Whether to provide incentives to broaden private coverage or to provide expanded public coverage through Medicare, Medicaid, or a new program structure is a critical unanswered question in the reform debate. Moreover, even among those advocating expanding public options for coverage, there is no clear consensus on whether to build on the social insurance structure of Medicare, provide a more targeted program for the low-income disabled through the means-tested Medicaid structure, or build a new program outside of Medicare and Medicaid as the President has proposed.

The scope of benefits and integration of services poses another challenge to policymakers. For researchers and policymakers, long-term care and acute care and nursing home and home care coverage are often separated as different issues that can be addressed as distinct initiatives. Yet, for people with disabilities and their families, service needs cannot be neatly classified and separated. There is a continuum of care needs that crosses the artificial line in benefit and package design between acute and long-term care. The challenge in long-term care reform is to provide flexible enough benefits to meet the diverse and complex needs of people with disabilities and integrate these services with the provision of medical care.

Health care reform that includes long-term care holds the promise of beginning to move toward an integrated system of health care services that meets the needs of the most vulnerable and disabled people in our society. Reform will not be easy and there are no agreed upon solutions, but unless we begin now, we will not achieve meaningful health reform for the millions of people with disabilities with on-going health and chronic care needs.

Thank you for this opportunity to testify. I would welcome any questions.

Figure 1: Distribution of Persons over Age 21 with Chronic Disabilities

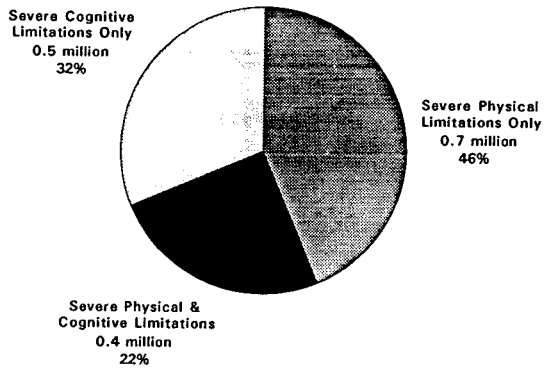


Total = 11.3 Million People

Source: Center for Vulnerable Populations, 1992.

The Kaiser Commission on THE FUTURE OF MEDICAID

Figure 2: Distribution of the Elderly Population with Severe Disabilities, 1989



Total = 1.6 Million Elderly People

Severe Physical Limitation: Requires personal assistance with 2 or more ADLs
Severe Cognitive Limitation: 5 or more errors on SPMSQ or reported senile

Source: Rowland, 1989. Estimates of non-institutionalized population.

The Kaiser Commission on THE FUTURE OF MEDICAID

Figure 3

Types of Long–Term Care Services

Residential Services

Institutional
- Nursing Home Care
- Hospitals*
- ICF/MRs
- Institutions for Mental Diseases
- Inpatient Psychiatric Hospitals

Community
- Assisted Living Programs
- Supervised Apartment Living

Community–Based Services

- Homemaker Services
- Personal Care
- Transportation
- Attendant Care
- Case Management
- Adult Day Care
- Nutritional Programs

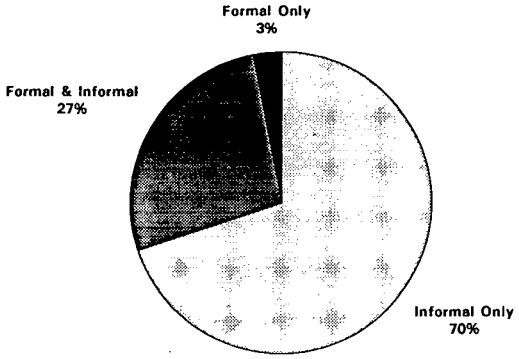
Specialized Services

- Medication Monitoring
- Skilled Nursing Care
- Psychological/Psychiatric Services
- Home Health Services
- Therapies (Speech, Physical, etc.)
- Emergency Response Systems
- Special Education

* Usually when a nursing facility is not available

Source: Center for Vulnerable Populations, 1992.

Figure 4: Source of Home Care for the Elderly Population with Severe Disabilities, 1989

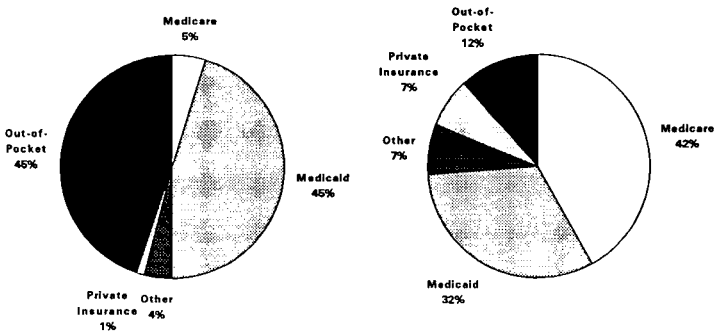


Total = 1.6 Million Elderly People

Source: Rowland, 1989

The Kaiser Commission on
THE FUTURE OF MEDICAID

Figure 5: Sources of Long-Term Care Funding, 1990



Nursing Home Care
Total = $53.1 Billion

Home Health Care
Total = $6.9 Billion

Source: Levit et al, 1991.

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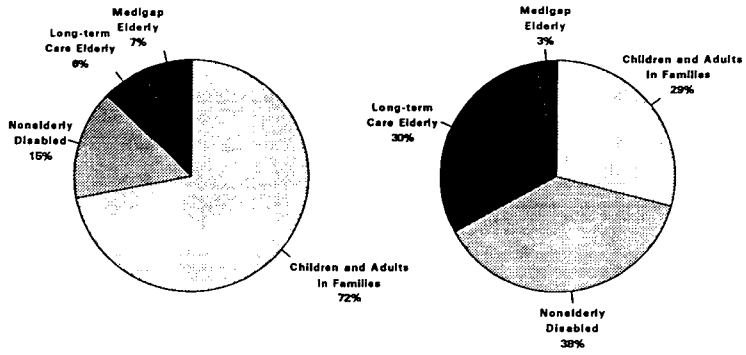
THE FUTURE OF MEDICAID

Figure 6: Medicaid Beneficiaries and Expenditures, by Population Group, 1990



Source: Rowland et al., 1992.

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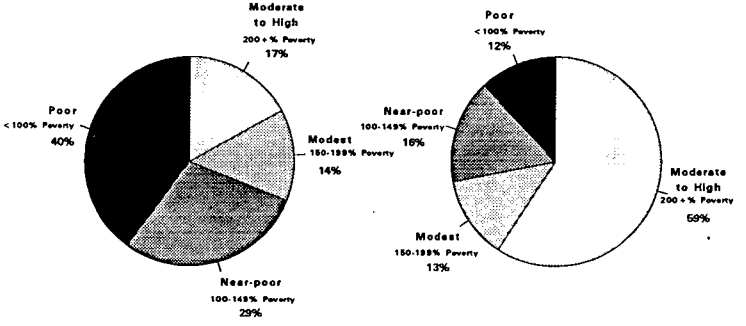
Figure 7: Income Distribution of the Total Elderly and Elderly Population with Disabilities, 1989



Source: Rowland, 1989. Estimates of the non-institutionalized population.

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[Subsequent to the hearing, the following information was received for the record:]

QUESTIONS FOR DIANE ROWLAND

From Senator Pryor:

1. As you pointed out in your testimony, there are many groups of people besides the elderly who have long-term care needs. Do you have any thought on how our present service models, particularly in the Medicaid program, might be expanded or changed in health care reform to better meet the diverse needs we will be looking at?

2. As we design a new system to provide long-term care, what efforts should we make to ensure that the needs of rural areas are met?

3. Testimony we have heard underscores the patchwork system we currently have for long-term care. If we were to strengthen private insurance coverage, would our current Medicaid system be sufficient to cover those who cannot afford insurance and fall through the cracks with respect to long-term care?

From Senator Feingold:

1. I thought your statement was excellent, and I especially thought you did an excellent job in highlighting the caregiver aspect of long-term care. Often long-term care is viewed with the individual needing direct assistance in mind, but as many in this room can attest, the caregiver should also be seen as a consumer of long-term care services. I also commend you for bringing out how much long-term care is a woman's issue—not only in caregiving, but also as individuals receiving care. Women live longer than men, and generally have far fewer resources from which to fund their own care. Long-term care reform should be high on the agenda of any group that advocates on behalf of women.

In your statement, you briefly touched on the consequences if we fail to reform our long-term care system—noting the growth of people who will need long-term care, and the potential pressure on publicly financed programs. Could you expand on that a bit, and supply us with any statistics that will help us better understand what will happen if we don't reform our long-term care system?

RESPONSES TO QUESTIONS FROM THE SENATE SPECIAL COMMITTEE ON AGING

Senator Pryor's questions:

(1) There are many groups of people besides the elderly who have long-term care needs. Do you have any thoughts on how our present service models, particularly in the Medicaid program, might be expanded or changed in health care reform to better meet the diverse needs we will be looking at?

Services designed for long-term care should provide that beneficiaries are cared for in settings best-suited for their needs and in environments that are the least dependence-fostering. Although efforts under Medicaid have been made to expand the scope of home and community-based services in the long-term care system, the program remains biased toward institutionalized care. Many elderly and non-elderly disabled individuals would prefer to stay at home, but cannot afford to do so because Medicaid coverage is more available in institutional rather than in community-based settings.

Medicaid today plays an expanding role in providing medical care and long-term care services to the disabled, including the mentally retarded, the chronically mentally ill, and the physically and developmentally disabled. This assistance also includes help to the growing numbers of disabled persons with AIDS who, impoverished by medical bills, turn to Medicaid for financing assistance when private insurance is no longer available. Yet, Medicaid's medically-oriented benefits often leave the disabled population without social support services critical to improved functioning.

The following are general suggestions to reform the long-term care system to enable individuals to be cared for in the most appropriate and desirable setting:

Home and community-based care must be expanded.

Discharge planning should be reoriented to promote discharge to home, with use of community services or various assisted-living options, rather than nursing home beds.

Improved integration of acute and long-term care services could produce improvements in efficiency, efficacy, and cost of Medicaid chronic care, personal support services, and housing.

Better mechanisms are needed to determine the appropriate balance between community and institutional care.

The challenge in long-term care reform is to provide flexible enough and affordable benefits to meet the diverse and complex continuum of needs of people with disabilities. Further integrating these services with the provision of medical care is also warranted.

(2) As we design a new system to provide long-term care, what efforts should we make to ensure that the needs of rural areas are met?

Research studies show that people in rural areas have lower participation in Medicaid and have been shown to have worse health status than those in urban areas. Further research into how Medicaid programs in rural areas can be more effective is needed to inform policymakers about the special needs of that population. It is important to examine factors pertaining to Medicaid eligibility such as the structure of the rural family, the extent of provider help with Medicaid enrollment, and the Medicaid eligibility policy in rural states. In addition, the availability of home and community-based services in rural areas and the availability of long-term care workers in the area need to be studied. Traditional models of delivering long-term care services are more effective in areas with large population concentrations. Thus, other models of service delivery need to be examined for effective long-term care delivery in rural areas.

(3) If we were to strengthen private insurance coverage (for long-term care), would our current Medicaid system be sufficient to cover those who cannot afford insurance and fall through the cracks with respect to long-term care?

Strengthening private insurance coverage for long term care to make such policies affordable for Americans is unlikely to solve the problem. Among the work done by the Brookings, Institute, findings show that even under an optimistic scenario, less than 20 percent of elderly people would have private long-term care insurance in 2018, and most of these would be elderly people with higher incomes. Thus, many Americans will still not have the means to purchase long-term care insurance without expansion of Medicaid, or an alternative public financing system, to include a broader base of non-poor people. Many will continue to impoverish themselves or continue to transfer their assets to secure eligibility for coverage under Medicaid.

Marketing private long-term care insurance primarily to a younger generation is likely to remain difficult. In particular, younger individuals will tend not to buy private long-term care insurance because the risk of any catastrophic event occurring seems remote, while the everyday financial strains of everyday life—car payments, phone bills, mortgages—are very real. In addition, some have raised concerns that broadening the means-testing scope will provide a disincentive to those with modest incomes to purchase private long-term care insurance.

Senator Feingold's questions:

(1) In your statement, you briefly touched on the consequences if we fail to reform our long-term care system—noting the growth of people who will need long-term care, and the potential pressure on publicly-financed programs. Could you expand on that a bit, and supply us with any statistics that will help better understand what will happen if we don't reform the long-term care system?

According to projections from the Brookings Institution, between 1993 and 2018, the number of elderly users of nursing home care is expected to increase from 5.2 million to 7.4 million. Without long-term care reform, expenditures are expected to double over the next 25 years, putting tremendous pressure on current public financing programs. Medicaid expenditures are projected to increase from $22.4 billion in 1993 to $49 billion in 2018. Currently nearly half of all long-term care costs are paid for by individuals out-of-pocket, and Medicaid is the only source of formal funding for long-term care. For the individual and his/her family, the financial burden of paying for long-term care services will continue to be difficult to overcome. As is the case right now, when their personal resources become depleted, these individuals will become eligible for Medicaid, adding to Medicaid's costs, unless another alternative is developed.

The CHAIRMAN. Thank you very, very much, Ms. Rowland.

Our next witness is Gail Shearer, Manager of Policy Analysis for the Consumers Union, Washington, D.C. Thank you for coming.

STATEMENT OF GAIL SHEARER, MANAGER, POLICY ANALYSIS, CONSUMERS UNION

Ms. SHEARER. Thank you, Chairman Pryor.

I appreciate the opportunity to present Consumers Union's views on the Nation's long-term care crisis and how best to solve it. In my testimony, I plan to address the dimensions of the long-term

care crisis, the flaws of the private long-term care insurance market, the need for Federal regulation care of long-term care insurance, and the need to include long-term care benefits in a reformed health care system.

The Nation's failure to create a long-term care safety net means that families in need of long-term care can be devastated. It is hard to overstate the impact that a chronic, long-term illness can have on a family. As you've heard from the compelling testimony of families this morning, American families have a very real and very urgent long-term care need.

Our present patchwork system for financing long-term care is not serving families well. A family whose baby is born with congenital problems that result in the need for extensive technological assistance to stay alive faces the need for long-term care assistance every day. Members of families whose primary breadwinner is paralyzed in an automobile accident must adjust their lives to provide the needed care and to come up with the financial plan to replace the needed income. Families with parents or grandparents with Alzheimer's disease must learn how to juggle the caregiving needs of their parent or grandparent with the financial and nurturing needs of other family members.

The long-term care problem is immense from a public policy perspective. The aging of the population will soon make today's long-term care financing challenges appear relatively modest. Over the next 25 years, the total bill and the public sector bill for long-term care will more than double in real terms.

The private long-term care insurance market is flawed and needs improved regulation. Consumer Reports magazine has published two in-depth analyses of the private, long-term care insurance market. Our findings were disturbing. We found widespread agent abuses, fine print restrictions in coverage, inadequate inflation provisions, failure to protect policyholders who pay in thousands of dollars in premiums but later drop the policy and pricing practices that mislead consumers into thinking the premium will remain constant when the fact is it is likely to increase.

In general, long-term care insurance policies serve the profit-protecting interests of insurance companies better than they serve the real needs of consumers. It is important for this Committee to fully understand the market flaws. Public policy solutions to the long-term care problem that rely on increased ownership of flawed private policies will not serve consumers' interests.

State regulation of this insurance is inadequate and Federal regulation is long overdue. Just as Congress recognized under your leadership, Chairman Pryor, in 1990 that State regulation of the Medicare supplement insurance market was inadequate and that market needed Federal regulation, Congress should take responsibility for improving regulation of the long-term care insurance market.

We believe that all purchasers of long-term care insurance should be protected against the abuses in this marketplace, not just those that live in States that regulate the market aggressively. The State insurance commissioners are on record accepting Federal regulation of long-term care insurance if States do not adopt adequate consumer protection. State adoption of consumer protections

of this insurance continues to be inadequate and we believe that Federal standards are long overdue.

However, even if regulation were improved, the private market cannot solve the long-term care problem. Even if Congress or the States enacted the ideal regulatory reform package that addressed all of the shortcomings of this market, the private market would be unable to solve the Nation's long-term care crisis. This is because the private market will never protect people with existing health conditions who would not qualify for a policy, the many millions of middle-income and low-income consumers who cannot afford a policy, and young people who are victims of illness or accidents before they would even consider buying a policy. Companies now reject as many as 30 percent of applicants, those with higher than average health risks.

There are estimates that by the year 2018, only 20 percent of the elderly would be able to afford a long-term care policy. The best public policy solutions to the long-term care crisis is to include long-term care benefits in a reformed health care system. The community-based benefit in the Administration's Health Security Act is a very important first step that health care reform should include at least a blueprint for expanded long-term care benefits.

The Health Security Act would provide, as you know, the important new home and community-based, long-term care program for persons needing assistance with three activities of daily living. Cost-sharing would depend on income and States would have some flexibility.

It is important to recognize that the requirement that potential beneficiaries must be unable to perform three activities of daily living limits the benefit to a small portion of people in need of long-term care.

Consumers Union supports including in the health plan a blueprint for future expansion of public long-term care benefits, including both expanded community-based care and nursing home care. We recognize that these benefits will require a new funding base and we have some recommendations for how to do that.

I thank you very much for the opportunity to testify today.

[The prepared statement Ms. Shearer follows:]

TESTIMONY OF GAIL SHEARER, MANAGER, POLICY ANALYSIS

Summary: Consumers Union Testimony

SOLVING THE NATION'S LONG-TERM CARE CRISIS

The nation's failure to create a long-term care safety net means that families in need of long-term care can be devastated.

The long-term care problem is immense from a public policy perspective.

Because of the aging of the population, the real dollar costs of long-term care will more than double over the next 25 years.

The private long-term care insurance market is flawed and needs improved regulation.

Problems in the market include inadequate inflation protection, high lapse rates, absence of nonforfeiture benefits in the event of lapse, marketplace confusion, agent abuses, and unanticipated premium increases.

State regulation of long-term care insurance is inadequate; federal regulation is long overdue.

In 1989, the President of the National Association of Insurance Commissioners conceded that federal regulation of long-term care insurance would be appropriate if states failed to protect consumers adequately by 1991.

Five years after the NAIC statement, states are not adequately protecting consumers.

Even if regulation were improved, the private market cannot solve the long-term care problem.

Companies reject as many as 30 percent of applicants; the private market will never be able to serve people with higher-than-average risk of needing long-term care.

The Brookings Institution estimates that only 20 percent of the elderly would be able to afford a private long-term care insurance policy in the year 2018, and that such insurance would reduce Medicaid nursing home expenditures by just 2 percent at that time.

The best public policy solution to the long-term care crisis is to include long-term care benefits in the reformed health care system.

The community based benefit in the Administration's Health Security Act is an important first step, but health care reform should include at least a blueprint for expanded long-term care benefits.

Consumers Union[1] appreciates the opportunity to present our views on the nation's long-term care crisis—and how best to solve it. Consumers Union has monitored the long-term care marketplace since 1988, and we have repeatedly found that the private market is severely flawed. In my testimony, I plan to address the dimensions of the long-term care crisis, the flaws of the private long-term care insurance market, the need for federal regulation of long-term care insurance, and the need to include long-term care benefits in a reformed health care system.

The nation's failure to create a long-term care safety net means that families in need of long-term care can be devastated.

It is hard to overstate the devastating impact that a chronic, long-term illness can have on a family. A family whose baby is born with congenital problems that result in the need for extensive technological assistance to stay alive, and various types of therapy in order to improve the quality of life, faces the need for long-term care assistance every day. Members of families whose primary breadwinner is paralyzed in an automobile accident must adjust their lives to provide the needed care and come up with a financial plan to replace the needed income. Families with grandparents with Alzheimer's disease must learn how to juggle the caregiving needs of their parent/grandparent with financial and nurturing needs of other family members.

Any family with a major long-term care problem must struggle to meet the challenge of the immediate health care and personal assistance needs of their family member. Many must also find a way to replace the income of the family member who becomes chronically disabled. And then the families must deal with the typically catastrophic cost of paying for their loved one's care. They soon discover that the patchwork financing system that we have provides very limited private long-term care health insurance benefits and public benefits only after severe means-tested (far-below-poverty) standards have been met. With the cost of a year in a nursing home easily reaching $50,000, it doesn't take long for most families to spend down to poverty, if one family member ends up in a nursing home.

Millions of families face these challenges every day. A recent Gallup poll revealed that 30 percent of Americans—57 million people—have a close relative who has needed long-term care in the past five years. 61 percent of these families reported increased family stress—23 percent reported a negative effect on family members' health, 20 percent reported a negative impact on job performance, and 18 percent reported a negative effect on their ability to hold a full time job.[2]

The long-term care problem is immense from a public policy perspective.

The aging of the population will soon make today's long-term care financing challenges appear relatively modest. The Brookings Institution projects that between 1993 and 2018, elderly users of nursing homes will increase 2.2 million to 3.6 million, while users of home care will increase from 5.2 million to 7.4 million. The total

[1] Consumers Union is a nonprofit membership organization chartered in 1936 under the laws of the State of New York to provide consumers with information, education and counsel about goods, services, health, and personal finance; and to initiate and cooperate with individual and group efforts to maintain and enhance the quality of life for consumers. Consumers Union's income is solely derived from the sale of Consumer Reports, its other publications and from noncommercial contributions, grants and fees. In addition to reports on Consumers Union's own product testing, Consumer Reports with approximately 5 million paid circulation, regularly, carries articles on health, product safety, marketplace economics and legislative, judicial and regulatory actions which affect consumer welfare. Consumers Union's publications carry no advertising and receive no commercial support.

[2] The Gallup Organization/Alzheimer's Association poll of January, 1994.

bill for long-term care will more than double (in real terms) during this time period, rising from about $75 billion in 1993 to about $170 billion in 2018.[3]

Without any change in public policy, the public sector (taxpayer paid) costs of long-term care will grow dramatically over the next 25 years. Total Medicare/Medicaid spending for long-term care is projected to grow from $40 billion in 1993 to $83 billion in 2018 (in constant 1993 dollars). The failure to include long-term care benefits in a health care reform bill—or at least a blueprint for expansion in the future—is likely to lead to efforts to control costs by cutting quality, and a continued deterioration in the level of care provided to people poor enough to qualify for public benefits. We believe that the quality of long-term care would improve and that cost containment efforts will be more effective if—as in Medicare—the entire population (not just the poor) has an interest in the success and quality of the program.

The private long-term care insurance market is flawed and needs improved regulation.

Consumer Reports has published two in-depth analyses of the private long-term care insurance market, in May 1988 and June 1991. Our findings were disturbing—we found wide-scale agent abuses, fine-print restrictions in coverage, inadequate inflation provisions, failure to protect policyholders who pay in thousands of dollars in premiums but later drop the policy, and pricing practices that mislead consumers into thinking the premium would remain constant when in fact it was likely to increase. In general, long-term care insurance policies serve the profit-protecting interests of insurance companies better than they serve the very real needs of consumers. It is important that this Committee fully understand the market flaws—public policy "solutions" to the long-term care problem that rely on increased ownership of flawed private policies will not serve consumers' interests.

I would like to elaborate briefly on some of the most egregious problems in the private long-term care insurance market.

Inflation.—Failure to adequately protect against inflation is one of the most severe flaws of the long-term market, a market in which benefits of a typical policy are expected to be paid (if at all) many years in the future. Without any inflation protection, a long-term care policy provides only illusory protection. Policies vary in how they define inflation coverage, in whether they calculate benefits with a simple or compound rate, in whether or not affirmative action on the part of consumers is needed for coverage to keep up with inflation, and the age limits for whom inflation adjustments are not available (e.g., people under 80 years old).

High lapse rates/nonforfeiture benefits.—Most policies provide no refund in the event the policyholder discontinues the policy. (And, according to the General Accounting Office survey, insurers expect 60 percent of policyholders to lapse within 10 years.) Consumers have a lot to lose: a person turning 75 would have spent about $20,000 for ten years' worth of a policy; a 90-year-old who has paid premiums for 25 years would have about $60,000 of equity in a long-term care policy.

Marketplace confusion: need for simplification.—No long-term care policies are alike, and it is virtually impossible to make a rational comparison of policies that are in the marketplace. The definition of terms—"skilled nursing facility," "licensed nursing facility," "custodial care," "medically necessary," "home health care benefit," "inflation benefit," "nonforfeiture benefit" varies from policy to policy. Terms like "inflation benefit" can have dramatically different values because of subtle differences in assumptions made by actuaries. These figures can easily be manipulated and are very difficult for consumers to understand. It is virtually impossible for consumers to make a comparison of similar long-term care insurance policies because the terms—and indeed the implications of the fine print in the defintions—vary so widely. Standardization of benefit packages—as adopted for the medigap market by the pathbreaking reform bill of 1990—is badly needed in this market.

Agents.—Agents selling long-term care insurance often do not understand the products they are selling, tend to misrepresent provisions in the policies, fail to take into account medical histories (subjecting policyholders to post-claims underwriting), fail to provide outlines-of-coverage or buyers guides, and sell policies that do not meet the long-term care needs of the purchasers. High first-year commissions give agents a strong incentive to make a sale—not to take the consumer's long-term interest into account. Many sales are inappropriate and result in lapsation (and loss of all equity) in the early years.

Premium stability.—Consumers are asked to purchase a policy without knowing the price of the protection they are buying. This is because companies (despite selling what are called "level premium" policy) are free to increase the premium in the future (sometimes with the need for approval for the rate increase from the from

[3] Joshua M. Wiener and Laurel Hixon Illston, "How to Share the Burden: Long-Term Care Reform in the 1990's," *The Brookings Review*, Spring 1994, Volume 12, Number 2.

the state insurance commissioner.) Once consumers buy a policy, they are locked into it because of the absence of nonforfeiture values. Premium increases are especially burdensome to senior citizens who live on fixed incomes. If premiums increase dramatically, forcing policyholders to drop their policies just as their risk of needing long-term care increases, then the market will not be serving consumers well.

Requiring noncancelable policies (i.e., policies whose premium can not increase in the future) is one option, and one that would be relatively desirable if there were satisfactory guarantee system in place. By requiring policies to be noncancelable, insurers would be forced to carefully assess risk, rather than shift the risk to the consumer.

State regulations is inadequate; federal regulation is long overdue.

Just as Congress recognized in 1990 that state regulation of the Medicare supplement insurance market was inadequate and that this market needed federal regulation, Congress should take responsibility for improving the regulation of the long-term care insurance market. We believe that all purchasers of long-term care insurance should be protected against the abuses in this marketplace—not just those that live in a state that regulates the market aggressively.

Consumers Union has worked with the National Association of Insurance Commissioners for many years to help them to improve their model regulation. Current issues under discussion include the need for premium stability and development of a standard minimum nonforfeiture benefit. The NAIC model does not require building in inflation protection, nor has the NAIC taken steps to standardize long-term care benefits in order to facilitate comparison shopping. Another major problem is that states are free to reject consumer protections that are included in the NAIC model—and too often do just this, after intense lobbying from the insurance industry. A recent report by the Health Insurance Association of America shows very spotty state efforts to comply with the NAIC long-term care insurance model regulation and act.[4] Only 37 states, for example, had adopted the (limited) inflation requirements (that require the offering of the inflation option); only 23 states complied with the NAIC model's standards for marketing long-term care insurance.

The NAIC is on record accepting federal regulation of long-term care insurance if states do not adopt adequate consumer protections.[5] State adoption of consumer protections of long-term care insurance consumers continues to be inadequate. We believe that federal standards for long-term care insurance are long overdue.

Even if regulation were improved, the private market can not solve the long-term care problem.

Even if Congress (or the states) enacted the ideal regulatory reform package that address all of the shortcomings of the market, the private market would be unable to solve the country's long-term care crisis. This is because the private market will never protect people with existing health conditions (who would not qualify for a policy), the many millions of middle-income and low-income consumers who cannot afford to buy a policy, and young people who are the victims of illness or accident before they would even consider buying a policy. Companies reject as many as 30 percent of applicants, those with higher than average health risks. Policies are expensive, costing $100 or more per month for a 65-year-old, and much more for older applicants. Policies often restrict benefits for certain types of care (e.g., custodial), and consumers seldom fully understand the implications of the fine print in the contracts.

The private market is not well suited to insuring the long-term care needs of people under age 65. The Pepper Commission heard compelling stories of a family who struggles to meet the daily needs of a husband crippled by multiple sclerosis and of a family whose child requires round-the-clock access to medical care because of a birth defect. Long-term care insurance is unable to help families like these who are in need today, or other young families who are at risk of having long-term care needs before they buy a private policy.

From a public policy perspective, affordability is a key reason why the private market cannot solve the nation's long-term care crisis. Even under optimistic assumptions about people's willingness to buy policies, the Brookings Institution estimated that a fairly limited private insurance policy could be purchased by only 20 percent of the elderly by the year 2018 and that such coverage could make an insig-

[4] "Long-Term Care Insurance: State Compliance with NAIC Model," December 1993.

[5] Then NAIC President (now Member of Congress) Earl Pomeroy, testifying before the House Ways and Means Committee's Health Subcommittee, said that there would be little (NAIC) resistance to federal long-term care insurance standard if a substantial number of states failed to adopt consumer protection standards within two years of this testimony, which took place on May 17, 1989.

nificant reduction in Medicaid long-term care expenditures, reducing Medicaid nursing home expenditures by only about 2 percent in 2018.[6]

The best public solution to the long-term care crisis is to include long-term care benefits in the reformed health care system.

We believe that the best and fairest way to finance long-term care is through a public program that is financed largely by tax revenues that are based on ability to pay. In 1989, Consumers Union developed the parameters that we believe should guide a public long-term care program.[7] They are:

The program should protect people of all ages;
The program should be financed progressively;
The program should be comprehensive and universal;
The program should be self-funded;
Administrative costs should be minimized;
Cost-sharing should be an integral part of the program, but should not impose undue hardship;
Cost control and quality control should be built-in to the program;
Costs should be shared equitably between generations;
Regulation of the private market should be effective and strictly enforced; and
Public costs should be minimized while meeting consumers' needs.

I would like to briefly expand on two of these points. First, the long-term care program should cover people of all ages, not just people over 65 years old. Many younger people are disabled or chronically ill. Approximately 40 percent of people who need personal assistance because of inability to perform one or more "activities of daily living" are under age 65. Children and young adults are the people least likely to purchase private long-term care insurance, and are least likely to be able to plan ahead for future long-term care costs.

Second, the program should be comprehensive, covering both community/home health care costs and nursing home costs and universal, protecting all Americans at risk of needing long-term care on a mandatory basis. We believe that the country should move away from a welfare approach to funding long-term care. The Medicare and Medicaid share of long-term care costs is already high, at about 50 percent. Even without a change in public policy, the increasing number of elderly would increase the Medicaid long-term care expenditures in the coming decades. The welfare approach is extremely inequitable. Since taxpayers already pay a large share of long-term care costs, many of them seek legal help to exploit loopholes to allow them (or their parents) to qualify for Medicaid. It does not seem fair to reward relatively sophisticated families with qualification for long-term care coverage, and leave others who comply with the spirit of the program without any protection. We believe that a social insurance program that protects all Americans against the devastating costs of long-term care is the best way to correct these inequities.

Consumers strongly support including long-term care benefits in a reformed health care system. 90 percent of those polled (in a 1993 Consumers Union/Gallup poll) support including both home care and nursing benefits in a benefits package. Support was consistent among all age brackets—even young adults recognize the importance of extending long-term care benefits to all.

Tax preferences.—We are troubled by the approach that several health reform bills (e.g., S. 1533) take with regard to long-term care. Putting aside our preference for including long-term care benefits in the benefits package, some of the bills encourage the purchase of private long-term care insurance policies through tax incentives, while failing to improve the regulation of this market. We are concerned that such proposals to provide tax preferences for the purchase of long-term care insurance would create a loss in tax revenues which would have to be financed by people in all income ranges, while the tax benefit will accrue to relatively high income people who can afford to buy a policy. At a minimum, tax preferences should be accompanied by tough federal standards for this market and should be funded by new tax revenues from relatively high income taxpayers.

The community based benefit in the Health Security Act is an important first step, but health care reform should include at least a blueprint for expanded long-term care benefits.

The Health Security Act would provide an important new home and community based long-term care program for persons needing assistance performing 3 activities of daily living. Cost-sharing would depend on income, and states would have some flexibility in providing the benefits. While this community based benefit is an important first step in expansion of a public long-term care program, it is important to recognize that the requirement that potential beneficiaries must be unable to per-

[6] Wiener and Illston, p. 19.
[7] *Long-Term Care: Analysis of Public Policy Options,* Consumers Union, January 1989.

form three "activities of daily living" limits the benefit to a small portion of people in need of long-term care. For example, a person incapable of moving around (e.g., from bed to a chair) and unable to got to the bathroom by herself can not be left home alone all day long, but may not qualify for the new community based benefit.

Consumers Union supports including in the health plan a blueprint for future expansion of public long-term care benefits, including both expanded community based care and nursing home care. We recognize that these benefits will require a substantial new funding base, and we recommend that you consider increasing estate taxes (possibly by taxing capital gains at death), charging premiums for persons with incomes above a certain level, and increasing income taxes, and/or payroll taxes to pay the bill. We believe it is preferable to spread the long-term care burden widely, rather than having families who are already in crisis with a long-term care need have to foot the whole bill, often leading to impoverization. As a nation, we will be facing the increasing long-term care costs one way or another—through personal family hardship and regressive out-of-pocket payments, or through a safety net with protection for all, with financing based on ability to pay. We urge you to take any steps you can to help the nation work toward a fairer way to pay for long-term care costs.

If the Congress decides not to expand long-term care benefits in the benefits package, then the second-best alternative would be to create a voluntary Medicare Part C program to allow people enrollment opportunities at a limited number of ages (e.g., 45, 55, and 65) that would provide for long-term care benefits that are funded entirely by premiums paid on a voluntary basis. By designing a system that is accountable to the public rather than insurance company shareholders, this type of approach would be better able to provide true protection for many consumers in need of long-term care, without the fine print restrictions and loopholes that exist in today's private long-term care insurance market.

Thank you very much for the opportunity to testify today. We look forward to working with this Committee as this important debate continues.

[Subsequent to the hearing, the following information was received:]

QUESTIONS FOR GAIL SHEARER

From Senator Pryor:

1. In any health care reform plan that is passed, there will undoubtedly be some role for long-term care insurance. What do you think is the best way to avoid developing a two-tiered system whereby people who can afford long-term care insurance have access to better services?

RESPONSE OF GAIL SHEARER, CONSUMERS UNION, TO QUESTION OF SENATOR PRYOR

The best way to avoid the development of a two-tier long-term care system is to build long-term care benefits into the standard benefit package that covers all eligible consumers. The Health Security Act takes the first step through the inclusion of community based long-term care benefits. The Congress should spell out in the health reform bill the blueprint for expanding these benefits—both reducing the very high level of disability required to qualify, and expanding the benefit to include nursing home benefits.

In the absence of the inclusion of expanded long-term care benefits, people at low income levels will continue to be at risk of impoverization because of long-term care costs. Higher income people may have the resources to purchase a private policy. Middle income consumers will continue to have incentives to divest their assets to enable them to qualify for Medicaid benefits, creating continued inequities in terms of the distribution (by income) of benefits.

In sum, the best way to avoid a multi-tiered long-term care system is to build in comprehensive long-term care benefits as part of the standard benefits package.

From Senator Feingold:

1. First, I want to commend Consumer's Union for the superb work you have done on long-term care insurance. You should know that your 1988 report on long-term care insurance very much shaped my thoughts on the issue while in the State legislature.

I continue to be skeptical about how private insurance can fit into a long-term care system. One concern I have is that any restrictions on which services could be reimbursed by private insurance might distort the plans of care that case managers and consumers develop. There could be huge pressures on consumers and their case managers to seek only those services that were covered by insurance, even if an alternative service were more appropriate or cost-effective.

I am not yet ready to endorse any use of long-term care insurance, but some have suggested that, in addition to other protections, one approach might be to require that long-term care policies cover the consumer's co-payments on any service in the plan of care. This would leave the decision about services to the consumer and the case manager. The insurer would cover any service in the plan of care that consumer might use—limited only by the co-payments charged to the consumer, and by any aggregate limit we place on consumer charges. What are your thoughts on this approach?

RESPONSE OF GAIL SHEARER, CONSUMERS UNION, TO QUESTION FROM SENATOR FEINGOLD

Like you, Consumers Union continues to be skeptical about the role that private long-term care insurance can play in solving the nation's long-term care crisis. There are so many restrictions and loopholes in present policies, consumers can not count on having coverage when they need it. And even if the regulation of the product were perfect, policy ownership would be out of reach for most American consumers who simply can not afford the high premium.

As I understand your question, you are suggesting pushing the market in the direction of long-term care policies that would be neither a "home care" or "nursing home care" policy, but a hybrid. Instead of gatekeepers/disability requirements that would be separate to qualify for the home care or nursing home care benefits, I believe that you are suggesting that the specific status/needs of the insured person should dictate whether the benefits be met through home care or nursing home care. Currently, there are several comprehensive policies that do offer both nursing home and home care benefits, and there is a growing trend toward the use of an integrated approach to determining a plan of care for the insured, with care managers. These comprehensive policies may be appropriate for many consumers; by combining home and nursing home benefits (and presumably community-based care as well), case managers could help the policyholders develop a plan of care suited to the policyholder's needs.

I expect that some companies would resist total reliance on this approach, since some prefer to offer nursing home only or home care only policies. Some consumers may prefer the either-or approach (and possible premium savings) if they have an extended family that can provide extra home care assistance (leading a home-care only policy to be appropriate for them), or if they can not imagine the circumstances under which they would want to remain at home if disabled (someone, perhaps, with no nearby family members and reaching a point of frailty at which living alone is no longer practical).

Consumers Union believes that the best way to solve the nations' long-term care crisis is to build comprehensive long-term care benefits into the standard benefit package available to all eligible. The Health Security Act provides a start, but we hope that the Congress will clearly lay out a blueprint for expanded long-term care benefits. With accountability to the public, such expanded benefits could allow for plans for care that take individual needs into account and shape the most family-friendly and cost-effective means of meeting these needs. If the private long-term care insurance market evolves so that a lot of higher income consumers are pushed before-there-time into nursing homes, then as a nation we will not have achieved a satisfactory or cost-effective approach to solving our long-term care crisis.

The CHAIRMAN. Thank you very, very much, Ms. Shearer.

Now Mr. James Firman who is President and CEO of United Seniors Health Cooperative, Washington, D.C.

STATEMENT OF JAMES FIRMAN, PRESIDENT AND CEO, UNITED SENIORS HEALTH COOPERATIVE

Mr. FIRMAN. Thank you for the opportunity to be here today to discuss what can be done to address our Nation's long-term care service needs.

As the witnesses have so eloquently stated, there clearly is a crisis that must be addressed. Unfortunately, there is no magic bullet; the needs of people are too complex and too diverse. We strongly believe that the only effective strategy will be a comprehensive and multifaceted approach which will include, at a minimum, public funding for home care, establishment of medically needy nursing

home programs in every State, substantial reforms of the private long-term care insurance market, tax credits for people with substantial disabilities who continue to work, and guaranteed access to primary and acute care for all disabled persons.

The most pressing need is for a major public new investment in home and community care. Maximum flexibility should be given to each State. Wisconsin and Oregon, for example, have demonstrated convincingly that local flexibility and control allows for creative and cost effective use of funds.

The United Seniors Health Cooperative has recently completed a research study that shows that many countries around the world are now using cash payments or vouchers because they believe they are the most effective way to help people pay for long-term care. We strongly support approaches that allow consumers maximum choice and flexibility.

A good case can be made for targeting public home-care benefits on people with the most severe disabilities, which is the approach proposed in the Health Security Act. People with severe disabilities are the highest users of doctor, hospital and nursing home services. Several studies have shown that when home care services are provided to people with severe medical needs, it is possible to produce dramatic overall savings. We are also sympathetic to the need of a policymaker to draw a line somewhere in order to control costs.

However, we believe that any public home care program would be improved significantly by allowing States to use up to 10 percent of the available funds for helping less-severely disabled persons to help themselves and to develop more comprehensive systems of long-term care.

Ms. Rowland discussed that there are 13 million people with severe disabilities in this country and only 3 million would qualify for the major benefit. We think those other 10 million people ought to be given the information, advice, and assistance to at least do a better job of helping themselves. A specific proposal along these lines is included in my written testimony.

It is also critical to require all States to have medically needy nursing home programs. Currently, one-third of all States do not permit middle-income, older persons to qualify for Medicaid, even if they become impoverished due to high nursing home expenses. What happens now is that residents of 17 States are moving when they need long-term care to Maine, to Pennsylvania, to New York, to Wisconsin to get nursing home benefits. This is a matter of interstate equity. States ought to share the burden fairly. Every State should be responsible for caring for its disabled people and should not be pushing them across State lines. This puts undue pressure on the 33 States which offer more generous coverage.

Since 1988, our organization has testified before many congressional committees about the need for Federal standards for private long-term care insurance, for funding for consumer information programs, and for better State enforcement of long-term care insurance regulations. The Health Security Act does a good job of addressing these concerns. However, we have several specific suggestions for improving the legislative language which are included in the appendix to my written testimony.

Guaranteed access to health care will produce major benefits for disabled persons including a significant reduction in the public costs of caring for disabled persons. Currently, many disabled people can't qualify for health insurance because of preexisting conditions and consequently use too many emergency room and tertiary care services. Other disabled persons are afraid to take a job because they might lose their Medicaid eligibility which is often based on their SSI eligibility which is in turn contingent upon them not working. Guaranteed access to health care will make it possible for many low income, disabled persons to take jobs without fear of losing their health coverage.

Tax credits for disabled persons will also be very beneficial. Many disabled people are willing and able to work but find it uneconomical to take a job because of the cost of transportation or attendant care. Tax credits will make it feasible for more people to work, many of whom would otherwise be receiving SSI and Medicaid.

The United Seniors Health Cooperative has looked at various legislative proposals that have been introduced through national health reform. In our view, the Health Security Act provides the most comprehensive and well-balanced approach to addressing our Nation's long-term care needs.

Unfortunately, it has become clear that many people do not understand what is in the President's plan, especially the long-term care provisions. To help consumers understand the Health Security Act, our organization recently wrote a report entitled, "The President's Health Plan, Benefits and Costs for Older People." I call it to your attention and urge you to use it and perhaps share it with your constituents.

In summary, United Seniors Health Cooperative urges the Congress to enact legislation that includes a comprehensive and multifaceted approach to long-term care as an integral part of national health care reform.

Thank you for the opportunity to make these remarks.

[The prepared statement Mr. Firman follows:]

STRATEGIES FOR IMPROVING LONG-TERM CARE AS AN INTEGRAL PART OF NATIONAL HEALTH REFORM

Testimony of James P. Firman, President of the United Seniors Health Cooperative

Ladies and gentlemen, my name is James Firman. I am President of the United Seniors Health Cooperative. Thank you for the opportunity to discuss strategies for addressing the nation's long-term care needs as part of national health care legislation.

United Seniors Health Cooperative (USHC) is a non-profit consumer organization that helps people to be informed consumers of health care and health insurance. Each year, USHC staff and volunteers counsel and educate several thousand consumers about long-term care and insurance needs. We have conducted several major studies of various aspect of long-term care. We have written books for consumers and professionals on home care, long-term care and health insurance. For the past four years, we have worked closely with the NAIC to implement the Medigap provisions of OBRA 1990 and to develop better model laws and regulations for private long-term care insurance.

As several Senators and expert witnesses have already said, comprehensive health care reform must include long-term care. Severe disabilities can afflict people of any age, not just the elderly. Millions of Americans live in fear of losing their savings and independence due to a long-term catastrophic health problem.

There appears to be little disagreement about the magnitude of the problem and the need for some action. The question before us today is what can and should be done to address the nation's long-term care crisis.

We need a comprehensive and multifaceted social policy to best meet the needs of our nation's disabled population. There is no single "magic bullet": the problems and needs of disabled persons are too complex and too diverse.

The Health Security Act implicitly recognizes the need for a comprehensive and multifaceted strategy for long-term care. It contains many different provisions that will address different aspects of the problem. To help consumers understand the Health Security Act, our organization recently write a report entitled The President's Health Plan: Benefits and Costs for Older Persons. A copy of the full report is included in an appendix to this testimony. Below I have excerpted the sections that describe for consumers the various provisions of the bill related to long-term care. After each section, I also provide some key comments and specific recommendations for improving provisions of the bill.

KEY LONG-TERM CARE PROVISIONS OF THE HEALTH SECURITY ACT

Home Care

Description: For the first time, people of all ages and incomes with severe disabilities would be eligible for home and community-based services. Every community would have an organization to help consumers assess their needs, develop a plan-of-care, and arrange for assistance. Medicare does not now pay for long-term home care services. Funding would be phased in over a seven-year period. When fully funded, the program would provide $38 billion per year for this coverage—a six-fold increase over current levels. States would have flexibility in deciding what home care, rehabilitation, and support services to provide and how to administer the program.

Based on income, consumers would pay a percentage of the cost of long-term home care. Individuals with incomes below $10,500 might pay a nominal fee. People with higher incomes would pay between 10% and 25% of the actual costs.

Comments and Recommendations: There is clearly a great need for new public funding of home care services. We strongly support the provisions that allow states the flexibility to implement the program how they best see fit. States such as Wisconsin and Oregon have clearly demonstrated that local flexibility control allows for creative and cost-effective use of funds. USHC recently completed a research study that shows that many countries are moving to use cash payments or vouchers to help people pay for long-term care. State flexibility to use different payment methods is in the plan now and should be preserved.

The Health Security Act targets all of the new public spending on people with severe disabilities (3+ ADL dependencies or severe cognitive impairment). To a certain degree, this makes a lot of sense. People with severe disabilities are high users of doctor, hospital and nursing home services. Studies have shown that when home care services are provided to people who have severe medical needs, it is possible to produce dramatic overall savings. We are also sympathetic to the need of policy makers to draw a line somewhere in order to control costs.

However, I think it would be a big mistake to use all of the new public dollars for home care to purchase services for severely disabled persons. I believe it would be much more cost-effective to use a portion of the funds (10% for example) for more general strategies to help people maintain independent living.

Specifically, I recommend that states be allowed to use up to 10% of the new public dollars for purposes other than purchasing services for severely disabled persons. States should have the option of providing these funds to area agencies on aging, centers for independent living, and other organizations for two purposes:

Assessment, consumer information and advice.—Help people who are in earlier stages of disability to understand their needs and assess their options. Help disabled persons and their families to figure out how best to cope and possibly avoid or delay the onset of more serious disability. Help people who don't (yet) qualify for public services to figure out how to spend their own resources to remain independent and in the community.

Systems development.—There is a critical need in every community for an appropriate organization (such as an area agency on aging) to have the responsibility and resources to promote the development of comprehensive community-based long-term care systems. For example, some organization needs to make sure that the supply of home care providers is adequate to meet the need. Under this program, public funds might be used to help establish a local registry of independent providers, offer training and support groups for caregivers of Alzheimer patients, initiate licensure or certification programs for home care agencies or encourage the development of

more volunteer programs. Systems development funds might also be used to encourage or support the development of reverse mortgages for people with disabilities: this would help older persons to use the equity in their homes to stay at home.

I am convinced that this suggested use of the 10% of the total home care funds would be very cost-effective in the long-run. It is shortsighted to draw an artificial line (3 ADLs) above which people get comprehensive assistance and below which people get no help at all. Under this proposal, disabled people who don't quality for publicly-funded personal care or other in-home services would at least get the basic information, advice and help they need to figure out how to best cope for themselves.

Private Long-Term Care Insurance

Description: The Act provides for uniform national standards, consumer protection measures and consumer information programs to improve private insurance that pays for nursing home and home-care expenses not covered by the plan.

Comments and Recommendations: Since 1988, USHC has testified before many Congressional committees about the need for federal standards for private long-term care insurance, funding for consumer information programs and better state enforcement of insurance regulations. We strongly support most provisions of this section, but we recommend several specific changes which are detailed in an appendix to this testimony.

Guaranteed Access to Health Insurance

Description: Every American would be guaranteed access to health care regardless of their health status or ability to pay.

Comments: This guarantee will produce major benefits for disabled persons and will reduce public costs of caring for disabled persons. Currently, many disabled people can't qualify for health insurance because of pre-existing conditions. The result is excessive and inappropriate use of expensive emergency room and tertiary care services.

Other disabled persons are afraid to take a job because they might lose their Medicaid eligibility (which is based on their SSI eligibility which is contingent upon them not working). Guaranteed access to health care will make it possible for low-income disabled persons to take a job without fear of losing their health coverage.

Nursing Home Coverage

Description: For the first time, people in all states would be able to qualify for Medicaid nursing home coverage if they have high medical expenses in relationship to their income and assets. Currently, one-third of all states (including Florida, Texas and Ohio) do not permit middle-income older adults to qualify for Medicaid, even if they become impoverished due to high nursing home expenses. The plan would also continue new national quality standards for nursing home care and increase the monthly allowance that nursing home residents could keep for personal needs.

Comments: This provision will provide much-needed security to the residents of seventeen states: if they become disabled and impoverished, they won't have to move to another state to get help with nursing home expenses. In our view, this is a matter of fairness and equity. Today, some states simply shirk their share of responsibility for caring for their disabled citizens and consequently place an unfair burden on other states.

Tax Credits

Description: Working adults with severe disabilities would receive a tax credit of 50% of the cost of personal assistance and other services, up to a maximum of $15,000 per year.

Comments: Many disabled persons are willing and able to work, but find it uneconomical to take a job because of the costs of transportation or attendant care. Tax credits will make it feasible for more disabled persons to work, many of whom would otherwise be receiving SSI and Medicaid.

Conclusions

We need a comprehensive and multifaceted strategy to address the nation's long-term care needs. The Health Security Act includes many essential elements of an effective and comprehensive long-term care strategy. We strongly agree that:

1. The proposed major new public investment in home and community-based care is greatly needed and appropriately provides much flexibility to states. However, the proposed program would be improved significantly by allowing states to use up to 10% of the available funds for helping less severely disabled persons to help themselves and for systems development.

2. Substantial reform of private long-term care insurance is sorely needed and we present several specific recommendations in an appendix to this report.

3. Tax credits for working disabled persons, elimination of medical underwriting and guaranteed access to basic health services will, in combination, have a very positive effect on the ability of disabled persons to be more productive members of society.

4. Medically-needy Medicaid programs for nursing home coverage in every state should be required as a matter of interstate equity.

Appendix I

Comments on the Long-term Care Insurance Provisions of the Health Security Act.

In our opinion, Title II, Part 3 provides an excellent general framework for regulation of private long-term care insurance. These changes are consistent with recommendations USHC has made to several Committees of the Congress over the past several years.

Specifically, the bill contains several key elements, which we strongly support, including:

1. Enacting national minimum standards which are to be applied in every state. This approach has led to dramatic improvements in the Medigap market and is even more sorely needed for long-term care insurance.

2. Assigning to the Secretary of HHS the responsibility for developing most of the specific regulations with the help of a National Advisory Council. Given the very ambitious task of developing comprehensive regulations, we strongly support assigning the responsibility to a federal agency with sufficient advisors, professional staff and financial resources to do the job right.

3. Establishing a good process for developing appropriate regulations, rather than specifying the details of regulations in the legislation. Given the complexity of many specific regulatory issues to be addressed and the need for more analysis, we believe the bill appropriately avoids the temptation to legislate details in most areas.

4. Recognizing and providing funding for both enforcement and consumer education regarding long-term insurance. Both of these areas are critical to improving the marketplace for private long-term care insurance.

Despite our great enthusiasm for most of Title II, Part 3, we recommend consideration of specific improvements to several sections. The comments that follow are limited to those sections which we think need to be changed or clarified.

Section 2301 requires that states comply with several sections of the current NAIC Model Act and Regulations until the time that new federal standards are developed and become effective. We support all of the specific requirements. However, we strongly urge that section 2301(2)(h) which concerns sales through employers or membership organizations be expanded to include discretionary groups. Discretionary groups have been the source of the most egregious abuses in the group market: To exclude them from this section would vitiate the intent and value of the entire section.

Section 2302 establishes a National Long-term Care Insurance Advisory Council. Section 2302(b)(1) states the Council shall consist of five members, each of whom has substantial expertise in matters relating to the provision and regulation of long-term care insurance. We strongly urge that one or more of these seats be designated for persons with suitable expertise who represent consumer interests and perspectives. Adequate consumer representation is essential to the integrity of the process as well as the quality of the final results.

Section 2302(i) describes activities of the Advisory Council. We recommend that this language be strengthened to require the Council to consult with consumers, industry representatives, service providers and other interested parties.

Section 2321 discusses many specific areas for which the Secretary will develop federal standards and requirements. We agree about the need for and appropriateness of virtually every aspect of this section. However, section 2321(e)(2), which requires companies to provide comparisons of their policies to policies offered by other private insurers, is neither appropriate nor feasible. It is unreasonable to ask a company to provide an unbiased comparison of its product with those of competitors. We believe that the approach used in Section 4012(f)(1) regarding information on Medigap insurance would be a better way to achieve the same objective.

Section 2324 addresses many important requirements related to sales practices. It is very important that Section 2324(g) regarding sales through employers or membership organizations be expanded to include discretionary groups. Without this change, we will have a good law that applies only to those groups that least need to be regulated.

Section 2325(c) addresses the rights of insurers to cancel or deny benefits based on fraud or non-disclosure. This section limits the ability of insurers to practice post-claims underwriting. The provisions in the proposed legislation are considerably weaker than the prohibitions against post-claims underwriting that are already in Section 7 of the NAIC Long-term Care Model Act. We recommend that the current NAIC language be used as the basis for federal law in this area.

Section 2361 authorizes grants for consumer education to states, alliances and national organizations. This effort could have a very beneficial effort on the long-term care market. However, we have serious concerns about Section 2361(a)(3) which authorizes grants to national organizations representing insurance consumers, long-term care providers and insurers. This provision is fraught with potential conflicts of interests. It is unrealistic to expect that organizations that have a vested financial interest in the sale of private long-term care insurance will be able to provide objective, unbiased information and counseling to prospective purchasers. This section needs a clear prohibition against grants to organizations where there may be such conflicts of interests.

Title II, Part 3 fails to address an important issue: Modifications of private long-term care insurance benefits to dovetail with public long-term care coverage. Most long-term care policies currently in force and on the market today specifically say that they will not pay for any service covered by a government program. Other policies are silent on the issue. Only a few companies (for example, Metropolitan Life) have specific language in their policies that says that if government benefits for long-term care change, the company will make appropriate modifications in the private coverage.

The Health Security Act clearly intends to phase in public coverage for home and community-based long-term care that will not be subject to a means test. Some action is needed for at least three reasons: 1) to ensure that private insurance becomes a true complement to public coverage, 2) to prevent the possibility of windfall profits to current insurers, and 3) to remove a potential reason not to purchase private insurance. Our recommendations are as follows:

1. New policies being offered for sale should have explicit language stating that as government benefits for long-time care change, the company will make appropriate modifications in the private coverage as specified by the Secretary. These changes should be cost-neutral for both consumers and insurers.

2. Long-term care insurance policies currently in force that provide home and community care benefits should also be required to amend their coverage in cost-neutral ways to ensure that the introduction of new public benefits doesn't result in a de facto devaluation of private insurance. If insurers do not make this change, they should not be allowed to deny benefits because of services paid for by the new public program.

Subtitle G of Title VII addresses the tax treatment of long-term care insurance policies and accelerated death benefits under life insurance contracts. We agree with the need for clarification of the tax consequences of long-term care insurance. We agree that benefits paid to meet long-term care needs should be tax-exempt.

However, we have serious concerns about whether the federal government should provide tax incentives for people to purchase private long-term care insurance. We suggest more study of the benefits and costs of this proposed tax expenditure, including: a) the likely costs to the federal government of the proposed tax subsidies, b) how many consumers in various income categories would benefit from these tax breaks, c) the likely impact on the overall market penetration of long-term care insurance, and d) the potential savings to the Medicaid program because of more people having private long-term care insurance.

In our view, this issue should be considered on a cost/benefit rather than an ideological basis. Tax subsidies may or may not be the most efficient way to encourage more consumers to purchase private long-term care insurance. For example, programs such as the Robert Wood Johnson Public/Private Partnerships may be a less expensive alternative. Direct subsidies for moderate-income individuals might also be more cost-effective.

A recent article in U.S. News & World Report (January 31, 1994) exposed a new scam to bilk senior citizens. Several companies are promising to provide home care services at substantially discounted rates to people who pay an upfront "service fee" that can exceed $6,000 and an annual membership fee of up to several hundred dollars. Unfortunately, many of these plans fail to honor their contracts because the plans are financially unsound and/or the company is unscrupulous. Currently, most state insurance departments do not regulate these plans because they are uncertain if they are insurance and/or what kind of insurance. Hundreds of seniors have already lost thousands of dollars each on these scams.

Consumers who purchase these home care contracts need the same types of consumer protection that purchasers of long-term care insurance need. Federal legislation should enable and require states to regulate these home care contracts. Appropriate standards should be developed to apply to any company or plan that promises to provide home care at substantially-discounted rates in exchange for a significant upfront or periodic fee. Suggested thresholds for deciding if a home care contract might be regulated would be if the plan offers a service discount of more than 15% and requires an upfront fee of more than $100 or an annual fee of more than $50.

Conclusions

United Seniors Health Cooperative strongly supports the general thrust and most of the specific details of the Health Security Act regarding regulation of long-term care insurance. However, we urge Congress to carefully consider the changes we have proposed to strengthen the legislation.

THE PRESIDENT'S HEALTH PLAN: BENEFITS AND COSTS FOR OLDER PERSONS

A SPECIAL REPORT FROM UNITED SENIORS HEALTH COOPERATIVE

The Health Security Act proposed by President Bill Clinton would guarantee comprehensive health care coverage to all Americans without regard to age, income, health or employment status. United Seniors Health Cooperative (USHC), a non-profit consumer organization, has written this report to answer the major questions older persons have about what the Act holds in store for them.

Benefits to Current Retirees with Medicare

The plan does not change the basic structure of Medicare for current retirees, but adds at least seven important new benefits.

1. Prescription Drugs

Everyone currently enrolled in Medicare Part B would automatically receive prescription drug coverage. After a $250 deductible, Medicare would pay 80% of prescription drug costs. There would be an annual out-of-pocket limit of $1,000, after which Medicare would pay 100% of drug costs. People would be free to use the pharmacy of their choice. High prescription drug costs are a major problem for at least 30% of all seniors. For people without prescription drug coverage now, this would be a significant new benefit. For government retirees and others who already have drug coverage, the cost of their supplemental insurance would go down.

2. Home Care

For the first time, people of all ages and incomes with severe disabilities would be eligible for home and community-based services. Every community would have an organization to help consumers assess their needs, develop a plan-of-care, and arrange for assistance. Medicare does not now pay for long-term home care services. Funding would be phased in over a seven year period. When fully funded, the program would provide $38 billion per year for this coverage—a six-fold increase over current levels. States would have flexibility in deciding what home care, rehabilitation, and support services to provide and how to administer the program.

3. Medicare Assignment

Currently, doctors may charge up to 115% of the fee that Medicare has deemed "fair and reasonable." Many older persons pay hundreds of dollars a year in doctors' fees that exceed the Medicare-approved amount. Under the President's plan, all doctors would have to accept Medicare-approved rates as payment in full.

4. Medigap Insurance

The Act would require all Medigap plans to have an annual open enrollment period. During that time, no person could be turned down for coverage due to existing medical conditions. For retirees who have Medigap policies that cover prescription drugs and excess doctor charges, the cost of supplemental insurance could be reduced substantially, perhaps by as much as several hundred dollars annually.

United Seniors Health Cooperative (USHC) is a nonprofit, charitable organization, founded in 1984 to help older persons become informed consumers. This Special Report was prepared by James P. Firman, Ed.D, USHC President, and other Coop members. Special thanks are due to Marilyn Moon, Ph.D., of the Urban Institute and Monique Rothschild, USHC *Health Report* editor.

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5. Private Long-Term Care Insurance

The Act provides for uniform national standards and consumer protection measures to improve private insurance for nursing home and home-care expenses not covered by the plan.

6. Nursing Home Care

For the first time, people in all states would be able to qualify for Medicaid nursing home coverage if they have high medical expenses in relation to their income and assets. Currently, one-third of all states (including Florida) do not permit middle-income older adults to qualify for Medicaid, even if they become impoverished due to high nursing home expenses. The plan would also continue new national quality standards for nursing home care and increase the monthly allowance that nursing home residents can keep for personal needs.

7. Tax Credits

Working adults with severe disabilities would receive a tax credit of 50% of the cost of personal assistance and other services, up to a maximum of $15,000 per year.

What Would the New Plan Cost You?

Prescription Drugs: Medicare Part B premiums would increase by $11/month. As with other Medicare Part B fees, the cost to beneficiaries would be only 25% of the average cost of providing this coverage.

Laboratory Services and Short-Term Home Health Care: The plan calls for a 20% co-payment on laboratory tests and a 10% co-payment on some short-term home health care services covered by Medicare. All Medigap policies would cover these co-payments.

Long-Term Home Care Services: Based on income, consumers would pay a percentage of the cost of long-term home care. Individuals with incomes below $10,500 might pay a nominal fee. People with higher incomes would pay between 10% and 25% of the actual costs.

Higher Part B Premiums for Wealthy Seniors: Retired persons with annual incomes over $90,000 and couples with annual incomes above $110,000 would pay higher Part B premiums. The most any person would pay for Part B premiums would be three times the rate paid by most older persons or 75% of the actual average cost of the program.

Health Alliances and Older People

Under the Health Security Act, states would be required to establish health alliances which would serve as purchasing cooperatives for consumers and employers to buy health insurance. The alliances would negotiate arrangements or "health plans" with insurance companies and networks of hospitals and doctors.

Members of an alliance would be free to choose from a wide variety of fee-for-service, health maintenance organization (HMO), or preferred provider plans.

In most cases, current Medicare beneficiaries would not be part of the health care alliances. In the future, when people turn sixty-five, they would have a choice of enrolling in Medicare or staying in an alliance plan for a somewhat higher premium.

A state could decide to include all Medicare beneficiaries in the alliances. To do this, a state would have to meet federal guidelines ensuring that older persons would have alliance coverage equal to or better than Medicare *and* that they would continue to have fee-for-service options.

What About Me If...

... I currently have Medicare Part A, but I'm still working?

As long as you continue to work past age 65, you will be covered by a combination of your employer's insurance and Medicare Part A. Your employer's policy would pay first, and in most cases, Medicare would pay the remaining co-payments and deductibles. When you retire, you would enroll in Medicare Part B and be subject to the same rules as other retired Medicare beneficiaries.

... I am a retired federal (state or local) government employee over 65?

Your situation would not change dramatically. You would still be covered by your current health plan and Medicare (if you have it). Like other Medicare beneficiaries your Part B premiums would increase by $11/month for prescription drug coverage, but the cost of your supplemental policy would be reduced significantly. Between Medicare and your supplemental policy, most (if not all) of your prescription drug costs would be covered. You would also be eligible for the new home care services if you should become severely disabled.

... I'm a veteran?

The U.S. Department of Veterans Affairs (DVA) would offer a health plan through V.A. hospitals and clinics. Veterans with service-related disabilities or low incomes would be eligible for the same basic benefits package as other Americans, but with no premiums, co-payments or deductibles. Other veterans could choose to join the DVA plan, but would have to pay 20% of the premiums as well as the usual co-payments and deductibles.

... I have Medicare and Medicaid?

Low-income older people who have dual coverage from Medicare and Medicaid would see it continue. Because all doctors would have to accept Medicare rates as full payment, patients with both Medicare and Medicaid would probably have a greater choice of doctors than they do today.

... I'm within a few years of qualifying for Medicare?

Most people under 65 would get health care through an alliance plan. When they turn 65, they would have two choices. One option would be to enroll in Medicare and perhaps purchase a Medigap policy. The other choice would be to stay with a health alliance plan, but only if it is an HMO that has a special contract with Medicare. If an older person stays in the alliance, he or she would have to pay a somewhat higher premium than younger persons.

... I am under 65 and want to retire early?

Retirees between the ages of 55 and 64 would have their health care subsidized by the government. Most early retirees would purchase their health insurance through the alliance. The government would pay 80% of the cost of an average premium while retirees would pay the rest. If a person continues to work part-time or has a working spouse, the government subsidy would be reduced. Wealthy early retirees (incomes over $90,000/year) would pay higher premiums.

This is a very good deal for early retirees. Currently, many unemployed or retired persons between the ages of 55 and 64 either can't get health insurance because of preexisting conditions or have to pay higher rates based on their age.

Single Payer: A State Option

There has been a lot of talk about single-payer plans. Under a single-payer health system all citizens would receive health care from private doctors and hospitals that are paid by a single insurance entity, usually the government. The Health Security Act allows any state to establish a single-payer system as long as it meets certain federal guidelines.

Key Consumer Concerns

Cuts in Medicare

The President's plan does not call for cuts in services to Medicare beneficiaries. Rather, it proposes to slow the rate of growth of future health care spending from three times to twice the inflation rate for medical care. Over five years, these measures would result in savings of $124 billion, three-fifths of which would be achieved by reducing the growth of payments to hospitals. Most of the other savings would come from slowing the growth of payments to doctors and some increase in consumer co-payments.

Critics of the plan are skeptical that these cuts can be achieved and believe they would lead to a diminished quality of care. Proponents argue that the plan reduces "fat, not bone." With or without health care reform, there will likely be pressure on the Congress to do something about the steep rise in Medicare costs.

Managed Care

The plan would not require Medicare beneficiaries to enroll in an HMO or other managed care program. Most older people would probably choose to continue in the Medicare fee-for-service system they have now, where they do not need to obtain prior approval for the services of medical specialists and could use any pharmacy they wanted. However, it is likely that more HMO options and other new delivery systems would also be available to Medicare beneficiaries.

Choice of Doctors

Medicare beneficiaries would still be able to choose their doctors, just as they do today. As long as Medicare pays doctors at rates comparable to those the alliances pay, most MDs would be likely to continue to accept Medicare patients.

The United Seniors Perspective

United Seniors Health Cooperative strongly supports the enactment of legislation that would guarantee universal, comprehensive health care for all people. We have carefully studied the Health Security Act and its implications for older Americans. In our opinion the Act would:

- Provide seniors with many substantial new benefits at a reasonable cost.
- Help many of our children and grandchildren who either can't get good health coverage or are at risk of losing it.
- Help maintain the quality of care and control rising costs.
- Strengthen the basic economic and social fabric of our society by guaranteeing health care as a basic human right.

Regardless of your views, we urge you to become informed about the Health Security Act and the changes that the U.S. Congress is likely to propose over the coming months, and to communicate your ideas to your representatives in Congress.

The CHAIRMAN. Thank you very, very much, Mr. Firman.

Mr. Meiners is the Director of the Robert Wood Johnson Foundation National Program Office, Partnership for Long-Term Care Insurance. Mr. Meiners.

STATEMENT OF MARK MEINERS, DIRECTOR, ROBERT WOOD JOHNSON FOUNDATION NATIONAL PROGRAM OFFICE, PARTNERSHIP FOR LONG-TERM CARE INSURANCE

Mr. MEINERS. Thank you, Senator.

I am pleased to have the opportunity to meet with you and the Committee today to discuss long-term care. The Committee's interest in the role of the private sector will help keep long-term care from continuing to be the forgotten stepchild in the health care reform debate.

The points I will make today on the private sector role in long-term care reform come from some 20 years of experience in research and development focused on topics related to long-term care.

Since leaving the Federal Government after a 17-year career and coming to the University of Maryland about 7 years ago, I have devoted a major part of my time directing several initiatives that have been undertaken with grant support from the Robert Wood Johnson Foundation.

Perhaps most familiar to those who track long-term care issues is the Partnership for Long-Term Care, an initiative currently operating in Connecticut, Indiana, New York, and California which is designed to encourage the sale of high quality, long-term care insurance by offering special protection from Medicaid's resource limits.

Most recently, we have embarked on a new effort with the Robert Wood Johnson Foundation to support State-based long-term care reform. I have submitted background on each of these programs with my testimony and will be happy to answer questions on them later.

In the limited time available for my formal remarks, I would like to make a few points I believe should enter into your deliberations on how to proceed with improving long-term care programs, systems, and options.

First of all, let me say that I do not believe that there is any plausible, comprehensible, private approach. I also do not believe there is any plausible comprehensive public approach. I believe there needs to be a partnership and that has been the track record that we have established in this country, roughly a 50–50 split between public and private payment for long-term care. However, as we think about reform and given these truths, the key public policy question is how to engineer an effective partnership of these resources. In this regard, I am encouraged by the basic message the Clinton health plan has conveyed. That is, long-term care is important and should be part of the health care reform plan but it is also expensive.

I want to congratulate my former colleague, Dr. Stone, and the others who have worked on the Clinton plan for the struggle that they have gone through to try to create a program that balances costs with need.

From my perspective, the Clinton team has concluded that we must proceed incrementally by encouraging improvements in our means-tested public programs, support for private sector responsibility, and innovation on the part of States to improve on what they have accomplished, particularly in the areas of home and community-care services.

Of course the devil is in the details as we hear so often, but acceptance of these basic goals is a step in the right direction as we proceed with long-term care reform. It is important to recognize that when we talk about the role of the private sector, we are talking about more than just private enterprise. Most long-term care is either provided by family and friends directly or purchased by them out-of-pocket. The interrelationship between these two forms of support can be complicated but the simple fact is that any realistic intervention must support not replace our willingness to take personal responsibility for our long-term care and needs.

Where private enterprise enters into the equation is that it needs to help this happen to the greatest extent possible. This means good, quality, affordable products and services that meet the need as perceived by the consumer and their family must be developed and must be marketed. We are just beginning to see this happen. Examples that have recently emerged on the market include the growing number of home and community-care options such as respite care and day care as well as assisted-living and long-term care insurance.

To have effective private programs, we need a clear delineation of where the public role ends and personal responsibility begins. This is essentially the case that if we expect people to plan for their risk, we must know where these splits occur. If planning does not occur, more people will be dependent on public support in which case the pressures on our limited resources will simply increase.

The Clinton plan suggests some examples where we can get confused when balancing support for private systems and new public programs with private insurance; for example, there is the potential for confusion with what the new home and community-care benefits will and won't cover since they are specified as a "capped" entitlement. It is hard to know what gaps need to be filled by private insurance. The fear is that this will lead to a situation where people think they are covered and don't understand that there are limits. When this happens, people will not plan for their long-term care needs to the extent possible.

The States are also concerned by these capped entitlements because they are not allowed to means-test the benefits. The States are familiar with means-testing benefits but are unfamiliar with some of the other mechanisms that have been suggested to stay within budget. They fear the new benefits will be too open-ended to meet their need to control costs.

Consumers need affordable and appealing options that encourage them to save for their long-term care expenses. Incremental strategies that encourage as much personal responsibility as possible are necessary for progress to be made. There are really no easy answers as I think you've heard today but we must take this oppor-

tunity to move forward, being clear about the relative roles that we are expecting for the private sector versus the public sector.

I'll be happy to answer any questions.

[The prepared statement of Mr. Meiners follows:]

TESTIMONY OF MARK R. MEINERS, PH.D., ASSOCIATED DIRECTOR, CENTER ON AGING, UNIVERSITY OF MARYLAND AND DIRECTOR, ROBERT WOOD JOHNSON FOUNDATION PARTNERSHIP FOR LONG-TERM CARE AND ROBERT WOOD JOHNSON FOUNDATION STATE INITIATIVES IN LONG-TERM CARE

I am pleased to have the opportunity to meet with your committee today to discuss long-term care. Your interest in the role of the private sector will help keep long-term care from continuing to be the forgotten step-child in the health care reform debate.

The points I will make today on the private sectors role in long-term care reform come from some twenty years of experience in research and program development focused on topics related to long-term care. Since leaving the Federal government and coming to the University of Maryland about seven years ago I have devoted a major part of my time directing several initiatives that have been undertaken with grant support from the Robert Wood Johnson Foundation.

Perhaps the one most familiar is the Partnership for Long-term Care, an initiative currently operating in four states (CA, CN, ID, and NY) designed to encourage the sale of high quality long-term care insurance by offering special protection from Medicaid's resource limits. Most recently we have embarked on a new effort with the Robert Wood Johnson Foundation to support state based long-term care reform. I have submitted background on each of these programs with my testimony and will be happy to answer questions on them now or later.

In the limited time available for my formal remarks I would like to make a few basic points that I believe should enter into your deliberations as to how to proceed with improving our long-term care programs, systems, and options.

There is no comprehensive private approach. There is no plausible scenario in which private insurance can provide financing for all persons needing long-term care services. However, there are portions of the likely users of long-term care who are in a position to prepare themselves to contribute to the cost of their care. Some portion of the future need for financing should be pre-funded.

There is no comprehensive public approach. There is no plausible scenario in which public resources can provide financing for all persons needing long-term care services. There are however many groups who have never had and will never have the opportunity to prepare themselves to pay for their own services. Public funds must be available and in sufficient supply to assist these groups.

Given these truths, the key public policy question is now to engineer an effective partnership of resources. In this regard, I am encouraged by the basic message the Clinton Health Plan has conveyed. That is, long-term care is important but expensive. For progress to be made the Clinton team has concluded that we must proceed incrementally by encouraging improvements in our means tested public programs, support for private sector responsibility, and innovation on the part of the states to improve on what they have accomplished, particularly in the area of home and community care. Of course, the devil is in the details. But acceptance of these basic goals is a step in the right direction as we proceed with long-term care reform.

It is important to recognize that when we talk about the role of the private sector we are talking about more than just private enterprise. Most long-term care is either provided by family and friends directly or purchased by them out of pocket. The interrelationship between these two forms of support can be complicated but the simple fact is that any realistic intervention must support not replace our willingness to accept personal responsibility for our long-term care needs.

Where private enterprise enters into the equation is that it needs to help this happen to the greatest extent possible. That means good quality affordable products that meet the need as perceived by the consumer and their family must be developed and marketed. We are just beginning to see this happen. Examples that have recently emerged on the market include the growing number of home and community care options, assisted living communities, and long-term care insurance. These developments should be encouraged.

To have effective private programs we need a clear delineation of where the public role ends and personal responsibility begins. This is especially the case if we expect people to plan for this risk. If planning does not occur more people will be dependent on public support. This places even more pressure on our limited resources.

The Clinton Plan suggests examples were things can get confused. On one hand it supports the notion of private action and preparation through tax clarification and the national insurance regulations. On the other it proposes a home and community care benefit that conveys the impression that government programs will be sufficient to meet individual needs when the details really suggest a "capped entitlement" to states; in practice a much more limited intervention. There is considerable nervousness about how to implement the proposal on the part of states because they already see themselves in fiscal crisis and they worry about how to do it when they are not allowed to means test eligibility.

Means testing is the approach states are most comfortable with because they have experience with it through Medicaid. But means testing is unacceptable to some policy analysts and interest groups. It is viewed as leading to poorly funded inadequate programs because the political constituency is not broad enough to keep this from happening. Strategies need to be considered to minimize this risk so that this opposition can be overcome. One example from our experience in planning the Partnership Program is to link eligibility to the means tested program with the purchase of state certified long-term care insurance.

The Partnership long-term care insurance model and an improved means tested long-term care program in the states would be mutually complimentary. Currently the applicability of the model to other states is limited because of the variability in the Medicaid program across states. Many state Medicaid programs do not offer comprehensive home and community benefits or a system of care management which support the continuity of care desired in such a partnership. Furthermore, states which have not developed strong programs for the poor will have trouble justifying efforts at preventing poverty. On the other side, improvements to the Medicaid program cannot be sustained unless affordable and appealing private market financing options can serve to keep people for using those benefits unless it is as a legitimate last resort.

This strategy also serves to mitigate concerns about means-testing. By linking the Partnership incentive to Medicaid (or a new means tested long-term care program) the constituency for the means-tested program should be enhanced rather than eroded. This can serve to limit the drift toward a "two-tiered system" that inevitable plagues public programs that operate in our largely private market economy.

Consumers need affordable and appealing options that encourage them to save for these expenses. Incremental strategies that encourage as much personal responsibility as possible are necessary for progress to be made. The existence of a government program like Medicaid as a backup makes the financing structure of long-term care for the elderly relatively unique. Building on Medicaid, a state centered approach allows for the development of financing reforms which are consistent with the reality of economic and political considerations. It seems that the logical way to proceed from the structure laid out in the Clinton Plan is to support a new means tested program for long-term care that is designed to compliment private market options. The experience of states in creating and administering the Partnership Programs could provide the basis for further reform of the current system along these lines.

Robert Wood Johnson Foundation Partnership for Long-Term Care

PROGRAM OVERVIEW

With assistance from the Robert Wood Johnson Foundation four states, (CA, CT, IN, NY) are now operating public/private partnerships in long-term care. The partnerships finance coverage of nursing home and home care by joining Medicaid with private long-term care insurance. The combination of Medicaid and private insurance provides an incentive for elders to purchase insurance that is commensurate with their resources. Not only do they get a quality insurance benefit, they also get the security of knowing they will not have to spend all of their assets if their insurance benefits run out. Once private insurance benefits are exhausted, special Medicaid eligibility rules are applied if additional coverage is necessary. The following is short summary of partnership activity in each state.

Connecticut was the first state to make partnership policies available to its residents. Partnership policies went on sale in April 1992. Over 1,700 applications have been received and more than 1,300 policies sold. Seven insurers have been approved to sell partnership policies in both the individual and group markets.

New York State Partnership Policies went on sale in March of 1993. Seven insurers have been approved to offer individual policies and one insurer, a group policy. Over 2,000 persons bought Partnership policies in the first nine month of oper-

ations. New York is stepping up its education efforts with a number of brochures, booklets and television spots.

Indiana was the third state to begin its partnership program. Partnership policies went on sale in the summer of 1993. Nine companies have been approved to sell individual policies. More than 4,000 insurance agents have completed 15 hours of training on the partnership program. In the first quarter between 200–250 persons bought partnership policies.

California is well on its way toward implementing a partnership program. The target date for program start-up is June 1994. Over the last year the program office has modified state enabling legislation, revised the state's Medicaid state plan, and promulgated program regulations.

Robert Wood Johnson Foundation State Initiatives in Long-Term Care

PROGRAM SUMMARY

The Foundation's State Initiatives in Long-Term Care program helps states reform their systems of long-term care financing and service delivery. The overarching goal of this $3.6 million effort is to broaden access to long-term care coverage within the context of federal and state health care reform.

Over the last several years, the Foundation has invested in a variety of projects to design new chronic care service arrangements, to develop new financing packages, and, in four states, to develop new insurance partnerships for long-term care. The latter work has advanced the thinking of both private industry and public policymakers regarding how to finance long-term care. Under this new effort, the Foundation will support between five and seven states to plan and implement projects that:

Develop a stable, long-term financing base for the provision of long-term care to those who are now frail or disabled;

Develop affordable insurance mechanisms (public and private) that guarantee future access to comprehensive long-term care services;

Promote the availability of a full range of affordable home and community-based services and institutional options for people with chronic disorders; and

Promote the integration of acute and long-term care services for people with chronic illness and disabilities.

The broad focus of this Program is meant to encourage states to consider a wide range of alternative delivery systems and financing arrangements. Fundamentally this Program will be judged successful only if it prompts states to design comprehensive strategies that give all their residents a sense of security about obtaining and paying for long-term care.

The Program consists of an eighteen month planning phase and a followup implementation phase. By the end of the planning phase, states will have: (1) identified the reform(s) they wish to pursue; (2) analyzed the implications for long term care access and costs; and (3) outlined specific steps necessary to implement them. Implementation funding will be available to those states most able to achieve measurable and significant reforms in how long-term care is organized and financed.

[Subsequent to the hearing, the following information was received for the record:]

QUESTIONS FOR MARK MEINERS

1. Critics of our present health care system often say that we have a two-tiered system where the quality of service you receive depends upon whether you have insurance. With an expansion of the long-term care insurance industry, how do you think we should avoid the same thing happening with respect to long-term care?

2. Gail Shearer's testimony enumerates a number of problems which are present in relying on the private market to ensure that our nation's long-term care needs are met—problems such as complexity and variability of policies, high lapse rates, high premium rates, inadequate regulation, very limited participation by non-elderly, high rejection rates for individuals with existing health problems, etc. Is it your view that these problems can be overcome and that private long-term care insurance can be extended to the entire population eventually, or should private insurance remain only part of the solution?

UNIVERSITY OF MARYLAND AT COLLEGE PARK,
June 6, 1994.

Senator DAVID PRYOR,
Chairman, Special Committee on Aging, Washington, DC.

Attention: Theresa Sachs.

DEAR SENATOR PRYOR: Below are my answers to the two questions directed to me by your Committee.

Question 1: Critics of our present health care system often say that we have a two-tiered system where the quality of service you receive depends upon whether you have insurance. With an expansion of the long-term care insurance industry, how do you think we should avoid the same thing happening with respect to long-term care.

Answer. It is almost inevitable that there are concerns about a "two-tiered health care system" when we can only budget enough to provide a base of support for the most needy. Those who can afford more will want to use their resources as they see fit including the purchase of more care if that is what they prefer. A way to eliminate the concern that a program for the poor becomes a poor program because it lacks the political constituency to keep it adequately funded is to structure a linkage of the means tested program with long-term care insurance as is being done in Connecticut, Indiana, New York, and California with the support of the Robert Wood Johnson Foundation's Partnership for Long-Term Care Program. This program uses special asset protection under Medicaid rules as an incentive for people to plan for their long-term care financing needs by buying state certified private insurance. If the insurance is used up the person can then have access to Medicaid benefits without being impoverished. This approach helps secure middle and upper class insiders support for a viable and decent Medicaid program because it is part of what they too may need to depend on in the face of otherwise catastrophic long-term care expenses.

Question 2: Gail Shearer's testimony enumerates a number of problems which are present in relying on the private market to ensure that our nation's long-term care needs are met—problems such as complexity and variability of policies, high lapse rates, high premium rates, inadequate regulation, very limited participation by non-elderly, high rejection rates for individuals with existing health problems, etc. Is it your view that these problems can be overcome and that private market insurance can be extended to the entire population eventually, or should private insurance remain only part of the solution?

I believe that the problems mention by Ms. Shearer can be overcome as the market matures; particularly if there is a conscious effort to see that the public and private sectors work together with those improvements as a mutually agreeable goal. Too often these problems have been highlighted simply as a way to sway the audience toward a social insurance agenda without reflecting on the pitfalls of that approach given the current and future budget situation.

I also believe that private insurance is only part of the solution but an important part that must be encouraged by both the public and private sectors if it is to reach its potential. Overcoming the limitations of private insurance is often directly related to how much it will cost. Higher premiums tend to limit the market so there is a need to keep premiums down while increasing the value of the protection. The Partnership for Long-Term Care Program mentioned above is one approach to the trade-offs between product an improvements and cost that can serve to broaden the market for private insurance. In combination with an improved means tested program that strategy can be an effective way to accomplish manageable long-term care reforms.

If I can be of further assistance please let me know.

Sincerely,

MARK R. MEINERS, PH.D.,
Associate Director.

The CHAIRMAN. I think I will yield to Senator Feingold at this time and then Senator Cohen and then Senator Graham.

Senator FEINGOLD. I have a number of questions but given the hour, I'd ask consent if I can have these placed in the record?

The CHAIRMAN. Absolutely. The questions will be placed in the record. Are you not going to ask any questions?

Senator FEINGOLD. I'll pass at this point.

The CHAIRMAN. I'm going to yield to Senator Cohen.

Senator COHEN. Is that a precedent that we all should be following here?

The CHAIRMAN. No. I think this panel deserves a few questions. I think they'd like to answer some.

Senator COHEN. First, let me commend you, Ms. Chapman, Angela and Ms. Reed for your very moving, poignant testimony. Too often we hear the phrase "long-term care" and it doesn't really convey exactly what is involved to the minds of many people until it strikes them and when they have a family member who is suddenly touched by a disabling disease or simply through the aging process itself. You helped to put a very human face on the nature of the problem as confronted by the issue of long-term care.

I also want to thank Jane Ross. You've been very helpful to us on the issue of Social Security disability insurance programs and I just will ramble for a moment here to point out that we have a program that is designed to help people who are in need and yet there is a program which, because of the way in which it is written, because of laxity of enforcement, results in the wasting of literally hundreds of millions of dollars. That is a program that the Chairman and I have worked on, namely to make sure that when we enact a program, the programs go for the people for which it is intended and the money is not wasted.

I'd like to address a couple of questions to Ms. Shearer, perhaps Mr. Firman and Mr. Meiners. When we talk about partnership between the Federal Government and the private sector, that means that individuals are going to be called upon to exercise some responsibility for their own long-term care planning. Right now, most people don't carry insurance, about 3 percent is the national figure and for a variety of reasons. The cost is very high.

As you point out, Ms. Shearer, even the programs themselves, the plans, don't provide very much. The details are discouraging. It doesn't cover much that is not already provided, it is expensive, and very discouraging. So when we look at the so-called partnership, Mr. Meiners, you talked 50–50, is that something Ms. Shearer that you, as an advocate perhaps on behalf of Consumers, see as the right kind of split?

Ms. SHEARER. It is interesting to note that is approximately the split that we have today. When we look at the Medicaid budget and the percent of nursing home costs, for example, that are paid by the Medicaid Program, I think we would put the public sector percent at a higher rate ideally. What we find today is that people with families are suffering because it is not as if we don't have the long-term care costs, we have them now but they are paid largely out-of-pocket by families and this puts tremendous financial pressure on families, so I can't tell you the exact split that is ideal but it would probably be closer to 70 or 80 percent for the public program.

Senator COHEN. Mr. Meiners.

Mr. MEINERS. Well, 70 or 80 percent sounds high to me given the total costs that are anticipated for long-term care. I would say that because there are other demands on the budget that we must be careful setting figures of 70 or 80 percent as our expectation, because we could end up concluding that we simply can't afford to do anything in long-term care, and I think that would be a mistake.

I would be much happier with 50–50. I think there is a lot that can be done, I think probably when the debate winds down, we will move in the direction of means testing a little bit more on the home and community care side, but we certainly can use more resources for home and community care.

Senator COHEN. Let me just comment quickly and I'll yield to you, Mr. Firman. I agree one of the great dangers would be that we look at a price tag of the program and say it's $65 billion, it's $70 billion, whatever the figure is going to be, and as a result of the debate we go through in the House and Senate and say we can't afford it and lose it altogether. I share the view that we've got to come up with something that will do the job that is affordable but puts us on a track on which we can say there is a partnership there.

I agree with Ms. Shearer that a lot of reform is going to have to be introduced and adopted in the insurance field to make sure that the public is going to be well-served by the private sector, but I also believe we ought to be looking at some kind of a proposal. In fact, I have one in mind I'm going to be introducing in the next few days, perhaps next week to try and achieve that because I agree the last thing you want to do is have this component of the President's program dropped out because they are going to say the price tag is too high, we'll deal with it later. Now is the time to deal with it and to deal with it in a constructive fashion.

I'm starting to carry on, Mr. Firman, so I'm going to yield to you. My time has expired.

Mr. FIRMAN. Whenever we draw the line, we should do it as intelligently as possible. One thing that the President's plan does, by calling for a public home care program, is to recognize that private, long-term care insurance is much better able to ensure nursing home care than home care. If you talk to insurers, they will tell you it is much easier to write good nursing home and assisted living insurance than to insure home care.

The combined strategy of home care and improvements in the private, long-term care insurance market will enable the private market to emerge as well as it can. I still have my doubts about how good private insurance will be. We will always have the 60 to 65 percent loss ratios, I think the Clinton plan has done a pretty good job of recognizing the limits and the potential of private long-term care insurance.

Senator COHEN. It seems to me one of the problems that we have is when we are young people we are approached almost immediately by the insurance industry saying, you're a young man—I recall this being in law school, I was married and had children—you need life insurance, so you start saving for life insurance at the age of 21 at that time. We don't start even contemplating long-term care insurance until much later in the life span at which time the price is very high. Somehow, we've got to also really educate ourselves. This is something that each of us is going to be faced with and we've got to start early in order to reduce the cost to make it affordable. Otherwise, very few people are going to be in the income brackets where they can afford to purchase private insurance in order to cover the cost. So we've got a large educational responsibility ahead of us as well.

Thank you, Mr. Chairman.

The CHAIRMAN. Yes, Senator Cohen.

I will be just a moment and we will recognize you for another series if you desire.

Ms. Chapman, we're right now engaged or we are just about to engage ourselves in writing a very, very comprehensive health care reform bill for this country. As you know, it is most controversial. You mentioned in your statement about special interests; there are a lot of special interests out there that don't want us to do one thing. A lot of people like the system just as it is right now.

What would you recommend we concentrate on to help alleviate situations like you and Angela are now facing? What are the most important things that we could do for you because there are a lot of people like you, there are a lot of people like Shirley Reed out there who are caregivers and here you are about to vacate your home.

First, let me ask you, where do you contemplate moving when you vacate?

Ms. CHAPMAN. I haven't found a place yet. It's going to be difficult because I'm going to have to find a place within the amount of my income and I haven't found a place yet that I can afford.

The CHAIRMAN. You have no place for you and Angela to go at this time, is that correct?

Ms. CHAPMAN. Yes, and we have to be out by the 15th of May.

The CHAIRMAN. So you have about a month to vacate your home. Did you lose your home in a foreclosure?

Ms. CHAPMAN. No, I sold it before it was foreclosed because I kept getting behind on the payments and they told me they were going to foreclose if I didn't sell it.

The CHAIRMAN. I see. What could Senator Cohen and Senator Pryor and these other people here that have listened to you today really concentrate on that would help you in your life?

Ms. CHAPMAN. What would help me the most right now is either getting respite care, which Senator Bradley talked about, or if I could put him in a day care and I could afford it because day care is about $20 a day. When you are on a limited budget, that's a lot of money a week; it's about $400 a month.

The CHAIRMAN. If you could put your husband, Mr. Chapman, in a day care facility or center, then would you get a job, is that correct?

Ms. CHAPMAN. Absolutely. Then I could go to work.

The CHAIRMAN. You could go to work.

Ms. CHAPMAN. I would have enough money to take care of Angie and we could afford to do things together.

The CHAIRMAN. Is the day care there in your community 5-day or 7-day?

Ms. CHAPMAN. It's 5-day but 5-day would be all I would need.

The CHAIRMAN. You could then bring in some income for the family but you can't leave your husband right now under these conditions, is that correct?

Ms. CHAPMAN. Absolutely not. It looks like I may have to go to Medicaid to put him in a nursing home because when he dies, see that's what people don't know. I'm only 45 and when he dies, he's getting so bad now that when he dies, I won't have any income be-

cause his Social Security disability will discontinue and I won't have any income.

The CHAIRMAN. Is Mr. Chapman in what we might know as the advanced stages of Alzheimer's?

Ms. CHAPMAN. Yes. It's pretty bad.

The CHAIRMAN. Angela, you're in a very similar category with your mom there. Do you have any recommendations for us as we try to change some of these programs that you heard talked about? Do you have any suggestions for us?

Ms. ANGELA CHAPMAN. I just hope that this bill gets passed because everyone, not just my family but a lot of families need the bill passed and need the help that it can bring to them.

The CHAIRMAN. Well, we're sure going to try to have something. By October, we're hoping the President will have some kind of bill for him to sign that we have passed. We work very closely with our colleagues on both sides of the aisle here to try to shape a piece of legislation that will pass.

Let me yield to Senator Cohen and then I'll have a couple of questions.

Ms. CHAPMAN. Can I just say one thing that would help too is some of the existing programs that are already available if they would not put an age limit on them. A lot of programs in the Older Americans Act require you have to be at least 60 years of age. Tom could probably get some help with day care, with the funding of some of his day care, but because he is not 60 years old, he can't get that funding. He's not eligible for it. So that would be a big help if they would just take out those requirements.

The CHAIRMAN. Senator Cohen.

Senator COHEN. Just an observation. I think Ms. Rowland, you touched upon this in your own remarks. You pointed out it is very difficult to determine where acute care ends and long-term care begins. We draw all these distinctions in the law and frankly I am absolutely astonished when we on the Republican side like to hold up charts on the President's program but if you hold up a chart on the current health care system, I don't know if the average person knows where to begin. You say, I've got a problem, who do I call? Ms. Reed, who do I call under to get help? I think the average citizen has no idea where to go or what is available or the distinctions between what is acute, what is long-term, Medicaid, Medicare, which agency is involved, which area agency is involved on aging and what services are available.

We have a system that is so complicated that I think it is totally befuddling to the average human being, even those of what we like to think as superior intelligence sitting up here, are completely dumfounded by what the average person, including us, would have to go through.

I'll say this for myself, I won't comment on Senator Pryor, if I did not have the benefit of these young women behind me advising me on what is available, I'm not sure I'd know where to turn. So if you take the average citizen who doesn't have the benefit of these bright young people working for us, to lead us down these paths, saying this is what is available, it must be just completely not only confusing but really discouraging to the average citizen. So we've got to really formulate a health care plan that when we

say comprehensive, we also have to simplify it somewhat as well so that we don't have to go to different agencies and different entry points to find out what is going to be available at the other end.

I don't expect any of you to comment on this. It is just an observation on my part as I sit here, and have over the years, to say we've got to devise a system which is much clearer in terms of the availability of services, the way in which the costs are going to be absorbed or reimbursed and to start eliminating some of the distinctions that become so finite and so arbitrary and so disqualifying to people that they become completely frustrated with the process itself.

That is just an observation, not a question. I am always amazed with the ability of people to survive, to carry on their responsibilities to their family and to undergo the kind of financial strain that you're required to undergo in order to get relief under our system.

I have a lot of questions here which have been prepared and I will submit them to those of you who will have staff to help you formulate the answers. I wanted to take the time here today to thank all of you for coming forward. It's a very important element of health care reform. I reiterate here again today, it is too important to have it drop out because there is a high price tag and saying we simply can't afford it, we'll deal with it next year or the year after that. We've got to deal with it now.

We may have differences with the President's program, we may look at it and say we can't do this right now but we've got to come up with at least a better alternative or something that will be saleable to the vast majority of our colleagues and to our constituents.

That is what Senator Pryor and I are elected to do and what we pledge to do.

The CHAIRMAN. Thank you, Senator Cohen.

Ms. Rowland, let me ask this. You've done a tremendous amount of work in the Medicaid field and you're recognized as one of the specialists in the whole country in Medicaid. Do you feel that access to a community-based care program is going to be a problem? If so, do we have any recommendations to alleviate the problem? If not, why isn't it going to be a problem? It seems like it is a major expansion of access.

Ms. ROWLAND. I think it is extremely important to provide expanded access to home and community-based services and to day care facilities, and to all the kinds of services we've heard from the families this morning that they need to try and provide a full range of care.

One of the problems in the Medicaid program has been the slow growth of funding in that area to help support some of these services. As you well know, State budgets for Medicaid are not growing these days to accommodate new services because there is so much cost associated with paying for existing services.

I think this is one of the areas, however, where it is very important to look at providing incentives to develop resources in underserved areas and in rural communities because some of the kinds of services that we generally think of as home and community-based services may not develop in many of the low-income communities where many of the disabled population live. I think we almost need something equivalent to a community health center pro-

gram for some of the home-based, long-term care services that could be targeted toward underserved and low-income areas and could supplement the Medicaid program's financing stream.

The CHAIRMAN. Is this transition period going to be insurmountable or can we handle it?

Ms. ROWLAND. I think that as the funds become available, we'll handle it. I think our bigger problem right now is financing rather than providing services.

The CHAIRMAN. All of the area of long-term care, one of our previous witnesses talked about a million jobs being created. Senator Burns was curious as to whether these would be public or private jobs. Do you have a comment on that?

Ms. ROWLAND. We're currently doing a large study looking at the work force for home care at the Kaiser Foundation. As part of that study, we are looking at the kinds of individuals now working in the home care industry and new individuals coming into it. We've seen a tremendous transition in the home care field where we are using more and more individuals to provide personal care services in the home, which is a growth area for less skilled workers. So I think there will be some substantial growth in the private sector of companies and agencies providing in-home services. I think this work force competes against a lot of other low wage industries and it will not necessarily be as easy to find the workers.

The CHAIRMAN. Thank you.

Ms. Reed, if I may ask, there are a lot of people out there that we in government and politics deal with who don't want to see any changes in the whole health care system. I would like to say that your father is a very fortunate man to have someone like you.

Ms. REED. Thank you.

The CHAIRMAN. Who is literally committing your life at this time to caring for him. That is so moving.

Some people say that providing new long-term care benefits, family members who are currently providing most of the care, like you, would just no longer do this and just say, well, we're going to send you to a nursing home. How do you react to that feeling?

Ms. REED. I wonder if they are crazy or have no compassion.

The CHAIRMAN. In other words, you think no matter what benefits are available, you are going to, as long as you can, stay with your father?

Ms. REED. Right.

The CHAIRMAN. That is a wonderful commitment and it certainly speaks to something we talk about lightly around here and that is family values.

Ms. REED. I think that people, if you're in power or if you're in the decisionmaking system, you need to realize that you're not going to stay young forever yourself and you need to realize that you, if you live long enough, you're going to get old and who will provide or take care of you, or what bill will be passed to help you. Any of us, if we live long enough, we don't know whether you'll have a stroke, have a heart attack or what because you are born to die and you need to be provided for before you go.

The CHAIRMAN. Your contribution this morning is very, very useful and we thank you so much.

We're kind of at a point now where I'm going to have to conclude our hearing. I don't want to slight the other members by not asking them a question. I wonder if there are any comments that any other members of the panel might have?

We're going to ask your cooperation on something. We have several members today who had to come and leave for other committees but who have requested the option of submitting to various members of the panel questions in writing. If you could supply those back for the committee in due time, we would appreciate that in order to build our hearing record.

I think a lot of the questions for Ms. Ross of the General Accounting Office may be coming to you and we'd appreciate your prompt response.

Mark, would there be any comments from you, James, Gail, or whoever to the preceding statements or remarks? Do you have any follow-up?

Mr. MEINERS. I'll be happy to pass. I think it is an extremely important issue we are struggling with today and I know your deliberations will need to be informed by continual questioning. I will be happy to answer any questions I can. We are learning a lot from the States and working through the public-private insurance demonstration programs and we're happy to supply any of that information.

The CHAIRMAN. We are plowing a lot of new ground, all of us. I must say it is an extremely volatile challenge that we are facing but it is a great opportunity for us and I hope we seize upon it

Mr. Firman.

Mr. FIRMAN. We must focus the bulk of our resources on the severely disabled, but we also need to find ways to help people before they get to that point, even if it is in a modest way. We have to help people to help themselves as a matter of sound social policy and to ensure a wise investment of public dollars.

The CHAIRMAN. Thank you.

Ms. Shearer.

Ms. SHEARER. I think Senator Cohen raised a very important question about not risking all long-term care benefits by trying to expand too quickly. I would like to just comment in our survey about a year ago, we found that 90 percent of consumers surveyed support including both nursing home care and long-term care in a reformed health care system, but they are willing to wait for this benefit. Not long, but they are willing to let it be phased in. They are willing to wait longer for this benefit than for other health care benefits.

I think the important message is let's come up with the blueprint for phasing in long-term care benefits and not just leave it for the next generation to solve.

The CHAIRMAN. At least the blueprint is coming to the table and it is part of a discussion of everyone in this city, the Nation's capital and people all over this country are talking about what is going to happen with the health care reform package. I can say this, something is going to happen. Some people will say it goes too far, some will say it doesn't go far enough, but truly, it is an exciting challenge for all of us.

I'm going to take for just a moment a personal privilege if I could. I understand that in our audience we have a very well-known person, Shelley Fabares, who is a very well-known actress and who has members of her family who have Alzheimer's. Shelley, we welcome you this morning. You've been very patient out there and you are a great dignitary and you grace us with your presence today. I know you represent a lot of Americans out there who have had family members with Alzheimer's and we appreciate the work and the commitment that you do and how you help to sensitize this issue with the American people.

With that, ladies and gentlemen, our meeting will be adjourned. Thank you very much for attending.

[Whereupon, at 12:23 p.m., the Committee was adjourned, to reconvene at the call of the Chair.]

APPENDIX

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April 12, 1994

The Honorable David H. Pryor
Chairman
Special Committee on Aging
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

I am writing to you concerning the hearings your Committee held today focusing on long-term care within the context of health care reform. We respectfully request that this letter be included in the record of those hearings.

The American Bar Association supports legislation that would provide every American access to quality health care regardless of the person's income. Further, with respect to long-term care, the ABA has, since 1989, supported the enactment of federal and state legislation providing a co-ordinated and comprehensive system of care and support for Americans of all ages with long-term care needs.

Three ABA policy statements are attached: one on health care, and two on long-term care. The policies provide general principles that should guide the implementation of health care reform. The ABA enthusiastically supports inclusion of long-term care benefits in health care reform legislation.

We urge that procedural due process protections be made part of such a long-term care component. Even if the long-term care component is not envisioned as an entitlement program, procedural fairness is essential. For example, we are pleased to see that President Clinton's proposed "Health Security Act" contains a long-term care component. However, the proposal appears to lack clear procedural due process protections for the long-term care component. This shortcoming can be remedied by ensuring that substantially the same consumer due process rights that accompany health care benefits also accompany long-term care benefits.

We appreciate the opportunity to express the ABA's views on this important effort and would be pleased to provide additional information.

Sincerely,

Robert D. Evans

Enclosures

RESOLUTION

adopted by the House of Delegates

of the American Bar Association

February 1994

RESOLVED, That the American Bar Association reaffirms its support of legislation that would provide for every American to have access to quality health care regardless of the person's income. Any such legislation should include the following characteristics:

1. Universal coverage for all through a common public or public/private mechanism through which all contribute;
2. Procedural due process for consumers, providers and other interested parties;
3. Appropriate mechanisms to insure expenditure control;
4. Appropriate containment of administrative and health care costs and of administrative burdens on employers;
5. Mechanisms to assure the quality and appropriateness of care; and
6. Freedom of choice and administrative simplicity for consumers.

RESOLUTION

adopted by the House of Delegates

of the American Bar Association

February 1992

RESOLVED, That building upon previously adopted policy calling for a comprehensive and coordinated system of long-term care, the American Bar Association supports the adoption of the following federal, state and territorial legislation, regulations and other initiatives which encourage the appropriate use of private insurance, employment related benefits and other mechanisms that will address the long-term care needs of our aging population.

1. Possible tax law changes and interpretations which foster, rather than restrict, the growth of private insurance, employment related benefits and other mechanisms that offer benefits for long-term care;
2. Better enforcement of existing consumer protection provisions and the adoption of additional measures that will protect the consumer in the sale, financing, and delivery of long-term care products and services;
3. Generally, the initiation of public and private options for providing, financing, and delivering long-term care, including home and community based consistent with principles of equitable access, procedural fairness, autonomy, quality of care and responsible financing.

AMERICAN BAR ASSOCIATION

COMMISSION ON LEGAL PROBLEMS OF THE ELDERLY

AND

SENIOR LAWYERS DIVISION

REPORT TO THE HOUSE OF DELEGATES

RECOMMENDATION

BE IT RESOLVED that the American Bar Association supports the enactment of Federal and State legislation providing a coordinated and comprehensive system of care and support for Americans of all ages with long-term care needs. Any system of long-term care should be consistent with but not limited to the following principles:

1. Provide equitable access to care without undue financial hardship, such as impoverishing spouses or dependents;

2. Provide procedural fairness;

3. Provide for appropriate beneficiary choice with respect to the nature and setting for delivery of care, including institutional and home care, subject to costs and other constraints;

4. Assure appropriate quality consistent with the principles recommended by the Institute of Medicine for nursing home care and by the American Bar Association in its 1987 resolution with respect to home care quality;

5. Ensure responsible financing through appropriate means, which could involve a mixture of public funding and individual cost sharing.

Approved by the ABA House of Delegates February 7, 1989

NATIONAL ASSOCIATION FOR THE SUPPORT OF LONG TERM CARE

STATEMENT ON HEALTH CARE REFORMS

OF THE

NATIONAL ASSOCIATION FOR THE SUPPORT OF LONG TERM CARE

The National Association for the Support of Long Term Care (NASL), represents the interests of nearly 200 companies which specialize in providing an array of medical services, products and supplies to nursing facilities. In addition to our corporate members, NASL has a number of association and associate members many of whom are representatives from the nursing home and long term care sector.

NASL is unique, inasmuch as it brings all the different care programs operating within the nursing home sector together in an integrated, multi-disciplinary view. Our operating coalitions represent six areas of ancillary support: rehabilitation, portable x-ray, clinical laboratory, pharmaceutical, products/supplies and wound care programs. Through our Legislative Council these differing ideas and those of our host industry are brought together into a unified program for improving the quality of services in the extended care and long term care settings.

We wish to emphasize five key points for your consideration:

- ancillary supports (medical services, products and supplies) are necessary components of post-acute caring;
- ancillary support programs are often provided primarily by small, independent businesses;
- the success of these businesses comes because they are meeting identified patient needs;
- healthy competition among these businesses has improved the efficiencies of delivering ancillary support programs; and,
- these ancillary support programs make a major contribution to the quality of patient care.

Our testimony is divided into three parts. First, we will address the broad issues raised by the various reform measures and offer our viewpoints. Second, we will address several of the proposed reductions in Medicare, explaining why we opposed these changes. Finally, we will focus on the extended and long term care proposals and offer our analysis for your consideration.

I. BROAD ISSUES:

After careful analysis our Legislative Council has made the following recommendations:

1. Access: We are supportive of the access goal articulated by the President. Too many Americans are denied health care because of pre-existing conditions and discriminatory insurance practices; too many others cannot afford adequate coverage. Something must be done. While supportive of the goal articulated by the President, we are concerned that the solution proposed in The Health Security Act is too cumbersome and bureaucratic. We urge Congress to focus on the problem of access for those without coverage rather than attempt an experimental rewriting of the total system.

2. Employee Mandates: As small businesses and employers of many part-time employees, we are concerned that an employee mandated system would threaten the economic survivability of our enterprises. Given a large portion of our patients are Medicare and Medicaid eligible, we believe the Congress must make provision for the costs of such mandates. If they are enacted, Congress should enact a direct pass-through in reimbursement.

3. Simplification: We laud this goal. Simplification must occur not only in patient invoicing but in the redundant documentation required to justify our services. Our businesses are drowning in seas of paperwork generated to satisfy the oversight functions of multiple layers of government and insurance scrutiny. Hopefully, the reform system will start with the premise: "pay for caring" rather than "pay for paperwork."

4.Coverage: We strongly believe the Congress should statutorily define the core benefit package. Who gets what, where, and how are policy questions best addressed in an open forum where the politics of the decisions are understood as a given. The individuals responsible for designing coverage must be accountable for their decisions.

5. Cost Containment: As specialized businesses focused on providing services to specialized populations, we are frightened by the simplicity of many of the cost containment ideas advanced in a number of the reform packages. Global budgeting, pricing caps, competitive bidding, mandated fee schedules are great academic concepts which will drive small businesses out of the system. Many of the ideas proposed in the reform packages appear to reinforce the "big dogs eats first" rule. Our businesses grew because the "big dogs" i.e, hospitals, doctor practices, mega-health conglomerates were not meeting the specialized needs of individuals. Unless caution is exercised in segmenting containment initiatives, the net result will be to disrupt services, rather than to contain costs, i.e., the "big dogs" will stay fat, patient services will suffer.

6. Provider Discrimination: An underlying tenet of the free enterprise system is that competition brings cost efficiencies and improves quality. In order for these market forces to work, consumers must have choice. Proposals which attempt to restrict "any willing supplier" or which attempt to impose "single source monopolies" undermine choice. NASL urges the Congress to prevent provider discrimination.

7. Fairness and Due Process: Many of the reform proposals add significant requirements to providers with limited consideration of how these changes will be implemented. Pages of new fraud and abuse requirements are proposed; authorization is provided to new layers of government and quasi-governmental entities to impose rules and standards. The career paths in health care are increasingly away from the playing field of patient care services to the cushy jobs of overseeing and regulating. Measures which strip due process will only accelerate this trend. Balance must be restored; adequate notice, opportunities for public comment, and due process must be preserved.

II. MEDICARE/MEDICAID REDUCTIONS:

Members of the NASL Legislative Council are unanimous in their view that health care reforms should not be paid for on the backs of Medicare beneficiaries and Medicaid recipients. The demographics of utilization clearly underscore that prudent decisions must be made to assure the integrity of the services purchased through these two programs.
We are particularly concerned about three of the ideas proposed in the President's recommendations.

1. Competitive Bidding: We strongly oppose competitive bidding. Monopolies, whether sanctioned by the government or formed in the absence of vigorous anti-trust enforcement are anti-competitive. The net effect will be a deterioration of quality, difficulties in beneficiary access, and an elimination of competitive market behaviors. Sole source franchising will destroy small business. In the absence of market alternatives, the initial cost savings will evaporate and government will be locked into arrangements with no market alternatives.

2. SNF Routine Services Limits: We strongly oppose the idea of lowering the routine cost limit variance for skilled nursing facilities from 112% to 100% of the mean. This proposal would undermine Congressional initiatives to broaden access to high quality extended care services for Medicare beneficiaries. Racheting down routine cost limits will be a significant disincentive for those facilities which have moved to attract heavier care patients. It will reduce access, not improve access for patients, and its impact would be most felt in major metropolitan areas, especially in the Northeast and California.

Cost limits have been straightjackets inhibiting responsiveness to changing patient needs. As nursing facilities move to meet the needs of patients being discharged quicker from hospitals, an enlightened policy would be for the Congress to ease the routine cost limits, exploring alternative strategies for speeding exceptions from the limits and/or permitting a separate classification of subacute programming.

3. Clinical Labs: Policy recommendations should consider the differences between providing laboratory services to residents in long term care facilities from the delivery of such services in the acute and community settings. We are greatly concerned that policy recommendations do not differentiate between the types of services being purchased in the nursing home setting and the unique needs of the beneficiaries receiving the services. Most long term care facilities do not have their own clinical laboratories, and, therefore they must contract with laboratory suppliers to obtain this service. The provision of such specialized services is most demanding and costly. Service demands drive higher operating costs. Specially-trained and experienced lab phlebotomists supervised by senior clinical staff are required to meet the higher acuity levels of nursing facility residents. Additional costs are incured as these practitioners travel to the facility in order to draw and collect samples. Moreover, facilities are more conscious of their regulatory obligations under the OBRA 87 requirements contracting for labs to be capable of provided full service 24-hour, 7 day-a-week service.

For instance, stat (emergency) work requires a turn around of between 2-4 hours. Working with the facilities to assure attentive patient caring, many laboratories provide technical assistance in interpreting results and in meeting special patient monitoring needs. It is important to recognize that while the readiness to service costs are built into reimbursement in the acute setting, in the long term care setting these costs are shouldered by the clinical laboratory. As the medical acuity of nursing home patients increase, demands for laboratory performance have also increased, however reimbursement has not kept pace with expectations. In-service education, monthly chart reviews, standing order systems, summaries of test results and clinical data reports ranging from infection control and nutrition reviews to therapeutic drug histories are demands placed upon clinical laboratories in the long term care setting which are not reflected in current and proposed payment systems. Our fear is these specialized services will not be available to nursing facility residents, especially under competitive bidding proposals, and the progress which has been made in improving the quality of laboratory services to nursing home residents will be undermined. Unless separately considered, nursing facilities will have few cost effective options for meeting the needs of their residents.

III. EXTENDED/LONG TERM CARE:

As experts in the delivery of ancillary services in the extended care setting, we applaud the consideration which is being given to improving extended and long term care services. Reform initiatives which do not address issues of transition from acute to longer term services will be most disruptive; proposals which do not address long term care are incomplete.

The nursing facility sector has been evolving over several decades from programs oriented to sheltering and protecting to programs oriented to caring and discharging. OBRA 87 reforms accelerated this evolution, imposing a myriad of requirements on nursing facilities transforming them into the mainstream of post-acute services. NASL members currently provide many of the supportive services which help nursing facilities comply with the Congressional directives. Our ancillary supports - - rehabilitation, clinical laboratories, portable x-ray, pharmacy services, specialized products and supplies - - bring the medicalized services of the acute setting to the extended care environment.

1. Preserve Core Benefits for Nursing Facility Residents: Unless the reforms of the past decade are to be ignored, these services must be required in the core benefit package, and specific instructions provided to health plans to assure access for subscribers who reside in nursing facilities to necessary ancillary support services.

2. Improve Medicare Extended Care Benefit: Congress has the opportunity to greatly improve upon current Medicare policy. The extended care benefit which is authorized under current Medicare law provides only shallow coverage. Few beneficiaries are covered for more than 30 days of skilled nursing services and many are denied access because of restrictive prior hospitalization requirements. Stringent co-payment and medical review criteria have so narrowed coverage as to make the claim of 100 days of extended care coverage a fraudulent statement.

3. Enact meaningful long term care reforms: The reform initiatives offer an opportunity for change. Several of the plans call for a 100 day extended care benefit. We urge the Congress to enact such coverage as a minimum. We urge Congress to remove the three-day prior hospitalization and to alter the copayment requirements under Medicare. Nursing facilities are stepping up to the challenge of caring for heavier care patients and reimbursement and certification requirements should facilitate sub-acute programs.

4. Exercise Caution in developing SNF Prospective Reimbursement: One of the ideas which has been proposed is shifting reimbursement for skilled nursing facility services under Medicare to a prospective payment system. Initiatives are underway within HCFA exploring the appropriate methodologies for categorizing patient needs and grouping these needs for payment. Because of data availability, these demonstrations have focused primarily on routine nursing services; few ancillary needs are being analyzed. Given this significant flaw in the research designs, we urge caution in making the reimbursement transition. HCFA should focus first on completing its design and implementation of a system which captures the routine services, continuing the current reimbursement methodologies for ancillary programs. Separate data collection and analysis will be required to design a more inclusive system which is fair to patients and which capture the evolving role which ancillary services perform. Simply stated, nursing facilities are rapidly becoming something different than they use to be and the change is being driven by ancillaries. Premature conversion of reimbursement systems will stifle change. The potential for error is particularly great because there is so little data to predict what might occur. Let us be clear, NASL supports the movement towards a prospective system for routine services, but we urge that ancillaries be considered separately.

IV. CONCLUSIONS:

The health care reform debate challenges the Congress to make a series of major decisions reshaping and restructuring the health care delivery system. We have attempted in this testimony to offer constructive guidance, soliciting your understanding that a very specialized ancillary services structure has emerged meeting the unique needs of the nursing facility sector. These ancillary programs are cost effectively meeting a real market need. These ancillary services might be significantly harmed in the restructuring decisions. Patient care will suffer; nursing home reforms will erode.

NASL stands as a resource to work with you and your staffs so that policy changes will continue to improve the quality of services in the long term care setting.

Testimony for the Senate Special Committee on Aging on the Issue of Long-Term Care

by
Linda Gantt, Ph.D., A.T.R. (Registered Art Therapist)
Legislative Coordinator,
National Coalition of Arts Therapies Associations
April 12 1994

Mr. Chairman and Committee Members:

Thank you for the opportunity to submit testimony on behalf of our coalition about the pending health care reform legislation and long-term care. The National Coalition of Arts Therapies Associations (NCATA) represents the following 6 professional membership organizations:

American Art Therapy Association
American Association for Music Therapy
American Dance Therapy Association
American Society for Group Psychotherapy and Psychodrama
National Drama Therapy Association
National Association for Poetry Therapy

Collectively, we have approximately 8,000 members and we estimate that there are some five thousand more like-minded practitioners across the country. Like the larger and better known groups representing such professions as social work, psychology, nursing, or occupational therapy, each of our organizations has an ethical code, standards of practice, professional credentialling, scientific theories, a body of knowledge, and specific training requirements.

Each of the associations developed independently as the result of people with a special interest and background in various art forms and processes working with groups and individuals in special settings. The types of facilities where we work include:

- General and psychiatric hospitals
- Nursing homes, extended care facilities
- Group homes, sheltered workshops
- Rehabilitation programs
- Day treatment programs
- Community mental health centers
- Congregate eating programs
- Substance abuse centers

Programs using the creative arts therapies can be found in some of the most innovative hospitals and agencies in the country including Chestnut Lodge, the Menninger Clinic, the Cleveland Clinic, St. Elizabeths Hospital, Walter Reed Army Medical Center, Sheppard-Pratt Hospital, the Rusk Institute, Cedars-Sinai Hospital, and a number of Veterans Administration hospitals. The Institute for Therapy Through the Arts based in Winnetka, Illinois, provides the services of various creative arts therapists to agencies serving the blind, emotionally disturbed children and adolescents, the elderly, multiply handicapped, and the chronically mentally ill. Similar programs exist in New York City (the Creative Arts Rehabilitation Center) and Boston (the Boston Institute for Arts Therapies).

MAJOR ISSUES

There are several issues which we feel are important for the Senate Special Committee to consider as it addresses the issue of long-term care. These issues relate to the quality of that care:

- **Innovation in treatment should be preserved, especially for the hard-to-reach and difficult-to-treat individuals.**

We are gathering growing evidence to support the contention that nonverbal therapies (art therapy, dance/movement therapy, and music therapy) and arts-based treatments based on specific artistic processes (poetry therapy, psychodrama, and drama therapy) are effective ways to work with patients who are difficult to reach. (See the appendix for some recent articles and books which report on applications and research studies with the elderly using these therapies). In the past, most of our work has been done in psychiatric hospitals and special education settings but we have been expanding our services to a wide range of agencies and community programs because we can demonstrate our effectiveness in treating people who do not respond to more conventional approaches.

Medical patients also respond to our methods. The creative arts therapies are being used with patients who have:

Somatic complaints	Spinal cord injuries
Muscular dystrophy	Cardiac problems
Cancer	Aphasia
Parkinson's disease	Traumatic injuries
Dementias (including Alzheimer's)	

The creative arts therapies can be used in addressing the difficult period of adjustment to a long-term care program: "Upon admission to a long-term-care health facility, an elderly resident is confronted with the formidable challenge of adapting his or her identity, built up over a lifetime of experience as a healthy and capable person, to circumstances of dependence, increasing physical and cognitive impairment, and an institutional lifestyle. If depression, aggression, and other dysfunctional responses are to be prevented, opportunities must be incorporated into the resident's institutional experience for the maintenance of a positive sense of self and the development of a positive attitude toward living in the LTC facility" (G. Paul, 1993. Art and the frail elderly: A multifaceted approach. In: F. Bejjani (Ed.), *Current Research in Arts Medicine*. Pennington, NJ: A Capella Books, p. 127).

Innovative approaches should be recognized in Federal legislation and regulations so that they may be provided for those who can benefit from them.

- **Funding for milieu treatments should be preserved.**

The fee-for-service model can be an expensive way of paying for certain types of milieu therapies which are usually provided for groups of patients within a structured program. We urge Congress to consider specifying certain services including the various creative arts therapies which may be included in the day rates for particular programs such as nursing homes, day treatment programs for patients with dementia, and community-based prevention programs. The regulations for CHAMPUS (the Civilian Health and Medical Program of the Uniformed Services) already provide the language (see attached) for such inclusion and we ask Congress to give consideration to including similar language in the final version of any health care reform legislation.

- **Non-invasive treatments should be emphasized in any health care reform.**

A front-page article in the *Wall Street Journal* (January 13, 1994) described a special unit of Meridian Healthcare Inc., where demented residents participate in structured activities which are based on the arts. "In these 'special care' units, just 3% of the residents require psychoactive drugs to manage their behavior, compared with between 40% and 60% of Meridian's other residents." Given that many elderly patients have other health problems which are complicated by the use of psychotropic medicine it is important to use non-medical treatments whenever possible. By using behavioral interventions instead of tranquilizers care we can avoid some of the serious side effects of certain medicines. The creative arts therapists have specific therapeutic techniques which can be used with a variety of patients who have behavioral problems. For example, in nursing homes we work with those patients who need extra stimulation (such as those who are depressed and withdrawn) and those who need calming but structured approaches (such as Alzheimer's patients).

- **Preventive programs should be stressed, particularly those which engage the participants in such a way as to head off episodes which require hospitalization.**

Depression is a serious condition for many people with chronic physical illnesses. Programs based on the creative arts therapies involve participants in an active rather than a passive way and thus provide a method for dealing with depression. In community-based programs, the creative arts therapies are used to keep people functional for a longer period of time thus avoiding hospitalization. Loss, abandonment, loneliness, and isolation are counteracted by the arts-based therapies. The creative arts can also be used as a means of assessing a person's psychological state or compliance with treatment regimens.

- **Federal programs should recognize a broad range of reimbursable services which can be selected according to the specific needs of patients.**

Creative arts therapists typically work in multidisciplinary teams providing group services as part of a structured program as well as individual treatment. Generally, we are given referrals for special work by the team leader or physician. The arts serve as a catalyst for achieving specific therapeutic goals. By permitting health care professionals a range of permissible treatments we can assure that individual treatment plans can take advantage of any effective techniques. We are not advocating that the creative arts therapies be prescribed for everyone but these approaches can play a critical role in treatment when they are medically indicated and chosen by the physician or treatment team responsible for the over-all direction of care.

When President Carter convened a President's Commission on Mental Health in 1977, he included a Task Panel on "The Role of the Arts in Therapy and the Environment." One of the recommendations of the task panel was that <u>when "considered part of the therapeutic regimen prescribed for the patient, the services of arts therapists should be considered as a reimbursable service</u>. And, the panel added, "<u>future funding, including a national health insurance program, should also include these considerations</u>" (Task Panel Reports Submitted to the President's Commission on Mental Health, Volume IV, 1978, page 1935).

CHIEF RECOMMENDATION: Provide for Flexibility of Treatment Approaches

Our chief recommendation is that Congress insure that those who administer long-term care programs and other services covered by health care legislation be permitted to use a wide range of practitioners to provide services. <u>By inserting non-discriminatory</u>

provider language into the health care legislation (see attachment for suggested language) the services provided by creative arts therapists could be included in patient care plans and milieu treatment programs at the prescription or direction of the physician or program administrator.

If Federal legislation leaves the selection of types of health care providers entirely to the states, those professions such as the creative arts therapies may not be included on a listing of potential licensed providers because in many states our numbers are too few to warrant separate licensing boards. If, however, the creative arts therapies are included in Federal legislation as one of the possible types of therapies which may be used in state plans, then physicians and program administrators can have the flexibility to choose from a range of effective and appropriate treatments depending on a patient's needs.

The creative arts therapies should be considered reimbursable services (as they are in current CHAMPUS regulations) and creative arts therapists should be included in any Federal listing of health providers. At a minimum, those professionals who are licensed (such as physicians and clinical psychologists) should be able to designate particular creative arts therapies services for specific patients.

We Are Appreciative of the Increasing Federal Recognition of the Creative Arts Therapies

The contributions of the creative arts therapies are getting to be better known both by the general public and legislators thanks in large part to the prior efforts of the Senate Special Committee on Aging. In 1991 and 1992, your committee had hearings on music, art, and dance/movement therapy. As a result of these hearings amendments were added to the reauthorization of the Older Americans Act which included these therapies and provided money for research and demonstration grants.

This past fall, the newly created Office of Alternative Medicine (OAM) in the National Institutes of Health awarded research grants to study the use of music therapy to aid psychosocial adjustment after brain injury and the use of dance/movement therapy with cystic fibrosis patients. [The request for applications (RFA) for the OAM money brought in 452 proposals. The creative arts therapies grantees were up against rather stiff competition.]

St. Vincent's Hospital in New York City sponsored a one-day conference on the creative arts therapies with the frail elderly in October, 1993, and is devoting an entire issue of its PRIDE journal to publish the conference papers.

The issues pertaining to health care reform are extremely complex and we are appreciative of the committee members who must work out the myriad details in this legislation. Thank you for this opportunity to make our case.

-- Attachment --

FEDERAL COVERAGE OF THE CREATIVE ARTS THERAPIES UNDER THE CIVILIAN HEALTH AND MEDICAL PROGRAM OF THE UNIFORMED SERVICES (CHAMPUS)

The Federal regulations for CHAMPUS (*Federal Register*, Vol. 56, No. 202, Friday, October 18, 1991, page 52195-52196) authorize coverage of "ancillary therapies" including art, therapy, dance therapy, and music therapy for inpatient programs. The following is the exact language from those regulations:

"(C) *Covered ancillary therapies.*
Includes art, music, dance, occupational, and other ancillary therapies, when included by the attending provider in an approved inpatient, residential treatment plan and under the clinical supervision of a licensed doctoral level mental health professional. These ancillary therapies are not separately reimbursed professional services but are included within the institutional reimbursement."

PROPOSED PROVIDER NONDISCRIMINATION AMENDMENTS

[The sections refer to the President's bill.]

• In section 1161, deleting the word "class" and inserting in its place, "type, class, or category" and adding the following new sentence at the end thereof, "Each State shall institute adequate measures to prohibit the exclusion of or discrimination against any type, class, or category of licensed or otherwise State authorized health professional or his/her designee, by a regional or corporate alliance or health plan on the basis of the health professional's type of license or authorization, or scope of practice, except for restrictions limiting service to those functions which are within the health professional's licensed or otherwise authorized scope of practice.".

• In paragraph (2) of section 1402(c), inserting immediately after the first sentence the following new sentence, "In selecting among providers of health services for membership in a provider network, a health plan may not discriminate against any health professional on the basis of the type, class, or category of health professional.".

• In subparagraph (C) of paragraph (2) of section 1203(a), inserting immediately at the end thereof but before the comma the following, ", including the requirement that the provider network (as defined at section 1402(f)(3)) shall have a sufficient number and range of health professionals, specialities, and practice settings to provide adequate access to the comprehensive benefits package and to meet the requirements of section 1402(c)(2)."

• In section 1328(a), deleting immediately after "religion," "mix of health professionals," and adding the following sentence after the first sentence, "A regional alliance may not discriminate against a health plan on the basis of the types, classes, or categories of health professionals with which the health plan has entered into provider agreements or other such arrangements for the provision of services required by the Act and shall ensure that a health plan meets the requirements of the second sentence of section 1402(c)(2).".

APPENDIX

A Representative Bibliography on the Creative Arts Therapies with the Elderly and with Medical Patients

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CARETENDERS
HEALTHCORP

STATEMENT FOR HEARING ON PROPOSALS TO OVERHAUL THE HEALTH CARE SYSTEM, FOCUSING ON LONG-TERM CARE

SPECIAL COMMITTEE ON AGING
U.S. SENATE

APRIL 12, 1994

Chairman Pryor and Members of the Committee:

We appreciate the opportunity to present our views and recommendations on long-term care issues as a part of proposals to overhaul the nation's health care system. Caretenders Healthcorp. is a provider of comprehensive home health care services and is the nation's leading provider of adult day health care. Caretenders currently operates 13 adult day health centers (ADHCs) in Maryland and Connecticut under the name Almost Family. In 1993, we provided services to over 1000 disabled adults of all ages.

For purposes of this hearing, we urge you to consider the following issues:

- There is a growing need for home- and community-based long-term care services;
- Long-term care coverage should focus on the most severely disabled, regardless of age;
- There are different types of adult day care;
- Adult day health care must be included in any long-term care package, and
- The federal government and states have defined adult day health care.

There Is A Growing Need For Home- And Community-Based Long-Term Care Services

There is an immense and increasing need for home- and community-based long-term care services for disabled. The Administration estimates approximately 3.1 million persons would be served by the Clinton plan's home- and community-based long-term care program. Several factors are fueling this need, including:

Demographics

Nearly 31 million people were 65 or over in 1989.

Less than 14 percent of those aged 65-74 were disabled in 1985, while over 58 percent of those over 85 were disabled, according to data from the Brookings Institution and the Census Bureau.

The over-85 population is the fastest growing sector of the elderly.

The Urban Institute estimated there to be 9.2 million disabled elderly in the community in 1990.

Medical Improvements

Medical improvements allowing people to live longer and survive accidents and diseases that used to kill have resulted in an increase in morbidity, or sickness rates. Diseases such as Alzheimer's will become increasingly prevalent as more and more individuals live longer.

New Family Structure

The emergence of two-worker and single-parent households means that many families will need assistance in caring for elderly family members.

In the middle of the last decade, only one in five elderly with long-term care needs lived in a nursing home, according to the Brookings Institution. This clearly indicates that individuals prefer to remain in the community for as long as possible. However, as more and more households find it necessary to move to dual incomes, the ability to care for a disabled parent or child at home will lessen. The need for home- and community-based long-term care has been increasing over the past decade, and is only going to get worse under the status quo.

Fiscal Constraints

The current system of long-term care in this country is inequitable and inefficient. Public programs, such as Medicare and Medicaid, are experiencing astronomical rates of growth in expenditures, with no relief in sight. The private insurance market is beyond the reach of all but the most wealthy individuals.

Nursing home expenditures are increasing. In 1994, Americans will spend $85.5 billion on nursing home care, according to the Department of Health and Human Services.

Currently, there is an underdeveloped private long-term care insurance market. Several current health care reform bills, including the President's, contain provisions that would make it easier for insurance companies to offer coverage for long-term care services.

The market for home- and community-based long-term care is huge and growing, but supply has not increased to meet demand. If only one percent of the 31 million individuals over age 65 in 1989 needed adult day health care, that would translate to over 300,000 individuals. However, there were only 1200 adult day care centers in 1992, serving 60,000 individuals. This translates to a market where only 20 percent of demand has been met.

Long-term Care Coverage Should Focus On The Most Severely Disabled, Regardless Of Age

Any long-term care reform package should ensure that at least the most severely disabled -- those with limitations in three or more activities of daily living -- are granted coverage for those home- and community-based services that can provide for their needs. These services should be offered without regard to an individual's age.

Sec. 2103(a)(1) of the Clinton plan guarantees coverage for home- and community-based care to individuals *of any age who-*

(A) requires hands-on or standby assistance, supervision, or cueing (as defined in regulations) to perform three or more activities of daily living..., and

(B) is expected to require such assistance, supervision, or cueing over a period of at least 100 days.

The Clinton plan also guarantees care to "severely disabled children" and individuals with "severe cognitive or mental impairment" or "severe or profound mental retardation."

There are many non-elderly disabled. They should not be denied eligibility for long-term care benefits because of age. Specifically, 900,000 individuals under age 65 meet the Clinton plan's criteria for home- and community-based care eligibility.

Adult day health care is not a service limited to the elderly. Throughout our Almost Family centers, roughly 40 percent of our guests are under 65.

We recommend that any long-term care proposal adopt the disability requirements as outlined in Sec. 2103(a)(1) of the Clinton plan.

There Are Different Types Of Adult Day Care

There are many different levels of adult day care. Centers that are staffed and equipped to care for individuals with more intensive medical needs are called adult day health centers (ADHCs). Some centers focus on a specific disability or illness, such as Alzheimer's. Traditional centers, typically run by religious organizations, are called social day care (SDC) centers. They tend to provide more of a social atmosphere for elderly individuals, with less emphasis on health care.

The scarce resources for health care reform should be directed toward individuals with the most severe health needs, i.e., the population best served by an adult day health center. Coverage for home- and community-based long-term care should include those services that can be provided at an adult day health center. Specifically, we recommend that any adult day health center must meet the following minimum requirements to provide services to eligible individuals:

A full-time registered nurse on staff and a physician on call.

A full-time program director.

Open seven days a week.

Staffed at a ratio of one professional for every six guests.

Guests have limitations with at least three activities of daily living (ADLs).

Transportation is provided to and from the center in specially-equipped vans with drivers who are trained to assist disabled individuals.

Given the nutritional requirements of many of the disabled, day health centers maintain the services of a certified nutritionist to monitor guests' diets.

Must be able to dispense and monitor medication, change dressings, change colostomy bags, and perform other light medical tasks. In addition, trained staff are responsible for the coordination of appointments for physical therapy, infusion therapy, dialysis, and any other medical needs and providing transportation to and from appointments.

Many policymakers and health economists have warned that covering respite care services such as adult day care would result in inefficiencies. Specifically, they are concerned that the government would be paying for care that is being provided by family members anyway. This "double coverage," they argue, would be an inefficient allocation of scarce financial resources.

Coverage for adult day **health** care would alleviate this problem. Only the most disabled individuals, who may require frequent health care services, and without constant care would likely enter a nursing home, should be eligible for adult day health care. Typically, families are not able to care for individuals with higher levels of disability who have more acute health needs. This would limit the duplicative provision of resources.

Families are less likely to be able to provide health-oriented care, given the specialized health needs of the disabled population. Finally, from a social policy perspective, families deserve a respite.

Our Lanham, MD center has several examples of true success stories that underscore the benefits of adult day health care:

Four of their current guests arrived from a nursing home. This immediately and directly reduces long-term care expenditures.

Several families who were considering placing a parent in a nursing home were referred to Caretenders' Lanham center. This has allowed each individual to prolong their stay in the community.

Adult Day Health Care Must Be Included In Any Long-term Care Package

Adult day health care is typically 1/2 the cost of a nursing home. For many persons, adult day health care can act as a substitute for a nursing home. Individuals with three or more limitations in ADLs can be treated in adult day health centers (ADHCs).

Since the adult day health center often serves as a substitute for a nursing home, it can prolong the time that an individual remains an active participant in the community.

In short, adult day health care is a cost-effective substitute to a nursing home for many individuals. It also provides a respite for families whose time and patience are strained while caring for a loved one. It is the most effective community-based service that can meet the long-term care needs of the elderly and non-elderly disabled.

Adult day health care is an integral part of the continuum of long-term care. Any health care reform package enacted by Congress should ensure that families and individuals who could benefit from adult day health care have the option to choose and adult day health center over entry into a nursing home.

The Federal Government and States Have Defined Adult Day Health Care

At the federal level, the Clinton health care plan, introduced by Rep. Richard Gephardt (D-MO) and Sen. George Mitchell (D-ME) (H.R. 3600/S. 1757), and the single payor plan (H.R. 1200/S. 491) sponsored by Rep. Jim McDermott (D-WA) and Sen. Paul Wellstone (D-MN) are the only current legislative proposals that include coverage for long-term care services.

The Clinton plan does not make a distinction between social day care and adult day health care. Specifically, the bill defines adult day care as follows:

> Clinton plan Sec. 2304(2) -- *The term "adult day care" means a program providing social and health-related services during the day to six or more adults with disabilities in a community group setting outside the home.*

The single payor plan (H.R. 1200/S. 491) makes a distinction between adult day health care and social day care, but neither term is defined in the legislation.

Rep. Pete Peterson (D-FL) and Rep. Jim Cooper (D-TN) have collaborated on a package of long-term care benefits which specify coverage for adult day care. Their proposal makes no distinction between adult day health care and social day care, and neither term is defined in the current proposal.

Many state governments currently make a distinction between medically-oriented adult day health care and social day care. Here are some examples:

> CA -- Sec. 1570.7(a): *"adult day health care" means an organized day program of therapeutic, social, and health activities and services provided pursuant to this chapter to elderly persons with functional impairments, either physical or mental, for the purpose of restoring or maintaining optimal capacity for self-care.*
>
> AR -- *Adult Day Health Care is a program which provides organized and continuing therapeutic, rehabilitative and supportive health and social services and activities to meet the needs of four or more functionally impaired adults for periods of less than 24, but more than two hours per day in a place other than the adult's own home.*
>
> MD -- Sec. 14-301(b) of the Annotated Code of Maryland: *"day care center for adults" means a place that:*
>
> > *1) is operated to provide, with or without charge, care for medically handicapped adults; and* [is]
> >
> > *2) (i) designated for group day care for four or more medically handicapped adults*[.]
>
> Maryland requires the following services to be provided in adult day care centers:
>
> 1) Therapeutic arts and crafts
> 2) Community excursions
> 3) Hobby cultivation
> 4) Health services
> 5) Counseling services for elderly individuals and their families
> 6) Group dynamics, and
> 7) Other services that enhance social functioning and develop activities in daily living and personal independence
>
> NJ -- *Adult day care means a community-based group program designed to meet the needs of functionally or cognitively impaired adults through and individual plan of care structured to provide a variety of health, social or related support services in a protective setting during any part of a day but less than 24 hours.*

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