

**LONG-TERM CARE FOR THE 21ST CENTURY: A
COMMON SENSE PROPOSAL TO
SUPPORT FAMILY CAREGIVER**

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
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LONG-TERM CARE FOR THE 21ST CENTURY: A COMMON SENSE PROPOSAL TO SUPPORT FAMILY CAREGIVERS

TUESDAY, MARCH 23, 1999

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

The Committee convened, pursuant to notice, at 9:05 a.m., in room SD-106, Dirksen Senate Office Building, Hon. Charles Grassley, (Chairman of the Committee) presiding.

Present: Senators Grassley, Hutchinson, Santorum, Feingold, Dodd, Bayh, Bryan, and Lincoln.

OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN

The CHAIRMAN. I am Senator Chuck Grassley, Chairman of the Aging Committee. We are going to shorten up the presentations by members of the committee because Secretary Shalala has to be out the door at 9:30. Senator Breaux will be here in just a minute. He is introducing this bill with me and he is also the ranking Democrat on the committee and he is very faithful to come to these hearings. To depart from past traditions in this committee, staff of both Republicans and Democrats should inform your members that after Secretary Shalala leaves, I will give opportunity to everybody else to make opening statements.

I call this hearing to order, and as Chairman of the Special Committee on Aging, it is my pleasure to welcome my colleagues, our witnesses, and the public to this very important hearing. I especially want to express my appreciation to those citizens who took the time to participate in this hearing. A caregiver's time is very precious and I want to make sure that your attendance at this hearing is of value to you.

Today's hearing will evaluate part of a long-term care proposal made earlier this year by President Clinton. We are pleased to have Secretary Shalala here today to present the National Family Caregiver Support Program. Senator Breaux and I look forward later today to this bill's formal introduction.

With millions of baby boomers set to retire in the near future, it is crucial to begin preparing today for what will be dramatically increased long-term care needs in the next century. A critical part of long-term care is family caregiving. Roughly 22 million American families provide this sustenance to family members. The vast majority of caregivers are women, daughters, wives, and sisters, who,

on top of caregiving, probably also have jobs and children at home. The financial, work-related, personal, and emotional demands are very high.

Nationwide surveys find that caregivers, on average, spend \$171 per month for food, medication, and other expenses related to this type of caregiving. This amounts to \$2,000 a year, the equivalent of what we would call an IRA.

Another survey of U.S. employers finds that the loss in productivity from caregiving employees ranges from \$11 billion to \$29 billion per year. This comes in the form of adjustments to work schedules, including late arrivals and early departures, taking off extra time, and leaves of absence.

Despite all the sustenance they provide, caregivers themselves are, in a sense, malnourished. Caregivers are starved of resources that would help ease the overwhelming burden that they shoulder each day. They often have nowhere else to turn.

The Family Caregiver Support Program would marshal resources into the aging network to support family caregivers in a variety of ways. This resource network would parallel other Title III Act programs. Caregivers would receive valuable services, such as counseling, training, and peer support. This program reflects an important principle. Family caregivers reflect the best of our society and we want to help those who do it. We want more of it.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR CHUCK GRASSLEY

As Chairman of the Special Committee on Aging, it is my pleasure to welcome my colleagues, our witnesses and the public to this important hearing. I especially want to extend my most sincere appreciation for those citizens who took the time and made the effort to participate in this hearing. A caregiver's time is extremely precious. I want to make sure your attendance at this hearing is of value to you.

The purpose of today's hearing is to evaluate part of a long-term care proposal made earlier this year by President Clinton. We are pleased to have Secretary Shalala hear today to present the National Family Caregiver Support Program. Senator Breaux and I look forward to promoting this measure in the Senate with a bill that we will introduce later today.

With millions of baby boomers set to retire in the near future, it is crucial to begin preparing today for what will be dramatically increased long-term care needs.

This initiative we're focused on today recognizes the most effective, and most under-appreciated, aspect of long-term care delivery: the family caregiver. Family caregivers face a chronic shortage of resources. Roughly 22 million Americans provide this sustenance and critical care to our nation's long-term care apparatus. Yet, in a sense, they themselves are malnourished. Caregivers are "starved" of resources that will support and help ease the overwhelming burden that they are expected to shoulder on a daily basis.

The goal of today's hearing is to examine the viability of a comprehensive, multi-faceted support system in each state. The Family Caregiver Support Program would marshal resources into an "aging network" that would be constructed to support family caregivers in a variety of ways. This resource network would parallel other Title III Act programs. It would start with Federal funding allocated to States on a population-based formula. Each State, in turn, would use its allocation to work with local area agencies on aging, community-service providers and consumer organizations. Ultimately, the program would serve millions of family caregivers in their own communities.

This program is ambitious in that it would endeavor to provide a very wide range of caregiver support services. The design is aimed at addressing the following challenges: How can the family caregivers receive the support that they need to continue to care for loved ones at home or in a community-based setting? Most people prefer to receive care in their homes, rather than in institutions. That's understandable. Few would question the preferences of those who would rather receive long-term

care in a familiar, home-like setting. And, in addition to that, institutional care is more expensive.

We've learned a lot in recent years about the practical and substantial needs of family caregivers. We know that there are more than 20 million caregivers. The vast majority of them are women—daughters, wives and sisters—who, on top of caregiving, have jobs and children at home. The financial, work-related, personal and emotional demands are high. Nationwide surveys find that caregivers on average spend \$171 per month for food, medication, and other expenses related to caregiving. This amounts to \$2,000 a year. That's the equivalent of an IRA. Another survey of U.S. employers finds that a loss in productivity from caregiving employees ranging from \$11 billion to \$29 billion a year. This comes in the form of adjustments to work schedules, including late arrivals and early departures, taking off extra time and leaves of absence.

On top of that, caregiving can take an enormous physical and emotional toll on the caregiver. As many as 30 percent of caregivers report to experiencing physical or mental health problems due to caregiving. So, while caregivers find their role rewarding, it also can be extremely stressful.

This proposal we'll talk about today is a modest investment. It is meant to target the acute needs of caregivers by providing services to connect families with information about local services and caregiver resources, and to make available counseling, training, and peer support. The Family Caregiver Support Program would be an important first step toward addressing these needs. I am glad for the opportunity today to highlight

Secretary Shalala, I would call on you at this point to proceed with your opening statement.

**STATEMENT OF HON. DONNA E. SHALALA, SECRETARY,
UNITED STATES DEPARTMENT OF HEALTH AND HUMAN
SERVICES, WASHINGTON, DC.; ACCOMPANIED BY JEANETTE
C. TAKAMURA, ASSISTANT SECRETARY FOR AGING; AND
RICHARD HODES, DIRECTOR, NATIONAL INSTITUTE ON
AGING**

Secretary SHALALA. Thank you very much, Senator Grassley, Senator Feingold. Thank you for the opportunity to testify on one of the most important domestic issues facing our Nation, long-term care for our elderly and disabled Americans. I am joined today by two members of our outstanding team, Dr. Jeanette C. Takamura, the Assistant Secretary for Aging, and Dr. Richard Hodes, Director of the National Institute on Aging. We greatly appreciate your bipartisan leadership on the President's long-term care initiative, particularly the Family Caregiver Support Program.

I also want to recognize the special leadership role this committee has played in bringing greater focus and awareness to the many health and lifestyle issues facing our Nation's senior citizens, including Alzheimer's disease and related disorders.

Mr. Chairman, when the late Stanley Kubrick made "2001: A Space Odyssey" 30 years ago, his vision of the future was one of revolving space stations and rebellious computers. Now that 2001 is only 2 years away, we can argue about how close Mr. Kubrick came to the truth.

What we cannot argue about is the changing face of our country over the next 30 years. For all the images we see in movies and television of a Nation that is faster, younger, and healthier, the fact is we are heading for a world no demographer has ever seen before. The color of that world is gray. By the year 2030, the number of people in our country 65 and older will double, and people 85 and older will be commonplace.

These changing demographics are no cause for alarm, but they are a cause for action. We want life not only to be long but to be good, and that means having the tools we need to care for those ravaged by Alzheimer's and other chronic or disabling diseases. This will be one of the central challenges of the 21st century, to make dignity and comfort for the elderly as much a part of our national consciousness as education and safety is for our children.

Millions of families across America already face this challenge. Today, family members provide most of the care for older persons who can no longer manage on their own, and that is the reason for the President's long-term care initiative, to give these families and the loved ones they care for the support, the guidance, and the financial assistance they desperately need.

Let me be very clear. This initiative is not designed just to help older Americans. It is part of a much broader strategy to help Americans of all ages who are disabled, and this initiative is not just about money. It is about providing comprehensive assistance to family members who provide and receive long-term care.

Let me give you one example. Frank lives in the Chicago area. His wife is in a local adult day care center 3 days a week. Those 3 days are Frank's respite, a time of rest and relief, but also a time to buy what he needs to hold his family together. Frank lives a 24-hour-a-day, 7-day-a-week expression of love, but the stress and exhaustion are building. Now Frank says that although he might end up going before her, "at least my conscience will be clear."

Mr. Chairman, the time has come to ask, what about our conscience? Today, 95 percent of frail older Americans who live in the community and need long-term care receive unpaid assistance from informal caregivers like Frank. Research indicates that informal support for caregivers has a significant impact on their emotional well-being. It also delays the need for nursing home services.

Research also tells us that providing care to older persons exacts a heavy emotional, physical, and financial toll. Almost three-quarters of informal caregivers are women. Many are older and vulnerable themselves, or are running households and parenting children. Keep in mind, half of all the caregivers are over 65 themselves, and that means their own health is at risk. They suffer high rates of depression, and not surprisingly, one-third describe their own health as fair to poor. At the same time, many caregivers have had to cut back on their hours of work or rearrange their work schedules to provide care for their older loved ones.

Mr. Chairman, long-term care takes a huge financial and emotional toll on the family and friends who provide most of the care. Still, no single policy can solve this problem, and that is why the President in his fiscal year 2000 budget has proposed a multi-faceted initiative to provide immediate assistance with long-term care, while helping our nation to prepare for the day when the baby boom becomes a senior boom.

Mr. Chairman, we do not have all the answers, but we believe that this initiative provides a strong first step that we can build on in the future. First, the President's long-term care initiative includes \$125 million per year for the National Family Caregiver Support Program, to provide assistance to people caring for older family members. Through the established networks of the Adminis-

tration on Aging, this program will enable States, working with area agencies on aging, working with local service providers and consumer organizations, to create a community-based infrastructure of support for family caregivers. From gaining access to specific services to respite care to individual counseling, caregivers and their loved ones will start to get the help they need.

Second, the President's initiative includes a targeted \$1,000 tax credit. The tax credit will help to offset some of the direct costs of long-term care as well as indirect costs, such as unpaid leave taken from work.

Third, the President's initiative includes an expansive educational effort to inform all Medicare beneficiaries about long-term care options.

Fourth, the President's proposal calls for the Federal Government to offer private long-term care insurance at group rates to Federal employees and their families.

Fifth, our fiscal year 2000 budget would expand access to home and community-based care services to people of all ages with significant disabilities who prefer to live in the community.

Sixth, the President's budget provides \$100 million in competitive grants to convert some of or all of HUD's subsidized projects for the elderly into assisted living units.

Mr. Chairman, there are adult children all across America who live in fear that Alzheimer's disease will strike their parents or a loved one. I speak from personal experience. When I was home over Christmas, my cousins told me about caring for one of my aunts who has Alzheimer's. Every day, they rush home from work in the middle of the day to make sure that their mother gets the help she needs. They are loving, but they are also stressed and need help. My cousins' case is just one of many, and I know there are members of the Alzheimer's Association chapter from Cleveland here. For them, there is no "one size fits all" answer.

I also had a conversation with another family member in rural North Dakota. Their problem is that they can provide the help during most of the year, but when the planting season begins or when harvest begins, every family member is involved in that planting or that harvest. They need help during those times.

That is why we are proposing comprehensive assistance for people with Alzheimer's. That is why the President's proposal is a historic first step that will, in his words, give care to the caregivers. Nearly four million people who have Alzheimer's or related disorders, and that number is expected to double in the next 20 years, every victim will eventually require full-time care, and that is why I have directed the National Institute on Aging, under the leadership of Dr. Hodes, to step up its effort to study Alzheimer's disease and related disorders.

Just last week, NIA launched a nationwide treatment study targeting people with mild cognitive impairment, known as MCI, a condition characterized by memory deficit but not dementia. Other trials will help us to understand and treat Alzheimer's, and those are in the pipeline.

For those who now have Alzheimer's, research and information campaigns are being intensified to help alleviate part of the over-

whelming burden that Alzheimer's creates, with special emphasis on the needs of minority, of ethnic, and of rural communities.

NIA is also taking steps to make information about Alzheimer's disease clinical trials more accessible to the public. For example, NIA's Alzheimer's Disease Education and Referral Center (ADEAR), in collaboration with the Food and Drug Administration, is developing a data base of ongoing Alzheimer's disease clinical trials that will be accessible on the Worldwide Web and through trained specialists of the ADEAR toll-free hotline (1-800-438-4380).

The Administration on Aging's Alzheimer's disease demonstration grants will help States take advantage of research findings and demonstrate effective models of non-medical care for people with Alzheimer's.

I also want to note the Administration on Aging's highly successful national toll-free Eldercare Locator, (1-800-677-1116). I actually called it just before I came and it does not open until 9. [Laughter.]

However, the person on the other end of the line was very pleasant and offered to take my number and call me back this morning, so I left my number. The locator provides very important information and assistance to long-distance caregivers who are seeking help for their loved ones.

I would like to close, Mr. Chairman, by saying that the need for support for family caregivers has never been greater. We believe that the President's long-term care initiative offers an important first step toward ensuring that America's elders and their families are able to enjoy a good quality of life, optimal health, and access to critical support services.

Mr. Chairman, Members of the Committee, the Special Committee on Aging, and this committee is special, I greatly appreciate your leadership on long-term care and the other issues affecting senior Americans. My colleagues and I would be happy to address any questions that you might have.

[The prepared statement of Secretary Shalala follows:]



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

TESTIMONY OF
THE HONORABLE DONNA SHALALA
U.S. SECRETARY OF HEALTH AND HUMAN SERVICES
before the
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
March 23, 1999

Good Morning, Chairman Grassley, Senator Breaux and Members of the Senate Special Committee on Aging. Thank you for the opportunity to testify on one of the most important domestic issues facing our nation: long-term care for our elderly. I am joined today by two members of my team, Dr. Jeanette C. Takamura, Assistant Secretary for Aging, and Dr. Richard Hodes, Director of the National Institute on Aging (NIA). We greatly appreciate your bipartisan leadership on the elements of the President's long-term care initiative, particularly the Family Caregiver Support Program.

In fact, before I begin, I want to recognize the special leadership role that this committee has played in bringing greater focus and awareness to the many health and lifestyle issues facing our nation's senior citizens, including Alzheimer's disease and related disorders. I know the members of the audience and those they represent all across America join me in expressing our deep appreciation to you Mr. Chairman, and Senator Breaux, for the committee's fine work over the years.

Mr. Chairman, when the late Stanley Kubrick made *2001 A Space Odyssey* 30 years ago, his vision of the future was one of revolving space stations and rebellious computers. Now that 2001 is only two years away, we can argue about how close Mr. Kubrick came to the truth.

What we cannot argue about is the changing face of America over the next 30 years. For all the images we see in movies and television of a nation that is faster, younger and healthier, the fact is

we are heading for a world no demographer has ever seen before. And the color of that world is gray. By the year 2030, the number of persons in our country 65 and older will double. And people 85 and older will be commonplace.

These changing demographics are no cause for alarm. But they are cause for action. We want life not only to be long - but good. That means having the tools we need to care for those ravaged by Alzheimer's and other chronic or disabling diseases. This will be one of the central challenges of the 21st century - to make dignity and comfort for the elderly as much a part of our national consciousness as education and safety for our children.

Let me emphasize that millions of families across America already face this challenge. In fact, family members provide most of the care for older persons who are no longer able to manage on their own. So one of the reasons I am here today is to convey the Administration's strong commitment to the families and caregivers of people in need of long-term care. But we need to do more than stand with them. We need to help them. That is the purpose of the President's long-term care initiative. To give these families - and the loved ones they care for - the support, guidance and financial assistance they desperately need.

Let me be clear: this initiative is not designed to just help older Americans. It is part of a much broader strategy to help Americans of all ages who are disabled. And this initiative is not just

about money. It is about providing comprehensive assistance to family members who provide and receive long-term care.

That means the hundreds of thousands of Americans living in communities across our country, struggling to raise children, hold down jobs and protect their elderly parents. Let me give you an example of the type of person I am talking about. Frank is an older gentleman from the Chicago area. His wife is in a local adult day care center three days a week. Those three days are Frank's respite. They are a time of rest and relief - and also a time to buy the groceries and other supplies he needs to hold his family together. What Frank does is a 24-hour-a-day, seven day-a-week expression of love. At first the burden was manageable - and the fulfillment of a promise he had made on his wedding day. Now Frank says that although the added stress and exhaustion means he might end up going before her, "at least my conscience will be clear."

What about our conscience? Frank and so many others like him deserve more than our admiration; they deserve our support. Mr. Chairman, 95 percent of frail older Americans who live in the community and need long-term care receive unpaid assistance from informal caregivers like Frank.

Research indicates that informal support for caregivers has a significant impact on the emotional well being of caregivers, as well as in delaying the need for nursing home services. A recent

NIH study found that adult day care not only reduces caregiver stress, but delays the institutionalization of the care recipient. Another recent study indicates that counseling and support for caregivers of people with Alzheimer's can keep the care recipient out of a nursing home for an additional year.

Research also tells us that providing care to older persons exacts a heavy emotional, physical and financial toll. Almost three-quarters of informal caregivers are women. Many are older and vulnerable themselves, or are running households and parenting children. In fact, half of all caregivers are over 65 themselves. That means their own health is at risk. They suffer high rates of depression because they are emotionally strained. And not surprisingly, one third describe their own health as fair to poor. Many caregivers have had to cut back on their hours of work to provide elder care for their loved ones. Today, two-thirds of working caregivers report conflicts between work and caregiving that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence.

The National Family Caregiver Support Program

Mr. Chairman, long-term care does indeed take a huge financial and emotional toll on the family and friends who provide most of this care. Because of its complexity, however, no single policy can "solve" this problem. Thus, the President in his FY 2000 Budget has proposed a multi-

faceted initiative to provide immediate assistance with long-term care and help prepare for what will surely be one of the great challenges as the baby boom generation ages.

First, the President's long-term care initiative includes \$125 million per year for the National Family Caregiver Support Program to provide assistance to people caring for older family members.

Through the established networks of the Administration on Aging (AoA), this program will enable states, working with area agencies on aging, local service providers and consumer organizations, to create a community-based infrastructure of support for family caregivers. State offices on aging would be expected to put in place at least five important program components to meet complex and diverse care needs. These components include:

- Providing information to caregivers about available services;
- Assisting caregivers in gaining access to specific services;
- Individual counseling, organization of support groups, and provision of caregiver training to help families make decisions and solve problems related to their caregiver roles;
- Respite care to enable families and other informal caregivers to be temporarily relieved from their caregiving responsibilities; and
- Providing supplemental long-term care services, on a limited basis, to complement the care provided by caregivers.

Our proposal also includes competitive grants for the development of innovative solutions to specialized caregiver problems. The results from these demonstration projects and applied research will be put into practice through ongoing state programs. This will lead to an understanding of best practices; in other words, which programs are the most effective in helping caregivers and care recipients in the home, in the community or on tribal reservations.

Second, the President's initiative includes a targeted \$1,000 tax credit for people with long-term care needs or their caregivers. For some families, the tax credit will help to offset some of the direct costs of long-term care, such as adult day care or home health care visits. For others, it will help offset indirect costs such as unpaid leave taken from work.

Third, the President's initiative includes an expansive educational effort to inform all Medicare beneficiaries about long-term care options. Since most people who develop long-term care needs are Medicare beneficiaries, Medicare can be used to provide information on the limitations of its coverage, alternative sources of long-term care services and financing, and how best to choose the most appropriate options.

Fourth, the President's proposal also calls for the federal government to offer private long-term care insurance at group rates to federal employees, annuitants and their families. Participants would be responsible for paying the full amount of the premium and the market leverage of the

federal government is expected to save an estimated 15 to 20 percent from the cost of individual long-term care policies. It will also set an example for other employers.

Fifth, our FY 2000 budget would expand access to home and community-based care services to people of all ages with significant disabilities. Under this proposal, states could provide Medicaid coverage to people with incomes up to 300 percent of the federal Supplemental Security Income level who would be eligible for nursing home care but who would prefer to live in the community. This new Medicaid option will make eligibility for nursing homes and community-based services more comparable - and will eliminate one of the sources of Medicaid's "institutional bias."

Sixth, the President's budget provides \$100 million in competitive grants to enable existing HUD elderly subsidized (Section 202) projects to convert some or all units into assisted living in order to provide the additional services that many older Americans need to continue living as independently as possible. Finally, the Vice President has started a series of forums on family caregiving, raising important issues and educating people about their options.

Mr. Chairman, there are adult children in this country who - day in and day out - live in terror that their mom or dad will wander off or hurt themselves because of Alzheimer's or a similar disease. We want to keep families from having their lives wracked by stress, worry and despair. I speak from some personal experience. When I was home in Cleveland over Christmas, my

cousins told me about caring for one of my aunts who has Alzheimer's disease. My cousins rush home from work in the middle of the day, every day, to make sure that their mother gets the help she needs. They are loving. But they are stressed. And they need help. Unfortunately, there is little help for them because they are middle income and do not qualify for Medicaid.

Frankly, my cousins' case is just one example of many. We know that the lives and needs of caregivers are varied. We know that there is no "one size fits all" answer. A complicated challenge requires a comprehensive solution. Overall, our initiative is a pragmatic response to the growing problems of long-term care. It provides comprehensive assistance, not just financial assistance, to those requiring or providing long-term care. Our proposal is an historic first step that represents a compassionate response to what I have already said will be one of our nation's most compelling problems in the 21st century. We must, as the President has said, "give care to caregivers." The President's initiative helps to meet that challenge.

The Department's Alzheimer's Initiatives

Alzheimer's disease exacts a heavy toll on its victims, their families, and our health care system. Each year new research helps to sharpen the effectiveness of care for people with Alzheimer's disease. Nevertheless, the nearly four million people in the United States who have Alzheimer's disease, or related disorders, is expected to double in the next 20 years. Each victim will eventually require full-time care. This dreaded disease affects patients, their families, caregivers

and society. We must continue to evaluate the various models of care for people with Alzheimer's and models of support for their families so that successful approaches can be given broader implementation.

That is why I have directed the National Institute on Aging, under the leadership of Dr. Hodes, to step up its efforts to study Alzheimer's disease and related disorders. The NIH Alzheimer's disease prevention initiative is being developed to expedite our progress in delaying or preventing the onset of Alzheimer's disease. In collaboration with other federal agencies and the private sector, this initiative will foster new approaches to basic biological and epidemiological research; increase focus on drug discovery and development; improve methods for early identification of people at increased risk of developing Alzheimer's; and facilitate testing of possible new treatments in clinical trials. The initiative will also develop strategies for improving patient care and alleviating the burden of caregiving.

Just last week NIA launched a nationwide treatment study targeting people with mild cognitive impairment, also known as MCI, a condition characterized by memory deficit, but not dementia. Accurate and early evaluation and treatment of MCI individuals might prevent further cognitive decline, including the development of Alzheimer's disease. This study is the first such Alzheimer's disease prevention clinical trial carried out by NIH, and will be conducted at 65-80 medical research institutions throughout the United States and Canada. Other trials are in the

pipeline, many of which will piggy back cognitive studies onto ongoing trials for the treatment or prevention of other conditions..

For those who now have Alzheimer's disease, research and information efforts are being intensified to help alleviate part of the overwhelming patient and caregiver burden, with special emphasis on the needs of a diverse patient population. The NIA is also taking steps to make information about Alzheimer's disease clinical trials more accessible to the general public. As part of a NIH-wide initiative on all major clinical trials, the NIA's Alzheimer's Disease Education and Referral Center (ADEAR), in collaboration with the Food and Drug Administration, is developing a database of ongoing Alzheimer's disease clinical trials. When complete, both government and commercial trials will be represented. The database will be accessible on the World Wide Web, and information will also be available through trained information specialists of the ADEAR toll-free hotline (1-800-438-4380).

The Administration on Aging's Alzheimer's disease demonstration grants will help states to take advantage of research findings and demonstrate effective models of non-medical care for people with Alzheimer's disease. The demonstration programs have proven to be very successful in reaching out to, and providing support services to people with Alzheimer's disease and their family caregivers. Special attention is being paid to minority, low-income and rural families. Building on the approach instituted by the Health Resources Services Administration (HRSA), AoA supports states in developing model practices for serving people with Alzheimer's disease

and their families. Of the 15 grantees, 12 are state offices on aging, two are state health departments, and one is a state mental health agency. Nationally, almost 150 agencies are involved in the program. State and local Alzheimer's Association chapters are active in all of the projects. Approximately 8,000 families have been assured that their loved ones with Alzheimer's disease are able to maintain the highest possible quality of life.

I also want to note the Administration on Aging's highly successful national toll-free Eldercare Locator (1-800-677-1116). The Locator provides important information and assistance to long distance caregivers who are seeking help for their loved ones. We have found that many of the individuals who call our Eldercare Locator are caregivers for family members with Alzheimer's disease.

Let me close, Mr. Chairman, by saying that the need for support for family caregivers has never been greater. Caring for our elders has become a deeply emotional, sometimes heartrending matter for millions of families across America. The number of those families will only grow - as will the need for caregiving resources. The new century will bring longer life spans, more changes in family structure, more women in the work force, more geographic mobility and more delayed child rearing. We believe that the President's long-term care initiative, in particular the National Family Caregiver Support Program, offers an important first step towards ensuring that American elders and their families are able to enjoy a good quality of life, optimal health and access to critical supportive services.

Chairman Grassley, Senator Breaux, members of the Special Committee on Aging, I greatly appreciate your leadership on long-term care and other issues affecting senior Americans. I look forward to working with you to meet the challenges and opportunities of the gift of longevity. We have much to accomplish and many families to help. They are our friends, our neighbors, our fellow citizens. The time to offer them the supportive hand they need is now.

My colleagues and I would be happy to address any questions you might have.

The CHAIRMAN. I want to call on Senator Dodd at this point because we are going to kind of forego the tradition here. She has to go at 9:30, so I thought when Senator Dodd is done, then we would each ask her one question, rather than taking 5 minutes, so everybody can get a chance to ask Secretary Shalala a question. Senator Dodd

STATEMENT OF SENATOR CHRISTOPHER DODD

Senator DODD. Thank you very much, Mr. Chairman, and Madam Secretary, in light of your recent encounter in Georgetown, it is a pleasure to see you here this morning in one piece. [Laughter.]

I just have one question for you. I just wonder if there is any truth to the rumor that Jesse "The Body" Ventura has turned down your offer to meet him in a steel cage match someplace. [Laughter.]

Anyway, it is a pleasure to see you here this morning.

Mr. Chairman, thank you immensely and I thank my colleagues here for allowing me to appear at the committee. I served on this committee under the leadership of John Heinz, going back a number of years ago, and am deeply honored that you have allowed me to stop in this morning and to share some thoughts on a couple of matters that the Chairman and I are introducing.

I am a member of the Aging Subcommittee on the Labor and Human Resources Committee of the Senate, which Senator DeWine Chairs, and Senator Mikulski, my colleague from Maryland, serves on the full committee with me. I am not sure if you are a member of the subcommittee, as well. The issue of the Older Americans Act is coming up, and so clearly, some of these ideas are ones that we hope to be able to at least offer to our colleagues to consider in the very near term as part of the legislative effort.

I am pleased this morning to join you, Mr. Chairman, in introducing the National Family Caregiver Support Act, which we will be introducing along these lines. This legislation will help to ease, we believe, the significant burden as you have identified, Madam Secretary, many families take on by caring for elderly family members. It will provide \$125 million over 5 years, \$625 million in all, to State and local Agencies on Aging so that they can provide respite and educational services for family caregivers. The funds provided under this Act will go directly toward alleviating the great burden that many caregivers bear by providing assistance to care for their elderly family members.

The concept is a very simple one, and Madam Secretary, you have outlined it very, very well. With the help of this legislation, a person caring at home for a loved one would get some help so they could go do the basic things, the simple things that we all take for granted every single day, but for a person involved in elderly care become major hurdles and major burdens, things such as going grocery shopping, going to the hairdresser, very simple items, taking a walk, doing other things important to them in their lives, seeing other family members that they ought to maintain a relationship with, just alleviating some of the incredible stress involved in caring for a loved one at home.

By providing valuable respite services so that family caregivers may be afforded some needed time off, this initiative will move us in the right direction by recognizing the important role family caregivers play.

In addition, this initiative will provide educational services to family caregivers. Many caregivers assisting their elderly family members do not have any previous experience in providing health care services, and it is for this reason that this initiative will provide funds to local Agencies on Aging to provide educational services to family caregivers.

The Federal Government should do all that it can to aid family caregivers in their valuable, commendable, and often difficult efforts to help their loved ones. This provision would provide thousands of family caregivers with valuable assistance and educational services that they require.

Mr. Chairman, last year, I had the opportunity to witness first-hand the valuable services that these local Agencies on Aging provide to their elderly clients. Many of my colleagues certainly experienced a similar case that we did in Connecticut when more than 12,000 of my seniors in Connecticut and individuals with disabilities in Connecticut were notified by their Medicare HMOs that their HMO health insurance coverage would soon be terminated. Well, as you can well imagine, you may recall how many of our seniors affected by these HMO withdrawal decisions were obviously upset, confused, to put it mildly, about what to do next.

I was pleased to see one of my Area Offices on Aging take such a leadership role in calling together these seniors, 400 of them on 24-hour notice, to go over the decisions, the policy concerns. It was a wonderful example of how an Area Office on Aging can play such a critical role for older Americans. I was greatly impressed by the dedicated staff in this agency, their invaluable and tireless efforts to allay the fears and concerns of their clients. Having witnessed myself the important services the Older Americans Act makes possible, I cannot understate the great respect that I have for this valuable legislation.

Mr. Chairman, I would hope that as we pursue the enactment of this legislation, we will craft it in such a way as to support not only family caregivers but also men and women living in assisted living facilities. Today, more and more seniors are realizing greater independence and better help through services provided by our nation's assisted living facilities. Assisted living centers provide those services that allow seniors who do not require continual care to live full, independent lives without incurring the greater costs often associated with skilled nursing homes.

Today, many seniors simply require assistance with food preparation or light housekeeping services. Assisted living enables many Americans to avoid more costly alternatives by choosing a facility that provides only those services that they require. It is my hope that we can work within the Caregiver Support Act so that residents of assisted living centers can also benefit from these valuable services.

I look forward, as I said, to working with Senators DeWine and Mikulski and including the Family Caregiver Support Act within the larger scope of the Older Americans Act.

Mr. Chairman, I also believe there are two quick additional steps that we should take to support families who are now or one day will provide long-term care to loved ones. The first step is simply to educate people about the availability and importance of long-term care insurance. Senator Grassley, the Chairman of this committee, and I will later today introduce a sense of the Senate resolution stressing the importance of long-term care insurance. Senator Grassley has introduced this legislation along with me in the last Congress with eight cosponsors. We hope we will be joined by more of our colleagues in the Congress. This costs \$40,000 to \$50,000 a year, on average. More and more Americans will need to address their long-term care needs by obtaining sufficient long-term care insurance, and we think this resolution will begin to highlight this program.

Last, I plan to introduce in the next day or so, Mr. Chairman, to establish a tax credit to help more Americans meet the high cost of long-term care. I commend the President, and Madam Secretary, you, as well, for your \$1,000 tax credit to help allay the costs associated with long-term care. The initiative that I am developing is different in one aspect. It does include the out-of-pocket expenses that the President does for hospital-type beds, walkers, and other rehabilitation equipment.

Additionally, this proposal would add a new dimension that would allow credit to be used toward the purchase of long-term care insurance. This additional provision, we think, will create an incentive for families to buy insurance. We will also use Federal dollars in the form of tax credits to leverage much more in terms of long-term care. It is my hope that such a tax credit would allow more and more Americans to purchase this needed long-term care insurance and thereby reduce the number of seniors forced into poverty in order to receive the long-term health care services that they require, and the only place they can get it in the absence of having a decent insurance program.

So, Mr. Chairman, again, I apologize to my colleagues for taking these few minutes, but again, I commend you for your leadership on these issues. It has been a pleasure to work with you on a number of them, and again, I commend, Madam Secretary, you and the efforts of the agency and am delighted that this year we are going to have some strong, I think, bipartisan support for fighting these issues and doing something meaningful in the area of long-term care, respite care, things that our elderly are going to need more and more of. Thank you, Mr. Chairman.

The CHAIRMAN. We appreciate your cooperation and look forward to working with the authorizing committee on this.

You have 3 minutes left. Do you have time for questions from one member each?

Secretary SHALALA. Mr. Chairman, I would be happy to stay for an extra 10 minutes and keep the White House waiting, given the importance of this issue, to accommodate the committee's questions. [Applause.]

Senator DODD. That is a smart move, Madam Secretary.

The CHAIRMAN. I will go and then call on Senator Feingold, then Senator Hutchinson, then Senator Bayh and Senator Bryan for one question apiece.

It is my intent, and I hope Senator Dodd's intent, and I hope the President's intent, that this bill be sufficiently flexible to allow States and communities to respond to their diverse and changing needs through the grants and money that is available. I just wonder if you see it that way, and if you see it that way, if you support that proposition.

Secretary SHALALA. We do, Senator. There is no question about that. And again, I want to emphasize that we would like to get this program started and I am sure that the committee and the administration over the next year or so may have some other ideas as we learn more from the States. In fact, much of this program is modeled on things that we learn from the States, from Wisconsin, for example, which has long experimented with long-term care ideas.

The CHAIRMAN. Senator Feingold.

Senator Feingold. Thank you, Mr. Chairman, and it is good to see the Secretary here. She certainly knows about these Wisconsin programs that have to do with caregivers. Mr. Chairman, it is very encouraging to see this gathering again and to have the focus on the caregiver. That is really the heart of this issue, and the Wisconsin model on this has been twofold. I had the opportunity to write Wisconsin's Alzheimer's disease program in 1984, which was focused on the role of the caregiver. And then even more significantly, I did not author, but had a chance to support, the community options program, which to me is a model for exactly the kind of thing that I think this administration wants to do.

I have introduced in the last three Congresses a far more extensive bill that would provide for a very significant dollar commitment to long-term care and home and community-based care, and obviously, because of the fiscal demands, we have not gotten there, but this is a terrible mistake, because in Wisconsin, we have saved hundreds of millions of dollars for our State as well as provided people the opportunity to live where they want as long as they can.

So I just want to praise the chairman, the administration, Senator Dodd, and others for this Family Caregiver Support Program. It is the beginning. I do have to say that when you take \$125 million a year and you break it down, it is going to be about maybe \$2 million for Wisconsin and we have over 8,000 people on the waiting list for the community options program there where the State has shouldered the burden. So I think something like this has to start with a seed and that is exactly what this can be.

But as people talk about the big issues for seniors, Medicare and Social Security as the two pillars for seniors, they are missing the third one. The third one is long-term care, home and community-based care. Without that, you are not dealing with either the human or the fiscal issues that really relate to older people, and I might also add, people with disabilities.

So I just want to use my time that way. It is very fitting that the Secretary, with her deep knowledge of this issue but also what we have tried to do in Wisconsin, represents this issue here and I thank you.

The CHAIRMAN. By the way, I should have said this. I was going to give you a chance after she leaves to give an opening statement. Senator Hutchinson

Senator HUTCHINSON. Thank you, Mr. Chairman. Let me just take the opportunity of thanking Senator Grassley and Senator Breaux, Senator Dodd, and the President for recognizing what is a very real and pressing need. The cost in time, money, and emotional strain that home caregiver and family caregivers endure is something that has long needed to be recognized in our public policy and I want to commend you.

When my brother was elected to the House to succeed me and I was elected to the Senate, my mother, who was in her 80's at the time, came to Washington. It was her first trip to Washington since I was elected back in 1993. She was there at our swearing in. There are not many moms who have had two sons serving in Congress at the same time. She went to the White House and the President was so gracious in taking her through the oval office and giving her a personal tour.

A few months after that, she had a stroke. Medicare covered the time in the hospital. Medicare covered some of her rehabilitation. Then she went home. And it was in January a year ago when my brother and I were able to be there during the time when Congress was not in session. But soon, we had to return to Washington and it all fell to my sister, who is a third-grade teacher, to take care of mom, along with my two other brothers. The emotional strain and the time my sister had to endure was incredible. As soon as she was through teaching all day, she was there with my mom all evening and all night. She was the heroine in our family.

But I think of the millions across America who have equally, if not more compelling, stories of sacrifice and love and compassion and caring for their loved ones, and yet in our case, we were helpless in assisting my sister with those expenses, both time and out-of-pocket expenses. As a school teacher, she gets paid very little.

So this is something that desperately needs to be done and I want to commend you. I do not get that many opportunities to be on the same side and I really appreciate what you have done. [Applause.]

The CHAIRMAN. Usually, I do not allow applause, but I think we all kind of want to applaud things like that.

Senator HUTCHINSON. The President's \$1,000 credit, if I understand correctly, and correct me if I am wrong, would be given on the basis of certified need for long-term care rather than expenses for long-term care. That means that families and people with chronic illness or disability do not have to collect and submit receipts for paid home health or respite care. But how would that be administered? How would the certification take place and who would oversee the tax credit to prevent fraud and abuse from occurring?

Secretary SHALALA. Let me have Dr. Takamura answer that question.

Ms. Takamura. One of the things that we have available through our States and, of course, our area agencies, is a very good assessment process, and the \$1,000 tax credit requires that people who would, in fact, be interested in the credit have at least three ADLs. That is, the person receiving care. So there is a very prescribed sense of the level of disability, and as you know, this tax credit could go either to the person receiving care or to the caregiver.

The CHAIRMAN. One member of the family could claim it and a physician would actually certify that the individual that is being cared for has three ADLs, three identifiable, measurable disabilities. We wanted to make it as simple as possible. We have had enough experience paying bills in my Department to know that this ought to be straightforward and as simple as possible.

Senator HUTCHINSON. Very good. Thank you. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Bayh.

Senator BAYH. Thank you, Mr. Chairman. Madam Secretary, it is good to see you again, and I know from personal experience you care very deeply about these issues. They are particularly important to me for several reasons.

First, for my generation, very often we face not only the challenges of caring for an elderly or a sick parent or grandparent but also the presence of young children at home. Very often, this burden falls disproportionately on women, who find themselves as the principal caregivers not only for the parent but for the children, as well. I think the initiative of the administration heads us in exactly the right direction and I want to thank you for that.

It is particularly important in my State, as well, that you visited on several occasions. About 60 percent of the seniors in Indiana receive care from a family member in some form or another and polls among our elderly consistently show it to be among the most popular options. During my years as Governor, I was pleased to expand our State home care program substantially, both in terms of the participants involved and in terms of the geographic area covered.

My question to you, Madam Secretary, very briefly—I know you need to get to the White House. I am new to the Congress, so I am not accustomed to upstaging the President and do not want to do too much of that here today.

Secretary SHALALA. They are different branches of government.

Senator BAYH. That is true. I am reminded of that from time to time. But my question is, it seems to me in this Congress, we have a wonderful opportunity for some historic accomplishments that will provide long-term security for seniors, starting with Social Security and the chance to put that on a much more secure financial footing, extending the life of Medicare and perhaps reforming the functioning of that program, and then targeting some tax cuts in ways that will help our families meet the pressing needs of modern life, care for children, care for an elderly parent.

My question to you, Madam Secretary, simply it seems to me this tax credit included in the administration's proposal is a wonderful opportunity to combine something that is fiscally conservative with something that is socially progressive, helping families meet their needs. Can you just discuss, just very briefly, the philosophy behind that and why it is an important part of the package?

Secretary SHALALA. Well, obviously, we as a government and as a country take advantage of the fact that most of the long-term care in this country is not provided in nursing homes but from the family caregivers themselves. So what we are trying to do is to tilt back where the services are actually provided and both give people some financial help in as straightforward a way as we possibly can,

as well as begin to explore and try some different ideas about how we support families that are providing the care.

If you answer the question, what is the long-term care strategy of the United States at this moment, it is mostly nursing homes, even though the care is being provided in the home for millions of Americans. What we are trying to do is to get some balance and to focus on what families really want, and that is to keep their loved one with them as long as they possibly can.

I think this is, I think, the proper balance and the proper investment, and it is only a start to put it in place—and this is why this is an historic moment. I would not either spend more time or be up here unless this was as significant as anything that we have ever done, and that is beginning to really put in place a real long-term care strategy, not a single strategy but a flexible one for the States, for the families that are involved on the financing side as well as the service side and the education and information side, which is actually critical here.

Senator BAYH. Thank you.

The CHAIRMAN. Senator Bryan.

Senator BRYAN. Thank you very much, Mr. Chairman, and thank you very much, Madam Secretary. It is always a pleasure to have you before us. I want to commend you and the President on your leadership, the Chairman of this committee, Senators Breaux, Dodd, and others. I am pleased to be a cosponsor of S. 10, the "Health Protection and Assistance for Older Americans" and look forward to cosponsoring the legislation that is going to be introduced as a follow-on to today's hearing.

A generation ago when the Older Americans Act was passed by the Congress, it changed the fundamental attitude and relationship of the American people to the elderly people in America. Prior to that, I think the terminology "senior citizen" was not in use. We did not recognize that there are problems peculiarly unique to people who are getting along in life whose circumstances have changed. I think that that is something that the Congress can take great pride in having passed.

This is kind of follow-on legislation to amend the Older Americans Act and, I think, recognizes the changing demographics in America. I think most people in the country, recognize that if you look at the demographics in America, the fastest-growing segment in our population in terms of a percentage of growth are those people 85 and older. It is a group that is generally in particular need of this type of long-term care.

Nevada has experienced an extraordinary growth rate, and much has been written about that. But what has not been addressed as clearly in terms of the national media's focus on our State is that many of the people who are moving to our State are older Americans, people who have chosen to come there for various reasons, including weather, taxes, lifestyle. This presents a rather daunting challenge. Many of those seniors are separated, in effect, from their families who are traditionally a part of their support base.

I know in my own family, my wife's sister and my wife and I live some distance from where their mother lives, and their mother is in a situation now where she requires some care.

My question to you is how is this legislation structured to provide help to those who are, in effect, long-distance caregivers who, if you will, who do not live in the same community or in the same home as the person needing care? For whatever reason the person who needs the care feels more comfortable staying at home. That individual has lived there for a lifetime, does not want to move to another part of the country, and yet there is still a need for services. The family members, for reasons of personal choice, no longer live in the same community.

Secretary SHALALA. I think in three direct ways, Senator, and I appreciate both you and Senator Dodd emphasizing the need to reauthorize the Older Americans Act, which, is another bipartisan opportunity for us.

First, the information part. The toll-free number that I included in my testimony is specifically for those that need information who are not in the community to find out about what information is in the community and what services are available in the community where their loved one lives.

Second, this provides for direct services, by individuals who are not members of the family but help people to put those appropriate services together.

And third, part of our recommendation provides for demonstrations. We have already demonstrated with adult day care, but we need some other variations.

And then, of course, the tax credit that would be available for the individual that is paying for the services or for a caregiver who is a member of the family providing those services.

So this is structured as flexibly as we could think of for those of us who have loved ones that are living a great distance or for those of us who are providing those services directly, and I think that is the point the chairman very much wanted me to respond to in his own question. So it really makes that point.

Senator BRYAN. Thank you very much, Madam Secretary, and thank you, Mr. Chairman.

The CHAIRMAN. One last question from Senator Lincoln.

Senator Lincoln. Thank you, Mr. Chairman. I apologize for being late, but we are delighted to have you, Madam Secretary, here with us today on such an important issue to all of us.

I grew up in a small rural community within walking distance of both sets of my grandparents, and I think the days are long gone when I used to carry the evening meal over to my grandparents because my parents at that point were caring for them. It is a very real issue for many of us across this nation.

I have a two-part question. We are excited about what is going on at the University of Arkansas's Medical Sciences, in their Aging Division. They actually, I think, are only the second geriatric center university, in the Nation, and we are quite excited about what is going on there. We would like to encourage you to work with them in terms of your research so that we do not reinvent the wheel.

The Arkansas Department of Aging wants to know more about the money being made available to States for demonstration grants in the Family Caregiver Support Program. How much flexibility will they have in designing programs that meet State-specific needs

and how they can really fine-tune those to their specific needs? Coming from a rural State, obviously, some of our problems are different in terms of long-term care. Does the Administration on Aging have research that is available on best practices, available to the States, so that, again, we can avoid having to reinvent the wheel?

Secretary SHALALA. Our proposal includes \$12.5 million for the demonstrations. Yes, we will be flexible. And yes, we have best practices information. Medicare actually has been financing some demonstrations, too, so we intend to take from different parts of the Department, the National Institute on Aging, from the Medicare and Medicaid programs, where we have been funding demonstrations, as well as from the Administration of Aging.

Let me also add, since I made reference to rural America, that one of the problems that rural Americans have, particularly those on farms, is during certain times of the year when they are planting or there is a harvest, often, family members are not available. They are very much tied up. And getting some support during those periods are very important for rural Americans. That happens in my own family who live in North Dakota, where every member of the family is out in the fields or supporting those that are out in the fields and they need support during certain periods of the year.

Senator Lincoln. Well, as you know, being from rural America, these are very real problems to you and I personally, as well as many Americans out there. We are looking forward to working with you to come up with a solution. Thank you for being here today.

The CHAIRMAN. Secretary Shalala, we thank you very much. You will probably get some questions to answer in writing because of the short period of time. I also apologize to Dr. Hodes and Dr. Takamura for not introducing you. I knew you were going to be here; I just forgot it. Thank you very much. We will let you go to the White House now and about your other responsibilities.

Secretary SHALALA. Thank you.

The CHAIRMAN. Any members who want to give opening statements have that opportunity now.

Senator BRYAN. Mr. Chairman, could I ask unanimous consent that an opening statement be made a part of the record?

The CHAIRMAN. So be it.

Senator BRYAN. I thank the chair.

[The prepared statement of Senator Bryan follows:]

PREPARED STATEMENT OF SENATOR RICHARD BRYAN

The issue of long-term care is one with particular importance for my State of Nevada. Nevada's rapidly growing population is due in part to the influx of seniors who are choosing to retire there.

Many of these retirees are younger, healthy, and active. For many of these seniors, the move to Nevada has separated them from their families. As these people age, and are unable to care for themselves, they will find themselves without the family members normally looked to when an aging senior needs help. This means their spouses will face providing sole care, or these individuals will need to be placed in facilities like assisted living and nursing homes—if those facilities are available and affordable.

The need for long-term care is an issue for all seniors whether their families are nearby to help provide care or not. We want to do what we can to enable older people to stay in their own homes as long as possible, but we must also recognize that this option relies very heavily on the willingness of spouses and other family care-

givers. I support, as a cosponsor, legislation to provide an income tax credit of \$1,000 for individuals or their family caregivers as a first step toward recognizing the incredible financial burden facing those who are or who care for a person at home.

With our lengthening life spans, and the upcoming Baby Boomer demographic, the need for long-term care is going to continue to grow. We all want to remain in our homes for as long as possible as we age—our quality of life is better, and the financial cost to our families will be less. But we cannot continue to depend upon unpaid caregivers. Caregivers need help too—they need respite care, they need financial help, and they need support for the jobs they are doing. We also need to encourage younger people to consider long-term care insurance as part of their retirement planning.

I look forward to this morning's hearing, and learning from the witnesses today how the proposed National Family Caregiver Support Program can help address these issues.

Senator LINCOLN. Mr. Chairman, I would also like to make my opening statement a part of the record.

The CHAIRMAN. So be it.

[The prepared statement of Senator Lincoln follows along with prepared statements of Senator Breaux and Senator Craig.]

PREPARED STATEMENT OF SENATOR LINCOLN

Thank you Mr. Chairman for your ongoing leadership on the family caregiving issue.

There is nothing more important than caring for our loved ones.

Today's hearing on supporting family caregivers is one which touches all of our lives. Most of us provide care to our older parents and relatives or will do so in the near future.

We live in a time when our parents are living longer lives—thanks to advances in medical science. Consequently, while many Baby Boomers are in the prime of their careers and raising our own families, we may face the dilemma of providing care for an aging parent or relative. Forty percent of caregivers are between the ages of 35 and 49 years old. Sixty two percent of caregivers are married.

Not surprising, 71 percent of caregivers are women. These statistics tell us that families—primarily women—are the backbone of caregivers in America.

In Arkansas, caregivers Gaytha Hansard and Debbie Heller wrote their personal accounts of caregiving in Alzheimer's Association newsletters. They are working women who cared for mothers with Alzheimer's. They shared very personal accounts of the emotional and financial strain that they and their families experienced.

Here's an excerpt from Gaytha Hansard's story: "I got a telephone call in February 1991 that Mom had accidentally overdosed on prescription drugs and had ended up in the hospital. The time was long overdue. She had to be forced to go see a doctor. I went to Kansas so I could be with her.

I now know this was my first step in the role of long-distance caregiving. Her sisters had gone far beyond the point where they should have been responsible for her well being. It was time for me to face the truth I had tried to deny for years. After all, I was only 44. I wasn't ready to reverse roles and become the mother. That wasn't the way life was supposed to be."

The stories of Gaytha and Debbie are similar to other caregivers around the country.

Whether care is being provided for a family member with diabetes, emphysema, a heart condition or Alzheimer's disease, the needs are all the same. Caregivers need help dealing with the emotional, physical and financial aspects of caring for their loved ones.

Most people agree it is best for those with debilitating illnesses to remain at home for as long as possible. It is the more humane and dignified choice. It is also the more cost-effective option. The average cost of nursing home care is \$38,000 per year.

As our country faces demographic realities that can no longer be ignored, it is time for the Federal Government to step in and provide resources and services to assist families who are caring for loved ones. We must support our families who seek to juggle their own lives with the added responsibilities and stress of caring for a parent or other relative.

Right now, the leadership and innovation for family caregivers comes primarily from state and local government entities and non-profits. I am eager to hear from

today's panelists about their accomplishments and their needs. They are on the "front lines". They know what works. Let's listen to them and not recreate the wheel.

As a Senator from a rural state, I am particularly eager to learn more about how states and local agencies are able to provide support services to family caregivers in rural areas. I will insist that any new infusion of Federal dollars for family caregiving reflect the needs of rural areas.

I am also eager for the Geriatric Center at the University of Arkansas's Medical School—only the second Geriatric Center in the country—to undertake research in the area of caregivers assistance.

Finally, I want to thank those panelists in advance who are willing to share their personal stories with us this morning. It takes great courage to do this. I know your stories will inspire all of us to move forward and advocate for needed caregiving resources and services.

PREPARED STATEMENT OF SENATOR JOHN BREAUX

Thank you all for joining us today to learn more about a new initiative that could help millions of American families through the creation of the National Family Caregiver Support Program. I would like to especially thank Secretary Donna Shalala for appearing today to discuss the Administration's commitment to family caregivers and our nation's elders. It is an honor to have you with us, Madame Secretary. Your participation is a clear sign that the National Family Caregiver Support Program is a high priority not only within the Department of Health and Human Services, but within the White House.

I would also like to welcome Assistant Secretary Jeannette Takamura, from the Administration on Aging and Dr. Richard Hodes, head of the National Institute on Aging. To all of you, your commitment to this issue is greatly appreciated by this Committee, and we certainly look forward to working closely with you on the establishment of this program.

I would also like to welcome the rest of our witnesses and thank them for their participation. Mr. and Mrs. Awbrey, you have shown tremendous courage in appearing today to speak about your personal battle with Alzheimer's Disease and the caregiving issues that you will face in the future. Representative Boyd, you also have demonstrated great strength in traveling to Washington to share your story. I would also like to welcome Richard Browdie, who is the Secretary on Aging for the State of Pennsylvania and Donna Harvey, who is the director of the Hawkeye Area Agency on Aging in Waterloo, IA. Thank you and welcome.

On January 4, 1999, President Clinton took the first step toward making life a little easier for family caregivers by announcing the creation of the National Family Caregiver Support Program as part of his long-term care initiative—the first new policy initiative that he announced in 1999. Today, Senator Grassley, Senator Dodd and I will take the next step toward reaching that goal. Later this afternoon, we will introduce legislation to establish this program under the auspices of the Older Americans Act. By doing this, we hope to acknowledge the contribution and sacrifice that American families make every day to adequately care for our nation's elders.

In my capacity as the Ranking Member of the Aging Committee and through my involvement with the National Family Caregivers Association, I have learned a great deal about family caregiving. Over twenty two million families in the United States provide care that has been valued at \$194 billion per year, and yet that care is truly priceless. Family caregivers pay on average \$2000 per year toward the care of their loved one, the equivalent of an annual IRA contribution. Many caregivers become isolated and depressed due to their constant efforts; more than 30 percent of caregivers experience physical or mental health problems as a result of caregiving. It is clear that we must do all we can to support these families.

Implicit in the creation of the National Family Caregiver Support Program is the need to reauthorize the Older Americans Act (OAA). The OAA has not been reauthorized since 1992. For 3 years, the issue has been tangled up in debates and differences of opinion. This year we must move forward to reauthorize and modernize the OAA. The creation the National Family Caregiver Support Program hinges on reauthorization; and as we will surely learn today through the testimony of our witnesses, this program will serve a crucial role in meeting the needs of our nation's families and enable our elders to receive the best and most loving care available.

Thank you, Mr. Chairman for your leadership on this issue. And again thank you to our witnesses, Secretary Shalala and others, for your participation and dedication.

PREPARED STATEMENT OF SENATOR LARRY CRAIG

I would like to thank the Chairman for holding this hearing today regarding long term care and the role of family caregivers. While there has been a great deal of discussion and debate regarding health care reform, long-term care has not been at the core of the debate. Yet many families focus on this issue every day, and they can certainly provide us valuable insight by sharing their experiences. Therefore, 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 or skilled nursing facilities as providers of long-term care, there are many other ways that care is being delivered today. These include residential care facilities, in-home nursing, and family caregiving 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 family in order to meet the needs and desires of the individual requiring care. If a family prefers to provide care for a loved one in the home, and this care will meet the needs of the patient at a reasonable cost, then home care should be disadvantaged in comparison to other, often more expensive, alternatives.

Flexibility in any reform proposal will be an important component, especially for the delivery of care in rural states like Idaho. Idaho has a variety of care providers in the area of long-term care that include different levels of care available in the home and in a hospital or institutional setting. As we look at health care reform and long-term care, we need to be cognizant of the different needs of long-term care patients and shape a system that will be flexible in both the public and private sector.

Again, I would like to thank the Chairman and our panel of witnesses here today. I am interested in hearing our witnesses' thoughts on this idea, and other insights they can provide on this problem today. Thank you.

Senator BAYH. Likewise, Mr. Chairman.

The CHAIRMAN. OK.

[The prepared statement of Senator Bayh follows:]

PREPARED STATEMENT OF SENATOR EVAN BAYH

Thank you Mr. Chairman and Senator Breaux for your leadership on this matter. I know you both have worked very hard to not only organize this hearing but also to sponsor legislation that would assist caregivers.

When our seniors are faced with the most difficult decision, where to spend the remainder of their time, they should have options. Yesterday we discussed how we can improve upon the complaint and enforcement processes of our nation's nursing homes. Institutional care should be an option. Today we evaluate how we can help those family members who decide to take care of their loved one in their own home. Home care should be an option. Families in America should have options for affordable quality long-term care for the loved ones in their lives.

If a person decides to dedicate their time and effort to care for another we should commend them, applaud them, support them, encourage them . . . not discourage them. The lack of support services for caregivers serve in essence as discouragement. Caregiver training, counseling, and peer support to help them cope with the emotional and physical stress of providing a loved one with constant assistance is vital.

The proposal initiated by the President moves us in the right direction. It changes the discouragement that exists to encouragement. It is family friendly and allows us to hold true to our long tradition as a nation to support good solid family values.

In Indiana 3 out of every 5 individuals needing long-term care receive their assistance from a family member or a friend. If a person wants to remain in their own home, be surrounded by the wonderful fond memories that keep them fighting for another day, and be taken care of by a loved one instead of a stranger, we need to not only respect that decision, we need to support it.

I am in support of several measures that assist caregivers and those receiving long-term care. Today we start the discussion and I look forward to the future when we implement some of these initiatives into law.

The CHAIRMAN. All of the statements, then, will be put in the record.

I guess we have no questions, then, of either one of you and we thank you for being patient, as well, although you will probably be

called upon to help to answer some of the questions we will submit in writing and we would like to have those responded to in 2 weeks.

Ms. Takamura. Thank you, Chairman Grassley.

The CHAIRMAN. Thank you very much.

Now I have the opportunity to introduce our second panel. We are very appreciative of these witnesses and they deserve a special thanks for participating. Not only do I want to say thank you for taking time out of your very busy schedule to be here, but I also want to say that I appreciate your willingness to share your experience with the world and foremost with us in the Congress. I commend your willingness to speak openly as you testify today at our hearing.

I would like to have you come now as I call your name. Our first witness is Stuart Awbrey. Mr. Awbrey is a community journalist from Westfield, NJ. He has already written a book on some of his experiences called, *Chronicles of a Community Journalist*. He was forced to retire early when he was diagnosed with Alzheimer's disease. Mr. Awbrey is here today, along with his family, to tell us how they are coping with Alzheimer's and the challenges of caregiving.

I think the strong support shown by the Awbrey family's attendance at today's hearing is an example of just how important these issues are to an entire family. He has his wife, Bev, with him at the panel and his daughters Kim and Lee and son-in-law here, as well, in the audience.

Next, I would like to call upon State Representative Barbara Boyd from the State legislature of Ohio to share with us her experiences as a family caregiver for her mother, who suffered from Alzheimer's disease. She has devoted a great deal of time and energy to educating policymakers on the real demands and challenges facing family caregivers. And I will bet that, as a policymaker in Ohio, she has probably shown leadership in a lot of these issues that come before her legislative body.

I am going to call on Stuart Awbrey to testify first, and then we will call on you, Representative Boyd. Stuart Awbrey.

STATEMENT OF STUART AWBREY, WESTFIELD, NJ

Mr. AWBREY. Good morning, Senator Grassley and other distinguished Members of the Senate Aging Committee. I feel privileged to be here with you today to share my story.

It does not seem so long ago that I was working here as a lanky 16-year-old page boy from Kansas. In fact, I still remember a terrifying March morning, 45 years ago, when I walked into the well of the House to find a Congressman lying on the floor writhing in pain with a bullet in his chest. That was my first sight of deadly fire. Typically, that incident did not scare me away. Later, I returned to Capitol Hill to write speeches for Congressman Sid Yates of Chicago and as a public information officer of the Peace Corps, working under Sarge Shriver. Those were exciting times.

Little did I know, 40 years ago, that one day I would be faced with another lethal bullet. The second attack would be a silent bullet and it would eventually kill me. I call it my hidden adversary. Others call it Alzheimer's disease. Unlike the Congressman who

doctors had the tools to heal his wounds, I would not find a cure for my condition. Perhaps that will be in the future, with your help.

Let me tell you how it happened. Four-and-a-half years ago, at age 57, I was editor of the *New Jersey Lawyer*, a 12,000 circulation weekly publication for the legal profession. Prior to that, I had owned and edited my own weekly newspaper, along with my wife along with me here. I had my warning signs and symptoms, but I was cruising along in my job, managing as best as I could. So imagine my surprise when I was told after an extensive medical workup that I had the symptoms of an early onset Alzheimer's disease.

When the doctor told me of my plight, I was in a state of total shock. My life was now twisting out of control and I felt as if I was heading for a nose dive. That very same day, I was told to stop working and stop driving. I did both, although I was having trouble absorbing the implications of my actions. In the next few days, we began the arduous tasks of telling our families and children. Words cannot describe the poignancy or sadness of those moments, or the support and incredible love which I have received from my family.

Within the month, I began slowly to adapt to my new destiny. Focusing on the activities I could still enjoy, I decided to record my memories, knowing that I would eventually forget my past. So I wrote the book, named the *Chronicles of a Community Journalist*, which was published a few years ago. I am told it is a pretty good read. [Laughter.]

In addition to writing, I also wanted to have quality times with my family and travel to some favorite places. I needed to keep on learning and stay active. I had been a longtime tennis buff and I planned on playing as much as possible. Right now, I am able to continue to do all these things, although in dark moments, I cannot help but be aware that my time is running out.

At this point, I cannot add or subtract, so Bev takes care of the business. Although I can understand conversations, it is harder for me to process them. I am having trouble finding the right words and organizing my thoughts. Speech writing is too complicated for me, so I had to turn to Bev for help on this. I tire somewhat easily. I have trouble making phone calls, feel less confident, and often do not have much to say. My past is slipping away from me.

I cannot allow myself to be preoccupied with the losses of the future, my longing to grow old along with my wife, sharing precious moments with my daughters and grandchildren. Instead, I focus on the present, living each day to its fullest.

I have done what I can to prepare for the inevitable. All the necessary legal and financial plans have been put in place. As I require more assistance, we will hire a live-in caretaker to help when Bev is at work. Naturally, I want to remain independent as long as possible. But when the time comes, we anticipate that a nursing home will be necessary. The emotional and financial burdens this will place on the family are painfully obvious to all of you sitting here today.

In case you are wondering about how I am dealing with the silent bullet, I would have to say that I am making the most of my time and taking stock in what I have. I have had a good life, and I really believe this. I have been fortunate to have been able to do

the things that I wanted to do and I am grateful for that. Our years owning a weekly newspaper were challenging and exciting. As a father, I helped to raise two delightful, sensitive, capable, and loving daughters and I am pleased with the directions their lives are taking. I have a loving wife, a supporting family, and many wonderful friends. So at this time, I have chosen to acknowledge these blessings.

I will continue to focus on what is possible rather than dwell upon my limitations. I want to make the most of the good time that is left. Finally, I am pleased to be able to make this contribution by speaking to you today. May others not have to travel as I have, but should they face their own silent bullet, may they benefit from the caring support network of the Alzheimer's Association.

In closing, I want to urge this committee to do what you can now to fight this deadly disease. So many of us will be grateful for your efforts. Thank you for giving me the opportunity to share my experiences with you.

The CHAIRMAN. We thank you, Mr. Awbrey.

[The prepared statement of Mr. Awbrey follows:]

**TESTIMONY OF STUART AWBREY
WESTFIELD, NEW JERSEY**

Presented to the Senate Special Committee on Aging
March 23, 1999

Good morning, Senator Grassley, and other distinguished members of the Senate Aging Committee. I feel privileged to be here with you today to share my story.

It doesn't seem so long ago that I was working here, as a lanky 16-year-old page boy from Kansas. In fact, I still remember a terrifying March morning, 45 years ago, when I walked into the well of the House to find a Congressman lying on the floor, writhing in pain with a bullet in his chest. That was my first sight of deadly fire. Typically, that incident did not scare me away. Later, I returned to Capitol Hill to write speeches for Congressman Sid Yates of Chicago and as a public information officer of the Peace Corps, under Sarge Shriver. Those were exciting times.

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Let me tell you how it happened. Four and a half years ago, at age 56, I was editor of the New Jersey Lawyer, a 12,000 circulation weekly publication for the legal profession. Prior to that I had owned and edited my own weekly newspaper, along with my wife, Bev. I had my warning signs and symptoms, but was cruising along in my job, managing as best I could. So imagine my surprise when I was told, after an extensive medical workup, that I had the symptoms of early onset Alzheimer's disease.

When the doctor told me of my plight I was in a state of total shock. My life was now twisting out of control and I felt as if I was heading for a nose dive. That very same day I was told to stop working and stop driving; I did both, although I was having trouble absorbing the implications of my actions. In the next few days we began the arduous task of telling our families and children. Words cannot describe the poignancy, or sadness of those moments. Or the support and incredible love which I received from my family.

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In case you are wondering about how I'm dealing with "the silent bullet", I would have to say that I am making the most of my time, and taking stock in what I have. I have had a good life. I really believe this. I have been fortunate to have been able to do the things I've wanted to do, and I am grateful for that. Our years owning a weekly newspaper were challenging and exciting. As a father I helped raise two delightful, sensitive, capable and loving daughters and am pleased with the directions their lives are taking. I have a loving wife, supportive family, and many wonderful friends. So at this time I have chosen to acknowledge these blessings.

I will continue to focus on what is possible, rather than dwell on my limitations. I want to make the most of the good time that's left. And finally, I am pleased to be able to make this contribution by speaking to you today.

May others not have to travel as I have. But should they face their own silent bullet, may they benefit from the caring support network of the Alzheimer's Association.

In closing, I want to urge this Committee to do what you can, now, to fight this deadly disease. So many of us will be grateful for your efforts.

Thank you, for giving me the opportunity to share my experiences with you today.

The CHAIRMAN. Would you stay at the table, please? We would like to ask questions, but we want to hear from Representative Boyd first. Please stay there.

**REPRESENTATIVE BARBARA H. BOYD, STATE LEGISLATOR,
COLUMBUS, OH**

Ms. BOYD. Mr. Chairman, thank you for the opportunity to address the Senate Special Committee on Aging. I was a primary caregiver. I am here today to stand for my mother, Sarah Hamlet, and caregivers who need to know someone cares.

Six years ago, I did not even know what a caregiver was. However, on June 30, 1993, my mother, Sarah Hamlett, was diagnosed with Alzheimer's disease. We immediately decided that mother was going to be taken care of at home. My two brothers went into instant denial of the potential progression of the disease. Her progression was rapid: Agitation and behavior swings, pacing from one room to the other, pouching of food, destruction of jewelry, clothing twisted and tied into knots, a packed suitcase, for home was never where she was, paper shredded. She literally destroyed the chair she sat in, thread by thread.

She became proficient in profanity. We learned to laugh when she could not get it right the first time, but eventually, she did. She started wailing as she lost the ability to converse and forgot how to hold a glass in order to drink. As she progressed, feeding took up to 30 to 40 minutes. Incontinence and the use of Depends—diapering your parents as they are still walking is a real adjustment. She was incontinent within a year-and-a-half of diagnosis.

In the fall of 1994, I discovered two cancerous masses in her right breast. The masses were removed one morning and I took her home by 5 in the afternoon. No treatment was prescribed, for to anesthetize her would have further diminished her capacity. By the end of 1995, she had to be catheterized for fear of skin breakdown as her fluid intake diminished.

As a caregiver, I had to make life plans, nutritional plans, health and health care plans, family participation plans, and final day plans. As a caregiver, I found myself often alone in making decisions. My family became dysfunctional. Any decision I made was met with resistance. Denial led to fear because of the abrupt change in a woman who was the bridge that brought the family over during our lives.

My parents' goals were basic: Pay your bills on time, do not over-extend yourself, give your children an education for building a life, and the American dream, own your own home. That dream became a prison. She was locked in and locked out. They had saved for the retirement years, but it just was not enough.

As a caregiver, I was confronted with how to provide her with the best of care. I found barriers I did not know existed. One of the things I found was that HCFA had never clarified the decision of homebound. If a patient is determined to be homebound by a home care agency, that can change because HCFA will rule the patient not homebound and take services away.

In addition, Alzheimer's disease is not a disease recognized by Medicare. Medicare B provides no prescriptive care, and neither does Medifil. Alzheimer's drugs are very costly, over \$100 per

month. Tamoxifen for breast cancer is the same. Roxanol, a liquid morphine, and duragesic patches are approximately \$200 a month. Incidental antibiotics for urinary tract infections and other infections, drugs for constipation as a result of morphine, Depends, chucks or underpads, ointments to avoid skin breakdown, powder for yeast infections, liquid food supplements such as Ensure, Sustacal, and more.

Mother's Social Security check was initially \$480 a month. It was increased to \$540 a month in the 5½ years. It provided her with a sitter from 11 a.m. to 4 p.m. Monday through Friday. She had approximately \$20,000 in assets and savings. I was constantly transferring money from the savings to the checking account, robbing Peter to pay Paul. It cost \$168 every other month for her Medifil. I took care of her prescriptive costs out of my pocket, as well as the caretaking of her home. I never carried her as a dependent.

I will say to you that home health care was a life saver, 1 hour in the morning, 1 hour in the evening. She had returned to infancy. Pedicare, bed baths, and feeding were important. I cooked and they blended the food.

I am a legislator. My mother held the Bible as I was sworn into the General Assembly. I thought I knew a lot about how things worked. However, I was helpless. I was helpless in the web of Medicare. I found that ambulance transportation costs mounted as she became atrophied. One morning, I questioned whether God had forgotten me.

My brothers financially did not come forward, and mine is not an unusual case in the real world of caregivers. One was in denial. The other just excluded himself from the situation. When I realized my circumstance, I called a family meeting in 1996 and decided to pre-pay her final day service. She was indigent, but the final plan was in place.

My mother passed over on October 21, 1998. We were in her bedroom with her at the time of her final breath. I gave her the final bed bath and clean gown. I lotioned her body, and then we waited. I have to say that respite care during the dying process gave me the relief I needed. I was exhausted. It was nothing like you see on TV. It was nothing like you see in the movies. I was not prepared.

I have to say, I regret nothing. She gave unconditional love. I could do nothing less. She was cared for at home, never a bed sore, never a skin breakdown. She was nutritionally sound. I have exhausted my savings. I had to take out a second mortgage on the home, but I will honor her debts.

I want to thank you for your kind attention, and I truly appreciate the opportunity to share my experience as a caregiver with you and I will be happy to take any questions.

[The prepared statement of Ms. Boyd follows:]

OHIO STATE REPRESENTATIVE BARBARA BOYD
Statement Given to the Senate Special Committee on Aging
March 23, 1999

Thank you for the opportunity to address the Senate Special Committee on Aging. I have no charts, no percentages to give you. There are plenty of people here today to provide you with those. I am here to put a face on the problem. I am here to stand for people like Sarah Hamlet and caregivers who need to know that somebody cares.

I was a primary caregiver. Six years ago, I did not even know what a caregiver was. However, on June 30, 1993, my mother, Sarah Hamlet, was diagnosed with Alzheimer's Disease. We immediately decided mother was going to be taken care of at home. My two brothers went into instant denial of the potential progression of the disease. Her progression was rapid: agitation and behavior swings, pacing from one room to another, pouching of food, destruction of jewelry, clothing twisted and tied in knots, a packed suitcase - for home was never where she was, papers shredded. She literally destroyed the chair she sat in, thread by thread. She became proficient in profanity, we learned to laugh when she could not get it right the first time, but eventually she did get it right. She started wailing as she lost the ability to converse and forgot how to hold a glass in order to drink. As she progressed, feeding her took up to 30 to 40 minutes. Incontinence and the use of depends (diapering your parents as they are still walking is a quick adjustment!). She was incontinent within a year and a half of diagnosis. In Fall of 1994, I discovered two cancerous masses in her right breast. The masses were removed one morning and I took her home by five in the afternoon. No treatment was prescribed, for an anesthetic her could have further diminished her capacity. By the end of 1995, she had to be catheterized for fear of skin breakdown as her fluid intake diminished. As a caregiver, I discovered I had to make life plans, nutritional plans, health and healthcare plans, family participation plans, and final day plans.

As a caregiver I found myself often alone in making decisions. My family became dysfunctional. Any decision I made was met with resistance. Denial led to fear because of the abrupt change in a woman who was the bridge that brought the family together during our lives. My parents' goals were basic: pay your bills on time, do not over extend yourself, give your children an education for building a life and the "American Dream", own your own home, but that dream became a prison in which she was locked in and locked out. They had saved for the retirement years, but it was just not enough.

As a caregiver, I was confronted with how to provide her with the best of care. I found barriers that I did not know existed. Health Care Financing Administration (HCFA) has never clarified the definition of homebound. For example, if a patient is determined to be homebound by a home care agency, HCFA can later rule the patient not homebound and take away services. In addition, Alzheimer's is a disease not recognized by HCFA. Medicare B provides no prescriptive care, neither does Medifil. Alzheimer's drugs are very costly, \$100 per month. Tamoxifen for breast cancer is the same. Roxanol, a liquid morphine, and duragesic patches are approximately \$200 a month. Incidental antibiotics for urinary tract infections and other infections, drugs for constipation (a result of morphine), depends, chucks or underpads, ointments to avoid skin breakdown, powders for yeast infections, liquid food supplements such as ensure, sustecal, and

more. Mother's social security check was initially \$480 per month and increased to \$540 per month in five and a half years. It provided her with a sitter from 11:00 am. To 4:00 p.m., Monday through Friday. She had approximately \$20,000 in assets and savings. I was constantly transferring money from the savings to the checking account, "Robbing Peter to pay Paul". It cost \$168 every other month for her Medifil. I took care of her prescriptive costs out of my pocket, as well as the caretaking of her home. I never carried her as a dependent. Respite gave me a break from the daily, often never-ending, tasks of caring for someone with Alzheimer's disease. Caregiving truly is a "36-hour a day" job. The aging of the baby boomers and changing family structures make respite an invaluable resource for caregiving families.

Home Health Care was a lifesaver. In the morning one hour and in the evening one hour, she returned to infancy. Pedicare, bed baths, and feeding were important. I cooked, they blended the food.

I am a legislator. My mother held the Bible as I was sworn into the General Assembly in January 1993. I thought I knew a lot about how things work. However, I was helpless in the web of Medicare. Ambulance transportation costs mounted as she became atrophied. That is 20% out of pocket. One morning I questioned whether God had forgotten me. My brothers, financially, did not come forward, and mine is not an unusual case in the real world of caregivers. One brother lived in her house, but he could not come out of his denial. The other brother just excluded himself from the situation. When I realized my circumstance, I called a family meeting in 1996 and ultimately decided to pre-pay her final day service. She was indigent but the final plan was in place. Mama passed over on October 21, 1998. We were there in her bedroom with her at the final breath. I gave her the final bed bath and clean gown. I lotioned her body. Then we waited.

I regret nothing. She gave unconditional love, I could do nothing less. She was cared for a home, ever a bed sore, never a skin breakdown, and nutritionally sound. I have exhausted my savings but will honor her debts.

Thank you for your kind attention. I truly appreciate the opportunity to share my experiences with you. I will be happy to take questions.

LEGISLATIVE RECOMMENDATIONS

1. Redefine Alzheimer's Disease so Medicare can apply.
2. Prescription drug assistance.
3. Voluntary disclosure statement identifying provisions provided in facilities that market themselves as "special care units" for Alzheimer's.
4. Respite care for caregivers.
5. Employee flextime for elder caregivers.
6. Allow elderly at the point of retirement to know what prescriptive care is available through Medicare and Medifil.
7. Enact a new homebound definition that does not restrict access to the Medicare home care benefit.

The CHAIRMAN. You both have given very moving statements and speak, obviously, with an expertise that some families would understand. But most of us cannot, and we need to understand that, and I thank you for bringing that to our attention.

I would like to ask Senator Bayh if he could go first with questioning so I could step out for just a couple of minutes. I will be right back, and if I do not get back, Senator Lincoln, proceed after Senator Bayh.

Senator LINCOLN. Thank you, Mr. Chairman.

Senator BAYH. Thank you, Mr. Chairman.

At a time in which many citizens across our country ask, where are the heroes, we are fortunate to have some with us here today, people who exemplify thousands and thousands of others across our country who, without public applause or desire for any reward, do the critical task of taking care of our loved ones with compassion and care. I, on behalf of all of us up here today, want to thank you for your courage and your eloquence in being here today.

Representative Boyd, I want to particularly say I think your presence here points out the importance of having citizen legislators. It is important that we have people who make our laws and guide our public policy that have life's experience, even the difficult ones like yours, I think particularly the difficult ones like yours.

And the Awbreys, I want to thank you. Mr. Awbrey, your appearance here today reminds me of my mother, who was diagnosed at age 39 with breast cancer. With the 7 years that she had left of life, she used to always say it is important to try and make lemonade out of lemons when that comes your way in life, and she used to also always say, none of us can really control how long we live. We can only control what we do with the time that we have. I think your presence here today is just a marvelous, marvelous example for the rest of us to follow. My mother went on to become a spokesperson for the American Cancer Society and tried to encourage other women to self-examine and seek early detection and tried to make her story an example for others to not be similarly afflicted.

I would encourage our colleagues in the press corps here today to take a real interest in the issue of Alzheimer's. There are studies that indicate that in the next 10 to 15 years, the number of people who suffer with this disease is going to increase substantially as the life expectancy of Americans increases, and the terrible personal cost that it takes upon our country is going to increase accordingly and the financial cost is going to increase accordingly.

Mr. Awbrey, I would just like to say that I hope that our ultimate objective can not only be to help assist those with the disease, but ultimately to find a cure for it. That should be our ultimate goal. And I hope, as one Senator, to do what I can to see to it that we put into place incentives for those in the private sector to engage in research in this area and also that we invest as a country in basic public research so that, one day, your testimony here can stand as a monument along the road to ultimately curing this disease. If, in fact, that is the case, as I hope that it will prove to be, you will have provided immeasurable service along that path.

So I want to thank you. Representative Boyd, I want to thank you. I really have no questions for you today, but just want to ex-

press, as one person, my heartfelt appreciation for your courage and your presence here. You have been an inspiration to me.

Senator LINCOLN. You have got two of the junior, new Senators here, and we are in control, so we might just take this one and go with it.

Senator BAYH. Absolutely. [Laughter.]

Blanche, I do not suppose we could bring the budget up here today, could we?

Senator LINCOLN. That is exactly right.

Senator BAYH. Maybe we can repeal the seniority rules. What do you think?

Senator LINCOLN. That is exactly right. [Laughter.]

You both have given moving testimony, and as an individual in the beginning stages of caregiving, it is most impressive that you have chosen to share your story. It is most helpful to us as legislators and as co-legislators to understand not only one another's problems and difficulties and challenges, but more importantly, what it is we can do working together on behalf of the citizens of this country and what we can do for the aging population.

I join my colleague, Senator Bayh, in saying that, hopefully, we can work together. The chairman is back. We will have to behave now. [Laughter.]

As I said, I am myself going through the early stages of caregiving. I do have questions and I want to share with you my experience but to learn from your experience as well. We would all benefit, I think, if the entire Senate body was in here. Hopefully, we as Members of this committee can take back to our colleagues what we have learned today.

Mr. Awbrey, your presentation was incredible and I would like to ask you and your wife if you have any intentions of any further publications in terms of your experience. I am interested, too, to ask Mrs. Awbrey if you have joined any support groups or received counseling in regard to your husband's condition. Has anything been particularly helpful?

Mrs. AWBREY. I guess I will go first. I got a lot of support from the Alzheimer's Association in New Jersey. The first part of learning about the disease was extremely difficult for us and I needed to know so much, so they provided lots of information, and more than the information, I think that they really were empathetic and very caring. That made a big difference for us.

There are support groups in New Jersey. I am a clinical social worker and I have led groups, and maybe because of that experience, I felt that I was not going to go to a support group. But everybody finds it very helpful. I personally thought that I did need some counseling to deal with the issue and, in my field, we like to receive counseling as well as to give it. So that is what I did and it has been very, very important for me. I encourage other people with when I speak to not be shy about reaching out for help.

Senator LINCOLN. In your research, through counseling as well as in dealing with what you were going through, did you ever find any pilot projects in terms of medical research? I know in our case, metrifphonate was one of the drugs that was being used that was something we looked into. Did you find any of that?

Mrs. Awbrey. Initially, when we talked about getting involved with a drug trial, the drug trials were 45 minutes away and it was just hard to do while balancing my work. I was then working full time. We thought, well, we would have to be thinking so much about the disease, maybe we just would not do it.

And then there became a change in feeling about it and Stu really wanted to participate in research and we found through the Alzheimer's Association a project nearby that allowed Stu to participate in a trial for Galantamine which is a new medicine in trial by Johnson and Johnson/Janssen Pharmaceuticals. So he was able to be in a double-blind study there, and we found later that he was actually taking the medicine all along and he has been taking it and it seems to be getting good results. So for us, it turned out to be a very positive experience that Stu was able to participate, and still is, in the trial.

Senator LINCOLN. That is great.

A question for Mr. Awbrey. I have read about a condition called sundowning which is a sense of disorientation as dusk appears. Do you have this?

Mr. AWBREY. Yes. I was told about that when I first learned about my condition, but it was not too bad. It depended. I would go out in the back yard, for example, when it is getting dark and I am going out there, and occasionally, I take a cigar out there, because that is my smoking lounge. So I really cannot give anything except the natural nature. Nature changes. But I have known this and I have been aware of it pretty often.

Senator LINCOLN. That is a step, being aware.

Mr. AWBREY. Yes.

Senator LINCOLN. I appreciate it. Thank you. That has been something I am reading a good bit about.

Representative Boyd, one of the things advocates for nursing home residents in our State are concerned about is the availability of compassionate workers, mostly in nursing home facilities, long-term care facilities. You have been an at-home caregiver, which is monumental in terms of on your time, your finances, and other things.

I just wondered if there was any work being done placing more nursing individuals in the nursing homes, qualified nurses.

There was a recent article just the day before yesterday in our home State of Arkansas that we are turning out less nurses in the field of nursing than we need and we are getting ready to hit a brick wall because we are not training the individuals that we need. Do you see some of that?

Ms. BOYD. Well, one of the things that I have found, and I serve on the Finance Committee for the Ohio General Assembly, the Department of Aging, and several other related departments that come under the subcommittee where I am the ranking minority, is the fact that it is something that we are finding very alarming. It is the case that we are not being able to find the people to go into the field. But also just within the home health care arena, they are having problems finding people to become part of the home health care piece because, I think, it is so new and it is so changing.

One of the things that I heard when I was with mother being taken care of at home was the fact that there are always such

changes with rules as far as Medicare and HCFA are concerned that as they think they are doing something right, they are finding they are doing something wrong and then they become afraid and they step back. Sometimes that affects how the agencies respond to the needs.

I just found out that the home-based health care agency that we were working with had layoffs, and I do not know the reason why, but I was concerned because I know how many people that they were going to be visiting and caring for as a part of their daily schedule. I do keep in contact with those who took care of my mother and when they were telling me the changes that are coming forth, I said, well, I do not know. It is not at the State level, it has to be at the Federal level.

So I think that some of the rules and some of the things that are happening with HCFA and Medicare, it is affecting what they are able to do, and I am concerned about that. But as I said, it is not at the State level, it is at the Federal level.

Senator LINCOLN. Well, it is definitely something we want to address, and I think you are right, that there are a lot of rules and regulations out there that we have got to make sure fit the needs of our communities and our constituency.

This is a very personal issue for all of us and I am proud of the attendance in the hearing today. I thank those that have taken the time, and most importantly, the willingness to be able to share your stories with us and with the nation, because it is a powerful story. It is one that we all need to hear. And certainly, as legislators, it is one that we must address in terms of the training of individuals who will be caregivers, the assistance that we need to give to family members who are caregivers, and those individuals who are suffering and understand the complications of their condition, being able to provide the much-needed assistance to groups like the Alzheimer's Association, who has obviously provided so much information to both of you all.

Thank you all for being here today, and thank you, Mr. Chairman.

The CHAIRMAN. Senator Bayh.

Senator BAYH. Mr. Chairman, could I be permitted—I made a statement in your absence, but passed on the opportunity to ask a question. I had one, if I could.

The CHAIRMAN. Yes.

Senator BAYH. Representative, Boyd, I would like to ask you this question. It deals with something I mentioned earlier when the Secretary was here. You are on the Ohio Finance Committee, so you deal with a lot of these financial issues at the State level.

My question to you regards the prospect of a \$1,000 a year tax credit from the Federal level to family caregivers and your opinion as to how helpful that might be. As you may be following, we are trying to balance a lot of different considerations up here, the importance of saving Social Security by paying down the national debt, trying to extend the life of Medicare, which is very important, and then looking at the prospect for some tax cuts.

I would just like your opinion about whether—some people favor the across-the-board kind, thinking that that would have more impact on the economy. I must tell you, I will admit freely, I have

a very strong interest in this particular tax credit, trying to help people who are trying to struggle to meet these needs, and you very eloquently outlined the financial challenges that you faced with your mother's illness and I applaud you for taking over her finances and trying to pay her obligations now that she is gone.

In your opinion, would this be wise Federal policy to enact such a tax credit? Would it be helpful?

Ms. BOYD. Yes. As I said, I never carried Mother as a dependent because it was always with me providing care. I mean, we did not have a chance. Mother moved so quickly through the stages of Alzheimer's that it was the Alzheimer's Association that I would contact, and they know me quite well. I found that respite, even though I was one of the champions for an increase in our State budget for respite care in the State of Ohio, I never used it until when Mother was in the dying process. As I said, I was exhausted and I was staying up at night because you have come this far. Why would you step away from the final hour or final day?

It would help. There are people that I work with in my district. They call me as a resource. They do not mind helping out, but I feel that they should not be placed in the situation where they have to mortgage a home, exhaust their savings. It is a step, and you are going to find as we become a nation of caregivers and the fact that the people in this room today, someone is going to have to take care of you. So many of us are not prepared. I am not prepared for it and I worry about that.

But I also know that if there is any way that they can see some assistance to help them to alleviate the financial pitfalls of being a caregiver. I mean, we find ourselves in poverty, near poverty. We do exhaust what we have. That is one of the problems that we have in this situation, is that it was coming. We thought we knew it was coming, but we did not know it was going to hit so fast and it was going to have such an impact on our lives.

Believe me, as I said, 6 years ago, I had no idea. I was quickly awakened when the diagnosis was made. I did not have time to think. When I would come home from the capital, I would just say, well, what has happened now? And that became a part of my daily life, and I work 153 miles away from our home. I can imagine what it is like to be there on a daily basis, and believe me, any help right now, it is a first step, but it is going to have to be continued. This is a growing issue in this country. It is the issue for the new millennium, as far as I am concerned.

I met with the hospice people in my district and they said to me, are you aware that in not too short a period of time, half of this nation will be taking care of the other half? That is a scary thought, because none of us are prepared for it.

At our memory day in the capital in Columbus, there was a young lady who approached me and she was 28, the same age as my daughter, and her mother had Alzheimer's and she was in tears. I told her, I said, stick with your Alzheimer's Association. I said, they will show you the way. I said, use your instincts. I said, that will help you the rest of the way, and trust in God, I said, because in the end, that is what is going to have to carry you over.

Senator BAYH. Thank you, Representative.

Just my final comment, Mr. Chairman. One of the debates we are trying to work our way through up here is the one, some people argue that reducing marginal rates is a better economic theory, sort of a rising tide lifts all boats. But it seems to me some boats may need a little bit greater lift than others, and by targeting our resources to take into account the practicalities of daily life and the real severe challenges that some people meet may combine, as I said in my comments to the Secretary, good fiscal policy with compassionate social policy, and that was the reason for my question and I appreciate your comments. Thank you.

The CHAIRMAN. I have several questions, of which I think I will probably only ask a couple of each of you and then submit some questions for response in writing because of time. I feel that the time that we have given here to all of our colleagues and all of you to get these real life experiences are very important. I do have one more panel of witnesses after you, and so that is why I will limit my questioning.

You made reference, Representative Boyd, to the access to your local Alzheimer's Association for some support and advice. Did you make use of any other local supportive services during the time in which you cared for your mother?

Ms. BOYD. No. I did turn to the Ohio Area Agency on Aging because I was looking at their program of Passport because I am a very strong advocate of Passport. But the estate recovery clause within Passport eliminated my mother from getting any service from Passport. So, therefore, that was taken completely away from my purview of where I could go.

It was really the home health care that we could benefit, because as I said, my mother became atrophied rather early. Therefore, that helped. But, again, as a caregiver, in a situation like mine, you have to plan and plan thoughtfully and be very common sense about it. You have to make adjustments very quickly.

The one thing that just amazed me, and I have to say this, was the fact that people did not realize how—or I did not realize how much I was going to need the ambulance, because when a patient becomes atrophied, and once you have gone through Alzheimer's and you get to that agitation phase, you cannot take them into the regular doctor's office for patient visits. You have to take them to the emergency room in order for them to get that blood test.

My mother was on Cognex, so she had to have a weekly stick in order for them to evaluate how Cognex was affecting her liver. Anytime something went wrong with her temperature or what have you, because she could not talk, the doctor, nurse on call, whomever I talked to said, you have to bring her into the emergency room. So that cost was something I never anticipated.

I think if you talk to some of the people who are here and they have dealt with it, those are the additional costs that we never considered. I mean, I knew I was going to have to deal with the prescriptive cost. I knew I was going to have to deal, which I did not really understand all that much, the fact that a hospital bed that was going to be brought in; and as she became atrophied and she could not turn herself, could not move herself at all, we had to have a special bed that would alleviate the development of bed sores or

skin breakdown. That was an additional 20 percent that came out of pocket.

As she lost the ability to eat and to swallow, but sometimes she would have difficulty, we had to have a machine to suction out her mouth in order for her to continue feeding. I mean, these are the kinds of additional costs that no one really thinks about, but Alzheimer's is a disease that as it moves through its stages, it takes you to another place and it does not stay the same.

I was concerned about her breast cancer because we could not do anything about it. They said, we will use Tamoxifen. That is the only thing we could use. We did not know how effective it was going to be. I had to make decisions.

When she got to the point of pain, and the wailing, we did not understand because she could not talk, whether or not the pain was so severe that the only thing she could do was to wail. You have to hear someone wail to understand that in a neighborhood like ours, with the windows open, you have to go out and tell the neighbors, we are not hurting her. She is sick.

I mean, these are additional things that we have to be confronted with, and I think that the more understanding, the more research you have with Alzheimer's, the more that we find out the cause, and perhaps as research develops better drugs, then I think that some of the things I experienced may not be experienced by others who are to find themselves in this situation.

The CHAIRMAN. I think we got an idea of the value of some respite care. Is this something that can be planned and regularly scheduled, or is it the kind of thing needed spontaneously?

Ms. BOYD. From what I understand from my Alzheimer's Association, they are really ready to do whatever fits the caregiver's needs, which ultimately fits the needs of the patient. I did not utilize respite as perhaps I should. I just did not think it was for me. I am a State legislator and you have to be careful in what you do.

I think if it was not for the fact that my mother took about a month to literally go through the dying phase and I was staying up and sleeping in the bed beside her, staying up at night, and I was just physically exhausted, doing my job in the day and then continuing with her through the night to make sure I did not miss anything or that she was really comfortable, it was the Alzheimer's Association who called me and said to me, "We do have respite, Barbara. We do have it available for anyone who is in need, and you are in need now whether you know it or not." That respite certainly helped me.

The CHAIRMAN. Mrs. Awbrey or Mr. Awbrey, when Stuart decided to have a physical examination, did he suspect that there might be a problem of this nature or was it just a regular physical examination? Did you suspect something was wrong? Why did you have your physical examination?

Mrs. AWBREY. Actually, I had thought there might be something wrong and had been concerned about that for at least half a year, maybe a little bit more, before I went to Stu and suggested to him that he ought to be evaluated neurologically. So that is a difficult decision point for a caregiver, and I discussed the issue with a psychologist who does neurological testing, about whether it was a good idea to have the testing. Would it make things worse? Be-

cause if you find out you have Early Onset Alzheimer's, then you could get depressed about it. Do you really want to know? That's the whole question.

We decided that it was a good idea to know for different reasons, and at that point, I suggested to Stu that he have the testing and he really went along with it, although I do not think Stu really felt that he had anything wrong at that time. So after all of the testing, it came as a big jolt.

But I would say now that finding out about it early on was a real advantage because Stu was able to do so many things to plan and to take advantage of the time, and he can speak to this better than I. But there are a lot of advantages to hearing about it early and also getting involved in some trials that can delay some of the symptoms.

Mr. AWBREY. I had lots of tips, like I had run out on a road and almost kill somebody. That was one tip-off. Another big one that has been enduring all the time is when I go to a restaurant, I cannot do the arithmetic, simple things like that.

The CHAIRMAN. As I indicated to you before, members may have some questions to submit in writing to each of you. If you have any problems with that process, please get hold of my staff, because we want to be helpful if we can.

I thank each of you very much for your moving statements and your reminders to all of us about the situation of families with Alzheimer's. Thank you very much, and I dismiss you. Thank you.

I am going to call the last panel. It is my honor to introduce the second witness on the panel because Senator Santorum may come to introduce the first one. She is a constituent of mine. Donna Harvey is executive director of the Hawkeye Valley Area Agency on Aging near my home town of Waterloo, IA. She is in Waterloo, IA. It is a suburb of the little town of New Hartford. [Laughter.]

She has served as executive director since 1987, working for and advocating on behalf of the more than 63,000 older persons who reside within her local ten-county area.

Next, I am going to introduce Richard Browdie. He is the Secretary of the Pennsylvania Department of Aging. Mr. Browdie has administered programs for the elderly for over 25 years. Prior to his appointment by Governor Tom Ridge, he was executive director of the National Association of Area Agencies on Aging here in Washington. I had an opportunity to address that group yesterday at their annual meeting. In his capacity as Secretary of Aging, Secretary Browdie coordinates the extensive network of services through a State-wide system of 52 local agencies. He is going to give the perspective of a State level in implementing this program, as Donna will do for the area subdivision of the State of Iowa.

We welcome your testimony in regard to how you think this program fits into the national pattern that we ought to have, any problems it might cause for you, your ability to deliver the services and to administer the program that Senator Breaux and I will be introducing today, along with other Senators before mentioned.

Before you start, I just want to say that I had mentioned earlier that Senator Breaux is always here. He cannot be here today at this meeting because he is one of the Democratic elected leaders

and the leadership of both political parties are at the White House right now for a meeting on Kosovo. So we understand his absence.

Would you start out, Secretary Browdie, please.

**STATEMENT OF RICHARD BROWDIE, PENNSYLVANIA
SECRETARY OF AGING, HARRISBURG, PA**

Mr. BROWDIE. Thank you, and good morning. My name is Richard Browdie and I am privileged to serve as the Secretary of Aging for the Commonwealth of Pennsylvania. I would like to thank the Senate Special Committee on Aging for the opportunity to testify on this very important issue.

Family caregiving is one of the central components of a truly comprehensive array of home and community-based services, which, in turn, is crucial to any strategy for developing affordable long-term care for our country. We are delighted that President Clinton's long-term care initiative provides for a family caregiver support program.

As you know, Pennsylvania began development of a family caregiver support program over a decade ago that provides all the services of the national program proposed by the President. Additionally, the Pennsylvania program provides reimbursement to caregivers for home modification and assistive devices. I am pleased to say that the Commonwealth, through the Department of Aging and its network of 52 Area Agencies on Aging, has provided the Family Caregiver Support Program and its services to informal caregivers of older persons State-wide since 1992.

Our program serves more than 3,500 families at any given time. More than 6,000 families benefit from the program over the course of any given year. It is estimated that more than 25,000 different families have benefited from the program since its inception.

The program is targeted directly at families through its requirement that the primary caregiver and the care receiver live in the same household. The program is popular with consumers because it respects the primary role of families as caregivers and seeks to support the efforts of family caregivers rather than to supplant them, change them, or manage them.

While Area Agency on Aging staff counsel and assist the consumer in becoming more informed and skilled caregivers, the primary caregiver, who in most cases is the care receiver's spouse or daughter, usually continues to manage the care within the family. The primary caregiver, along with the family and involved friends, what we refer to as the informal caregiving network, decides what support is needed from the program and other community resources. This could involve any combination of caregiving information and educational opportunities, respite services, supplementary care, consumable supplies, assistive devices, and home modifications.

Currently, the maximum benefit available under the program is \$200 per month in reimbursement for the purchase of services and supplies and a grant of no more than \$2,000 over the life of the case to help with the purchase of home modifications and expensive assistive devices. Families within 200 percent of the poverty level can receive full financial benefits. Families with incomes between 200 and 380 percent of the poverty level are eligible for reduced fi-

nancial benefits based on a sliding scale. The majority of participating families are eligible for full benefits.

For example, based on current Department of Health and Human Services guidelines, a household of five, a daughter, her spouse, two children, and a care-receiving parent, could have an aggregate income of \$38,500 before the financial benefit would be reduced at all, and they would be eligible for half of the financial benefit with an income of up to \$57,750.

Consumers typically utilize their monthly financial benefit for purchasing day care services, hands-on assistance at home, nutritional supplements, over-the-counter medications, incontinence supplies, and assistive devices. Families use their capital assistance benefit to help pay for items such as lift chairs, stair glides, portable ramps, and various assistive devices. They also use the grant to make modifications to their home to facilitate caregiving and safety, like adding a downstairs bathroom, building a ramp, or modifying an existing bathroom.

The program is extremely cost effective in that it serves families at an average cost of less than \$3,000 per year. Considering that care receivers in the program must receive substantial human assistance with at least one activity of daily living, which, I might add, is a pretty high standard, and either be at least 60 years of age or a victim of chronic dementia.

Traditional in-home service packages for these same consumers could easily cost five times that amount and more. In fact, many of our care receivers in our program would move into nursing home diversion systems or nursing homes if their families did not prefer this option. Thus, the cost effectiveness of the program does not even begin to consider savings resulting from prevention or delay of nursing home placement.

Pennsylvania's Family Caregiver Support Program is designed not only to meet the specific caregiving needs and reduce the stress and burden of care for each consuming family, but it also has the flexibility to allow each Area Agency on Aging to adapt the program to local caregiving needs and resources of the communities that they serve.

For example, in an urban community, there may be a number of caregiver support programs and groups available from a variety of local resources. Our program will assist and support these local resources. In other communities, particularly rural areas, the program may need to take a more direct approach by organizing and/or operating caregiver support activities to fill gaps in existing resources.

The program, both on the State and local level, has proved to be a catalyst for collaboration and growth among other family or informal caregiver support initiatives. The Department of Aging and its Family Caregiver Support Program is currently a key player in the development and implementation of family support initiatives State-wide, including establishing a network of trainers to teach caregivers about assistive technology, increasing the awareness of family violence and prevention programs among health care professionals and the general public, and publishing a user-friendly guide for informal caregivers on how to help elderly consumers maneuver

through Medicare and gain access to other health and long-term care benefits and services.

Pennsylvania's Family Caregiver Program is supported by a general fund appropriation of more than \$10 million. Pennsylvania's share of an estimated \$5 to \$6 million from the proposed Federal program will be a tremendous boost to this critically important program, which routinely has waiting lists across the State. Furthermore, there are additional informational and program support efforts we would like to develop with this new Federal support.

The prospect of a national program raises one important issue, however. The Federal program must be sufficiently flexible to allow for optimal integration with existing State efforts in this critical area. Overly restrictive Federal regulations would be counter-productive. Federal and State dollars available for this effort must be administered in a coordinated manner, and as much so as possible.

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

The CHAIRMAN. Thank you, Secretary Browdie.

[The prepared statement of Mr. Browdie follows:]

**TESTIMONY BEFORE THE UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING
ON TUESDAY, MARCH 23, 1999
ROOM 106, DIRKSEN SENATE OFFICE BUILDING
BY THE HONORABLE RICHARD BROWDIE
SECRETARY OF AGING
COMMONWEALTH OF PENNSYLVANIA**

GOOD MORNING. MY NAME IS RICHARD BROWDIE. I AM PRIVILEGED TO SERVE AS THE SECRETARY OF AGING FOR THE COMMONWEALTH OF PENNSYLVANIA.

I WOULD LIKE TO THANK THE SENATE SPECIAL COMMITTEE ON AGING FOR THE OPPORTUNITY TO TESTIFY ON THIS IMPORTANT ISSUE. FAMILY CAREGIVING IS ONE OF THE CENTRAL COMPONENTS OF A TRULY COMPREHENSIVE ARRAY OF HOME AND COMMUNITY BASED LONG TERM CARE SERVICES, WHICH IN TURN IS CRUCIAL TO ANY STRATEGY TO DEVELOP AN AFFORDABLE LONG TERM CARE STRATEGY FOR OUR COUNTRY.

WE ARE DELIGHTED THAT PRESIDENT CLINTON'S LONG TERM CARE INITIATIVE PROVIDES FOR A FAMILY CAREGIVER SUPPORT PROGRAM. AS YOU MAY KNOW, PENNSYLVANIA BEGAN DEVELOPMENT OF A FAMILY CAREGIVER SUPPORT PROGRAM OVER A DECADE AGO THAT PROVIDES ALL THE SERVICES OF THE NATIONAL PROGRAM PROPOSED BY THE PRESIDENT. ADDITIONALLY, THE PENNSYLVANIA PROGRAM ALLOWS FOR

REIMBURSEMENT TO CAREGIVERS FOR HOME MODIFICATIONS AND ASSISTIVE DEVICES. I AM PLEASED TO SAY THAT THE COMMONWEALTH, THROUGH THE DEPARTMENT OF AGING AND ITS NETWORK OF 52 AREA AGENCIES ON AGING, HAS PROVIDED THE FAMILY CAREGIVER SUPPORT PROGRAM AND ITS SERVICES TO INFORMAL CAREGIVERS OF OLDER PERSONS STATEWIDE SINCE 1992.

OUR PROGRAM SERVES MORE THAN 3,500 FAMILIES AT ANY GIVEN TIME. MORE THAN 6,000 FAMILIES BENEFIT FROM THE PROGRAM OVER THE COURSE OF ANY GIVEN YEAR. IT IS ESTIMATED THAT MORE THAN 25,000 DIFFERENT FAMILIES HAVE BENEFITED FROM THE PROGRAM SINCE ITS ORIGINATION.

THE PROGRAM IS TARGETED DIRECTLY AT FAMILIES THROUGH ITS REQUIREMENT THAT THE PRIMARY CAREGIVER AND THE CARE RECEIVER LIVE IN THE SAME HOUSEHOLD. THE PROGRAM IS POPULAR WITH CONSUMERS BECAUSE IT RESPECTS THE PRIMARY ROLE OF FAMILIES AS CAREGIVERS, AND SEEKS TO

SUPPORT THE EFFORTS OF FAMILY CAREGIVERS RATHER THAN TO SUPPLANT THEM, CHANGE THEM OR MANAGE THEM. WHILE AREA AGENCY ON AGING STAFF COUNSEL AND ASSIST THE CONSUMER IN BECOMING MORE INFORMED AND SKILLED CAREGIVERS; THE PRIMARY CAREGIVER, WHO IN MOST CASES IS THE CARE RECEIVER'S SPOUSE OR DAUGHTER, USUALLY CONTINUES TO MANAGE THE CARE WITHIN THE FAMILY. THE PRIMARY CAREGIVER, ALONG WITH FAMILY AND INVOLVED FRIENDS...WHAT WE REFER TO AS THE INFORMAL CAREGIVING NETWORK...DECIDES WHAT SUPPORT IS NEEDED FROM THE PROGRAM AND OTHER COMMUNITY RESOURCES. THIS COULD INVOLVE ANY COMBINATION OF CAREGIVING INFORMATION AND EDUCATIONAL OPPORTUNITIES, RESPITE SERVICES, SUPPLEMENTARY CARE, CONSUMABLE SUPPLIES, ASSISTIVE DEVICES AND HOME MODIFICATIONS.

THE MAXIMUM FINANCIAL BENEFIT AVAILABLE UNDER THE PROGRAM IS \$200 PER MONTH IN REIMBURSEMENT FOR THE PURCHASE OF SERVICES AND SUPPLIES AND A "GRANT" OF NO

MORE THAN \$2,000 OVER THE LIFE OF A CASE TO HELP WITH THE PURCHASE OF HOME MODIFICATIONS AND EXPENSIVE ASSISTIVE DEVICES. FAMILIES WITHIN 200% OF THE POVERTY LEVEL CAN RECEIVE FULL FINANCIAL BENEFITS. FAMILIES WITH INCOMES BETWEEN 200% AND 380% OF THE POVERTY LEVEL ARE ELIGIBLE FOR REDUCED FINANCIAL BENEFITS BASED ON A SLIDING SCALE. THE MAJORITY OF PARTICIPATING FAMILIES ARE ELIGIBLE FOR FULL BENEFITS. FOR EXAMPLE, BASED ON CURRENT DHHS GUIDELINES, A HOUSEHOLD OF FIVE (A DAUGHTER, HER SPOUSE, TWO CHILDREN AND A CARE RECEIVING PARENT) COULD HAVE AN AGGREGATE INCOME OF \$38,500 BEFORE THE FINANCIAL BENEFIT WOULD BE REDUCED AT ALL, AND THEY WOULD BE ELIGIBLE FOR HALF OF THE FINANCIAL BENEFIT WITH AN INCOME OF UP TO \$57,750.

CONSUMERS TYPICALLY UTILIZE THEIR MONTHLY FINANCIAL BENEFIT FOR PURCHASING DAY CARE SERVICES, HANDS-ON ASSISTANCE AT HOME, NUTRITIONAL SUPPLEMENTS, OVER THE COUNTER MEDICATIONS, INCONTINENCE SUPPLIES, AND ASSISTIVE

DEVICES. FAMILIES USE THEIR "CAPITAL ASSISTANCE" BENEFIT TO HELP PAY FOR ITEMS SUCH AS LIFT CHAIRS, STAIR GLIDES, PORTABLE RAMPS AND OTHER VARIOUS ASSISTIVE DEVICES. THEY ALSO USE THE GRANT TO MAKE MODIFICATIONS TO THEIR HOME TO FACILITATE CAREGIVING AND SAFETY, LIKE ADDING A DOWNSTAIRS BATHROOM, BUILDING A RAMP OR MODIFYING AN EXISTING BATHROOM.

THE PROGRAM IS EXTREMELY COST-EFFECTIVE, IN THAT IT SERVES FAMILIES AT AN AVERAGE COST OF LESS THAN \$3,000 PER YEAR. CONSIDERING THAT CARE RECEIVERS IN THE PROGRAM MUST NEED SUBSTANTIAL HUMAN ASSISTANCE WITH AT LEAST ONE ACTIVITY OF DAILY LIVING AND EITHER BE AT LEAST AGE SIXTY OR A VICTIM OF CHRONIC DEMENTIA, TRADITIONAL IN-HOME SERVICE PACKAGES FOR THESE SAME CONSUMERS COULD EASILY COST FIVE TIMES THAT AMOUNT OR MORE. IN FACT, MANY OF THE CARE RECEIVERS IN OUR PROGRAM WOULD MOVE INTO OUR NURSING HOME DIVERSION SYSTEMS IF THEIR FAMILIES DID NOT PREFER THIS OPTION. THUS, THE COST EFFECTIVENESS OF THE

PROGRAM DOES NOT EVEN BEGIN TO CONSIDER SAVINGS RESULTING FROM PREVENTION OR DELAY OF NURSING HOME PLACEMENT.

PENNSYLVANIA'S FAMILY CAREGIVER SUPPORT PROGRAM IS NOT ONLY DESIGNED TO MEET THE SPECIFIC CAREGIVING NEEDS AND HELP REDUCE THE STRESS AND BURDEN OF CARE FOR EACH CONSUMER FAMILY, BUT IT ALSO HAS THE FLEXIBILITY TO ALLOW EACH AREA AGENCY ON AGING TO ADAPT THE PROGRAM TO THE LOCAL CAREGIVING NEEDS AND RESOURCES OF THE COMMUNITIES THEY SERVE. FOR EXAMPLE, IN AN URBAN COMMUNITY THERE MAY BE A NUMBER OF CAREGIVER SUPPORT GROUPS AVAILABLE FROM A VARIETY OF LOCAL RESOURCES. OUR PROGRAM WILL ASSIST AND SUPPORT THESE LOCAL RESOURCES. IN OTHER COMMUNITIES, PARTICULARLY RURAL AREAS, THE PROGRAM MAY NEED TO TAKE A MORE DIRECT APPROACH BY ORGANIZING AND/OR OPERATING CAREGIVER SUPPORT ACTIVITIES TO FILL GAPS IN EXISTING RESOURCES.

THE PROGRAM, BOTH ON THE STATE AND LOCAL LEVEL, HAS PROVED TO BE A CATALYST FOR COLLABORATION AND GROWTH AMONG OTHER FAMILY OR INFORMAL CAREGIVER SUPPORT INITIATIVES. THE DEPARTMENT OF AGING AND ITS FAMILY CAREGIVER SUPPORT PROGRAM IS CURRENTLY A KEY PLAYER IN THE DEVELOPMENT AND IMPLEMENTATION OF FAMILY SUPPORT INITIATIVES STATEWIDE, INCLUDING ESTABLISHING A NETWORK OF TRAINERS TO TEACH CAREGIVERS ABOUT ASSISTIVE TECHNOLOGY; INCREASING THE AWARENESS OF FAMILY VIOLENCE AND PREVENTION PROGRAMS AMONG HEALTH CARE PROFESSIONALS AND THE GENERAL PUBLIC; AND PUBLISHING A USER FRIENDLY GUIDE FOR INFORMAL CAREGIVERS ON HOW TO HELP ELDERLY CONSUMERS "MANEUVER THROUGH" MEDICARE, AND GAIN ACCESS TO OTHER HEALTH AND LONG TERM CARE BENEFITS AND SERVICES.

PENNSYLVANIA'S FAMILY CAREGIVER PROGRAM IS SUPPORTED BY A GENERAL FUND APPROPRIATION OF MORE THAN \$10 MILLION. PENNSYLVANIA'S PROJECTED SHARE OF \$5 TO \$6

MILLION FROM THE PROPOSED FEDERAL PROGRAM WOULD BE A TREMENDOUS BOOST TO THIS CRITICALLY IMPORTANT PROGRAM, WHICH ROUTINELY HAS WAITING LISTS IN COMMUNITIES ACROSS THE STATE. FURTHERMORE, THERE ARE ADDITIONAL INFORMATIONAL AND PROGRAM SUPPORT EFFORTS WE WOULD LIKE TO DEVELOP WITH FEDERAL SUPPORT.

THE PROSPECT OF A NATIONAL PROGRAM RAISES AN IMPORTANT ISSUE, HOWEVER. THE FEDERAL PROGRAM MUST BE SUFFICIENTLY FLEXIBLE TO ALLOW FOR OPTIMAL INTEGRATION WITH EXISTING STATE EFFORTS IN THIS CRITICAL AREA. OVERLY RESTRICTIVE FEDERAL REGULATIONS WOULD BE COUNTER-PRODUCTIVE. FEDERAL AND STATE DOLLARS AVAILABLE FOR THIS EFFORT MUST BE ADMINISTERED IN A COORDINATED MANNER.

AGAIN, THANK YOU FOR THE OPPORTUNITY TO TESTIFY, I WOULD BE HAPPY TO ANSWER ANY QUESTIONS YOU MAY HAVE.

The CHAIRMAN. Now we will hear from Ms. Harvey.

**DONNA HARVEY, EXECUTIVE DIRECTOR, HAWKEYE VALLEY
AREA AGENCY ON AGING, WATERLOO, IA**

Ms. HARVEY. Thank you. This is the first time I have ever heard Waterloo referred to as a suburb of New Hartford, so I cannot wait to get home and share that with everybody else. [Laughter.]

If you do not know, New Hartford probably has 500 people—
The CHAIRMAN. Six-hundred-and-fifty.

Ms. HARVEY. Six-hundred-and-fifty. I am sorry.

Thank you for the privilege to be here today and also to address this important committee Chaired by Senator Grassley. I just want to tell you that he has really been a strong advocate of Area Agencies on Aging and specifically the Family Caregiver Program before it was even introduced. In our local paper, the Waterloo-Cedar Falls Courier—I guess now New Hartford Courier—on December 20, he had an op-ed article that talked about family caregivers and advice for making it work. I clipped it out and sent it to all of our State people and I shared it with our board and advisory committee because he really captured the essence of the importance of family caregivers and the Area Agencies on Aging and the important role that we can play with that. So, again, thank you for that wonderful article.

I would like to read an excerpt where he shared about a family that he is well acquainted with from New Hartford. The mother actually resides in Waterloo, but one of the caregivers is a local vendor of a restaurant in New Hartford. Senator Grassley states, "They join a growing legion of family caregivers who put their lives on stand-by to fulfill a commitment to a family member in need. Their story demonstrates how family caregiving can work with such strong family and community support systems. Marie's children agree that the rewards are irreplaceable. 'It is all worth it because it has kept Mother with us,'" and I think that is a good summary of what we are here to say today.

The fundamental purpose of Area Agencies on Aging is to keep older Americans in their homes and communities with maximum dignity and independence for as long as possible. We have been doing that for quite some time, and I think we could be seen as the single point of information for the complex and fragmented range of home and community-based services for older adults and their caregivers, which is actually an ageless topic.

The Older Americans Act binds together 655 Area Agencies on Aging and 232 Title VI Native American aging grantees across the country, providing a consistent structure for planning, service coordination, oversight, and advocacy. AAAs have the infrastructure in place to provide access to a host of services to older adults, links to local seniors and their family caregivers, and ties to a myriad of service providers in their communities. As such, the role of the AAA has steadily expanded to include programs that were not necessarily envisioned in the Older Americans Act when it developed the concept of Area Agencies on Aging.

AAAs pride themselves on developing unique and appropriate services and service delivery models based upon consumer choice and local need, and again, I want to emphasize consumer choice

and local need and our request for flexibility. This flexibility positions AAAs to be the natural coordinator of the Family Caregiver Support Program being proposed. Throughout the years, Area Agencies on Aging have had to be very creative in their strategies to meet the needs of older persons, particularly those residing in small communities and rural areas where services are very limited.

Additional funds provided to the Family Caregiver Support Program would allow us to work with existing providers to expand their services to better meet the needs of elders and their caregivers while continuing to embrace the importance of utilizing the informal support systems to reduce cost. Provided the funding allows for ultimate flexibility to meet needs, we believe Area Agencies on Aging could continue our creative approaches to unique needs.

In Iowa, we have a case management program for frail elders administered through the State Unit on Aging and the Area Agencies on Aging. It is available to all, older persons not just those dependent upon Medicare or Medicaid. This program is comprised of a screening process, a comprehensive assessment, the development of a care plan by a multi-disciplinary team that includes the elder and their caregivers, and the assignment of a case manager to the elder. The case management service is provided at no cost to the elder. However, they are responsible for any charges incurred for the services they receive.

Approximately 100 organizations in our ten-county area in Iowa voluntarily participate in the case management program. This system has allowed us a wonderful opportunity to become even more familiar with all the services that are available. The care plan that is developed clearly reflects the roles fulfilled by caregivers and other informal support systems, such as churches, neighbors, and volunteer organizations, as well as developing a system of formal services to support the informal network.

Throughout the process, the client and caregivers are ultimately involved to guarantee client choice as the centerpiece of the case plan. The case management program has also allowed us to become more aware of the needs and dynamics involved with caregiving.

In our service area, we are utilizing vouchers to purchase needed services for seniors without developing a whole new service delivery system. For instance, in small communities, we contract with local restaurants to provide meals, including home-delivered meals, to their seniors. We provide vouchers to be used toward the price of a meal if the restaurant cannot provide their daily, what we call "blue plate special," for the reimbursement we offer. This accomplishes several things. It keeps seniors in their communities interacting with long-time acquaintances, it provides a hot noon meal that meets the nutritional requirements, and it supports small business owners who struggle to keep their businesses operating.

We have also expanded that into a variety of other services, such as working with local volunteer fire departments to purchase and install smoke alarms and carbon monoxide detectors. We have done home adaptations and purchased adaptive equipment on behalf of seniors.

Since the mid-1970's, AAAs have demonstrated an extraordinary record of achievement in stretching a limited amount of Federal

money to help hundreds of thousands of older people avoid or delay costly nursing home placement and to help them remain independent in their community, near their loved ones.

In the past 20 years, the older population in America has grown twice as quickly as all other age groups. Iowa has the honor of having one of the highest percentages of older persons residing there, but that also gives us a variety of challenges, as well.

Our Area Agency on Aging has already tried to start addressing the caregiving issues by working with the local community college. We find that it is not only important to aging folks, but with me today I have the president of our board, John Hawse, who has a daughter who in her 50's suffered a stroke, and we have worked very closely with him to try to get him plugged into services because those folks tend to fall outside any formalized structure, and again, I think that is why Area Agencies on Aging are uniquely positioned to help persons of all ages.

So, again, we thank you very much for holding this hearing and inviting all of us to be part of that because it is crucially important to our existence.

[The prepared statement of Ms. Harvey follows:]



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**STATEMENT OF DONNA K. HARVEY
EXECUTIVE DIRECTOR
HAWKEYE VALLEY AREA AGENCY ON AGING, INC.
WATERLOO, IOWA**

SENATE SPECIAL COMMITTEE ON AGING

**HEARING ON THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM
March 23, 1999 at 9:00 a.m.
106 Dirksen Senate Office Building
Washington, DC**

Mr. Chairman and distinguished members of the Committee, my name is Donna Harvey. I am from the home state of Senator Grassley and serve as the Executive Director of Hawkeye Valley Area Agency on Aging in Waterloo, Iowa. I want to thank the Committee for inviting me here today to testify on behalf of area agencies on aging nationwide and the role I believe we can and should play with the proposed National Family Caregiver Support Program.

The fundamental mission of area agencies on aging is to help older Americans stay in their own homes and communities with maximum dignity and independence for as long as possible. Area agencies on aging are dedicated to enhancing the quality of life for older Americans and their loved ones and caregivers by advocating on their behalf and by providing information about and access to a variety of services in local communities. AAA's often serve as a "single point of information" for the complex and fragmented range of home and community-based services for older adults and their caregivers.

The Older Americans Act binds together 655 area agencies on aging and 232 Title VI Native American aging grantees across the country, providing a consistent structure for planning, service coordination, oversight, and advocacy. AAA's have the infrastructure in place to provide access to a host of services to older adults, links to local seniors and their family caregivers, and ties to a myriad of service providers in their communities. As such, the role of the AAA has steadily expanded to include programs that were not necessarily envisioned in the Older Americans Act when it developed the concept of area agencies on aging. AAA's pride themselves on developing unique and appropriate services and service delivery models based upon

consumer choice and local need.

This flexibility positions AAA's to be the natural coordinator of the Family Caregiver Support Program being proposed. Throughout the years, area agencies on aging have had to be very creative in their strategies to meet the needs of older persons particularly those residing in small communities and rural areas where services are very limited.

Additional funds provided through the Family Caregiver Support Program would allow us to work with existing providers to expand their services to better meet the needs of elders and their caregivers while continuing to embrace the importance of utilizing the informal support systems to reduce costs. Provided the funding allows for ultimate flexibility to meet needs, we believe area agencies on aging could continue our creative approaches to unique needs.

In Iowa, we have a case management program for frail elders administered through the state unit on aging and the area agencies on aging. This program is comprised of a screening process, a comprehensive assessment, the development of a care plan by a multidisciplinary team that includes the elder and their caregivers, and the assignment of a case manager to the elder. The case management service is provided at no cost to the elder, however, they are responsible for any charges incurred for the services they receive. Approximately 100 organizations in our 10 county area in Iowa voluntarily participate in the case management program. This system has allowed us a wonderful opportunity to become even more familiar with all the services that are available. The care plan that is developed clearly reflects the roles fulfilled by caregivers and other informal support systems such as churches, neighbors, and volunteer organizations as

well as developing a system of formal services to support the informal network. Throughout the process, the client and caregivers are intimately involved to guarantee client choice is the centerpiece of the case plan. The case management program has also allowed us to become more aware of the needs and dynamics involved with caregiving.

In our service area, we are utilizing vouchers to purchase needed services for seniors without developing a whole new service delivery system. For instance, in small communities, we contract with local restaurants to provide meals, including home delivered meals, to their seniors. We provide vouchers to be used toward the price of a meal if the restaurant cannot provide their daily "blue plate special" for the reimbursement we offer. This accomplishes several things. It keeps seniors in their communities interacting with long-time acquaintances, it provides a hot, noon meal that meets the nutritional requirements and it supports small business owners who struggle to keep their businesses operating. We have expanded this system to purchase unique items that make the seniors safe and able to stay in the home. For instance, we have worked with local volunteer fire departments to purchase and install smoke alarms and carbon monoxide detectors. We have also done home adaptations and purchased adaptive equipment on behalf of seniors. We try to work with local businesses to purchase and install these items. Since the mid-1970's, AAA's have demonstrated an extraordinary record of achievement in stretching a limited amount of federal money to help hundreds of thousands of older people avoid or delay costly nursing home placement and to help them remain independent in their community near their loved ones. In the past 20 years, the older population in America has grown

twice as quickly as all other age groups. The 85 and older age group is expected to be seven times its present size by the year 2050 (U.S. Select Committee on Aging, 1988). This population trend will result in a large number of frail elderly in need of caregiving services. The Family Caregiver Support Program and funding will allow us to continue to work with existing and new providers to expand services to elders and their caregivers.

Almost daily, area agency on aging staff meets with family members serving as caregivers. Unfortunately, these persons are generally at a crisis point. They have attempted to fulfill the role of caregiver without preparation and support. They are exhausted, frustrated, frightened, and torn between their roles as caregiver to older relatives, their spouses, their children, and friends. While we can generally provide access to support services to be purchased, it is not so easy to address the personal dynamics, especially guilt, involved between parents and adult child caregivers.

Education of caregivers is critical to their ability to continue to provide this support to our Older Americans and to keep older persons in their homes and communities.

Hawkeye Valley Area Agency on Aging is in the early discussion stages with the community colleges in our area to offer caregiving support instruction. The adult education director from Hawkeye Community College in Waterloo has expressed interest based upon requests she has received for this type of training. The National Family Caregiver Support Program could help facilitate this process. The Community Colleges offer courses through Iowa's Communication Network (ICN). The ICN is available in schools and libraries in virtually every community throughout our state making the information available at a very reasonable cost and easily accessible.

Education is critical to those who are currently caregivers or know they will be soon, however, I believe education needs to begin in elementary school about the important role family members play in caring for each other and to provide basic information about aging and special needs.

Area agencies on aging are recognized for their ability to collaborate with existing organizations and systems to develop support groups. These groups are important to give caregivers avenues to share ideas, frustrations, and develop partnerships. An important aspect in developing a support group system is the provision of care for the loved one while the caregiver participates in these activities. Currently, funding is not readily available for this type of support. In addition, respite services are vitally important to both the older person and their caregivers. Options need to be developed which will meet the needs of the senior and their caregiver. Many times, it is just as important for the caregiver to have time at home to relax without the older person as well as it is to have someone come to the home to provide care while the caregiver participates in the community. Again, area agencies on aging work to identify options that meet particular needs.

Recently, Hawkeye Valley Area Agency on Aging began a collaborative program with Covenant Health Systems in Waterloo to develop a patient advocate program. The concept of this program is to match trained volunteers with elderly patients through the hospital social work department. The philosophy of this program is that older persons often paint a "rosy" picture for the social worker and enhance the role of family, neighbors, and friends in their caregiving roles without letting those persons know.

They deny the need for assistance offered through the social work department not realizing the challenges they could face. Once they get home, they soon discover that these persons may not be available or interested in providing this support. Through this volunteer program, the trained volunteer meets with the patient while they are still hospitalized to review existing community services and to do a friendly visit. Once the patient is discharged, this volunteer will follow up with the older person to see if their needs have changed once they are home. The volunteer asks the patient to allow the volunteer to make a referral to the area agency on aging on their behalf to provide any information and assistance with home and community based services. The program is very new so I cannot report any successes (or failures!), however, this is an attempt to address the importance of support systems to frail elders. If it is beneficial to elders and their caregivers, we will replicate the program throughout our 10 county area and make the information available to any other area agency on aging nationwide. As the Family Caregiver Program is developed, we must remember that many times, older persons are caregivers. Our Board President, Dr. John Hawse, who is here today, recently found himself in the role of caregiver. John's daughter who is in her 50's suffered a stroke and is now wheelchair bound. John quickly found that locating services for a 50 year old person who was qualified for any formalized disability services was complex, difficult, and expensive. Our staff at the area agency on aging worked with him to provide him information and assistance on accessing services, housing, adaptive equipment, and provided him support throughout this process. I believe John could be a national spokesperson for the ability of the area agency on aging to have the information, patience, and tenacity it takes to work with complex

funding systems and service barriers that exist. While the Family Caregiver Support program is geared to caregivers of older persons, it needs to have the flexibility to also provide support and assistance to older persons carrying out the role of caregiver.

Area agencies on aging cannot continue to provide this kind of outreach, information, and assistance to a rapidly increasing older population without increased or additional funding sources. We are prepared and uniquely positioned to carry out the responsibilities of the Family Caregiver Support Program, however, adequate funding is necessary to insure its success. We are pleased the Administration recognizes the Older Americans Act as the natural place to expand services provided to assist caregivers. This initiative will enable many older persons to remain in their homes and out of more expensive institutional settings while providing a quality life envisioned by all Americans. This allows us a wonderful opportunity to strengthen families by providing them assistance in dealing with the challenges of being a caregiver to their loved ones.

Area agencies on aging commend you and your staff for holding this hearing on this new and exciting initiative that affects so many Americans. Funding for this program will make a tremendous difference in the ability of area agencies on aging and Title VI grantees to assist caregivers in local communities. We look forward to a continued working relationship with you and your staff as this program is developed.

The CHAIRMAN. Thank you both for your testimony.

Senator Santorum.

Senator Santorum. Thank you, Mr. Chairman. Let me apologize to my Secretary for not being here in time to introduce him to the committee. I was in the middle of questioning at another hearing. The Housing Subcommittee of the Banking Committee was doing an oversight hearing over the Department of Housing and Urban Development and I was in the midst of a rather intense discussion and I could not get away, so I apologize. I understand you did a remarkable job, which I would expect nothing less of you, Mr. Secretary, because you have done a remarkable job in your service to the Commonwealth of Pennsylvania. I just want to put my compliments to you and just share a couple of thoughts.

No. 1 is I think your admonition in your testimony about any Federal legislation providing for flexibility to working with State programs and allowing the States and local agencies to work to meet the needs of the caregivers is, I think, of paramount importance. I think it would be a crime if we, in an effort to try to help local agencies, end up hurting them more even though they are giving them more dollars in meeting the needs that are out there.

So while I intend to be a cosponsor of Senator Grassley's and Senator Breaux's legislation and will work to ensure its passage, I certainly will look forward to your comments and those who are working on the State and local level to let us know where we are stepping on toes where we should not be. I think that, to me, is of critical importance. In fact, if you would like to expand on that, I would appreciate any comments that you have.

Mr. BROWDIE. Thank you very much, and thank you for your kind words, also, Senator. It is good to see you.

Pennsylvania is a State that embodies many of the issues of flexibility requirements for management because, while on the one hand, we have Philadelphia and Pittsburgh, major urban centers, we are also home to the largest population of rural elders in the United States, all within one State. So even within our State, we need flexibility, not to mention the idea that we prove it is inconceivable that a one-size-fits-all sort of approach works all the way across the country. So your sensibilities and your sensitivity to this issue are very well appreciated. It is really important.

Senator Santorum. I appreciate that, Mr. Secretary. You mentioned, Ms. Harvey, that Iowa has one of the largest per capita population of seniors. Pennsylvania is No. 2 in per capita senior population, and I think No. 1 is Florida, if I am not wrong. I always say, which is absolutely true, that my seniors depend on these programs a lot more—Social Security, Medicare, these kinds of caregiver programs—a lot more than, frankly, the folks in Florida do because all of my wealthy seniors move to Florida and what is left in Pennsylvania are folks who are much more dependent on the government programs. So as Mr. Secretary said, we have the largest population of rural elderly, and they are usually lower income.

So this is a very important program to the citizens of my State and I certainly will seek its passage but will do so in a way to make sure that it needs their needs and not step on toes of what is going on in the communities.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, and Secretary Browdie, let me assure you that Senator Santorum is very faithful to the work of this committee and he is not normally absent as his schedule required him to be today.

I would like to ask one question for each of you to respond to and then I am going to adjourn the meeting and submit all the other questions for answer in writing because I promised the Alzheimer's Association to have a news conference with them, and second, at 11, I have got the Attorney General waiting in my office to visit about some antitrust things. So I cannot spend as much time with you as I hoped.

We heard from the family witnesses on the second panel about the importance of caregiver education and timely access to resources. Given the difficulty many seniors and their families already experience in dealing with this tangled web that we call Medicare, what could we do differently to inform people about caregiving resources? I will start with you, Secretary Browdie.

Mr. BROWDIE. It is always a challenge to reach out to people who are already so engaged in problems in their daily lives that their ability to stop and listen to people who are trying to kind of get to them from the outside of their responsibilities is sometimes diminished.

Also, with public information, the only thing that seems to work is to try, try, and then try again, and frequently, with public resources being in such demand for our services, one of the things that suffers is public information. Because we have waiting lists for all of our services, the first demand on our resources always goes to direct service. As a result, the continuing effort that is necessary to reach out to people, in a variety of ways that would be effective in getting through to them sometimes suffers.

One of the things we look forward to in this legislation is that when you have a national message being given, people pay attention. Some people pay attention differently to national messages than they do to local ones. And at the same time, we will have resources to expand our ability to carry that message from the State level, as well as complimenting it with the efforts of Area Agencies on Aging, because each family does not have the same sort of orientation.

The other thing is that it will give us an additional shot in the arm in our ability to reach out to other folks that families frequently turn to—members of the clergy, physicians, other kinds of health care practitioners—to help them be aware of the resources that are available, and particularly the support systems for the families that are there.

Unfortunately, we learned prior to the development of our program that in thinking about the needs of the consumer, we frequently focus on the person and think of them as a patient. We think of them as the focus of all of our energy and we sometimes bypass the interests of the caregivers in the process of doing that. One of the key things that we learned in Pennsylvania, and it led to the enactment of the Family Caregiver Program, is you really have to think of the family as a unit and think about the caregiver as being the primary target of your support activity even though you are doing it on behalf of the care receiver.

It takes an alteration in your approach that requiring a kind of adjustment to people's thinking. You really have to take busy professionals who you might think would know because of their frequent interaction with families and say to them, "You know, you really need to think about this a little differently." The enactment of a national program rivets people's attention in such a way as it gives a real opportunity to educate.

The CHAIRMAN. Ms. Harvey.

Ms. HARVEY. I want to echo what Mr. Browdie said, but also, I think we need to remember that we also have a group of seniors who are always more than willing to help carry out any program, and that has been demonstrated through our local project with the Medicare waste, fraud, and abuse, where we train seniors to advocate on their own behalf and to educate other seniors. We also do that through the insurance counseling program. We envision as the family caregiving issues become more visible that we will have to train seniors to be spokespersons, as well.

Our belief is, you need to keep it simple. So if we could have one access point that expedites the whole process—I think sometimes we inundate caregivers with all the information that we think they are going to need from the very early onset and we really need to just give them a common point where they can come to when they are ready for the next step and to keep checking back and forth. I think we can do that through a variety of sources.

We have the Medicare matrix now available through the national association, which helps seniors figure out some of the Medicare issues that are out there through a simple software program. We have a very organized information and assistance program through our Area Agencies on Aging and actually the National Eldercare Locator line.

So I think we are headed in the right direction. But, again, the more simple we can keep it for caregivers who are already dealing with a lot, the better we are going to be.

The CHAIRMAN. Thank you both very much.

The hearing is concluded. I thank all my colleagues for attending. Most importantly, thanks to everybody who attended this hearing to bring attention to this very important issue. There was wonderful attendance. Thank you very much.

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



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