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FAMILY CAREGIVING AND THE OLDER AMERICAN ACT: CARING FOR THE CAREGIVER

HEARING

BEFORE THE

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FIRST SESSION

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FAMILY CAREGIVING AND THE OLDER AMERICANS ACT: CARING FOR THE CAREGIVER

THURSDAY, MAY 17, 2001

U.S. Senate,
Special Committee on Aging,
Washington, DC.

The committee met, pursuant to notice, at 9:50 a.m., in room SD–562, Dirksen Senate Office Building, Hon. Larry E. Craig, (chairman of the committee) presiding.

Present: Senators Craig, Ensign, Breaux, and Carnahan.

OPENING STATEMENT OF SENATOR LARRY E. CRAIG, CHAIRMAN

The Chairman. Good morning, everyone. Let me apologize for the committee running a bit late. We had votes scheduled starting at nine and it took us a little longer than normal. Thank you for your patience. We also want to thank you for attending this Senate Special Committee on Aging's hearing on National Family Caregiver Support Program.

Last year Congress passed legislation authorizing the Older Americans' Act. I was an original cosponsor of legislation which updated and amended the Older Americans' Act, and I was extremely gratified after a good number of years of effort that we were finally able to enact and reauthorize.

As part of this reauthorization, Congress added an important and exciting new component to the act. Specifically, this legislation authorized $125 million to establish a new National Family Caregiver Support Program to assist those many daughters, sons, husbands, wives, who are struggling with the daily task of caring for older members of their family.

During our consideration of the reauthorization, we in Congress heard overwhelmingly from family caregivers all over America. Those caregivers let us know loud and clear what their most urgent needs are.

First, respite care, to give family members caring for an elderly loved one a little bit of time away, whether to attend to other family or professional matters, or maybe simply to take a few well-deserved hours of a break.

Second, basic and practical education about the nuts and bolts of being a caregiver. How do you bathe someone who can't walk? Where do you go to get special beds and other needs equipment? Those family caregivers are not formally trained and many are desperate for someplace to turn for answers to basic questions like these.

Third, support and counseling. Caring for an ailing family member can be almost among life's most demanding challenges. It is hard and often a lonely burden. For many in this situation, sometimes as simple as a local support group or a counselor to talk to can be a precious life line that makes the burden considerably more bearable.

At the moment, the States have just recently received their initial funding for the new caregiver program. And most are now in the process of making critical decisions about how the funds will be used.

Our first goal today will be to look at this new program before it gets fully implemented in the States and to assess how the States are setting up their programs. I believe it is imperative we ensure that the new funding be focused as directly as possible on those things the caregivers themselves tell us they need most, namely respite, education and support. Similarly, we must keep a watchful eye to make sure that as many as the new dollars as possible get to the actual caregiver on the front lines rather than simply being used for more agency staff and administration.

Second, we also hope today to examine whether or not the States are receiving the clear and effective guidance they need from the Federal Administration on Aging regarding the program's implementation. Again, I want to thank the witnesses for attending and look forward to hearing your testimony and the advice you have to offer.

[The prepared statement of Senator Craig follows:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Good Morning. Thank you for attending our Senate Special Committee on Aging hearing on the National Family Caregiver Support Program.

Last year, Congress passed legislation reauthorizing the Older Americans' Act. I was an original cosponsor of that legislation, which updated and amended the Older Americans' Act, and I was extremely gratified when it became law.

As part of this reauthorization, Congress added an important and exciting new component to the Act. Specifically, this legislation authorized $125 million to establish a new National Family Caregiver Support Program to assist those many daughters, sons, husbands, and wives who are struggling with the daily task of caring for older family members.

During our consideration of the reauthorization, we in Congress heard overwhelmingly from family caregivers all over America. These caregivers let us know, loud and clear, what their most urgent needs are:

First, respite care—to give family members caring for a elderly loved one a little bit of time away, whether to attend to other family or professional matters, or maybe simply to take a well-deserved break.

Second, basic and practical education about the nuts and bolts of being a caregiver. How do you bathe someone who can't walk? Where do you go to get special beds and other needed equipment? Most family caregivers are not formally trained, and many are desperate for someplace to turn for answers to basic questions like these.

Third, support and counseling. Caring for an ailing family member can be among life's most demanding challenges. It is a hard and often lonely burden. For many in this situation, something as simple as a local support group, or a counselor to talk to, can be a precious lifeline that makes the burden bearable.

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Again, I would like to thank the witnesses for attending and I look forward to hearing your testimony. Thank You.

The CHAIRMAN. Now, let me turn to the ranking member of the committee, Senator John Breaux.

STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Thank you, Mr. Chairman. I am delighted that you are holding the hearing today on something that is very important, and that is the whole question of family caregiving. This committee, under the leadership of Senator Grassley and many of us in the last Congress, was very concerned about the tremendous amount of difficulties families were facing and the whole question of giving that special care through the family support system to senior members of their immediate family and sometimes not so immediate families that need that help and assistance.

And so we were able to have field hearings outside of Washington and talk to real people who understood the nature of these problems. We had hearings in Washington on the concept of a National Family Caregiver Support Act. We were very pleased that we were able to authorize the National Family Caregiver Support Act. It authorized $125 million as part of the Older Americans' Act to be part of this program. I think it is very appropriate now that we take a look to see how is it working, what are the problems, where are the deficiencies? Are States able to participate like we wanted them to, particularly in the area of the matching funds requirement, because, as most Federal programs, it is not just a 100 percent federally financed program, but we require a 25 percent match that has to be put up by the States to get the 75 percent matching funds from the Federal Government.

And I am really concerned that some States and particularly my State may be not using new money to get the Federal match, but are taking money away from existing programs in order to make the match for this new program. That certainly wasn't the intent. We want to encourage States to utilize new dollars as the Federal Government has utilized new dollars to create a program, which I think is a real good partnership with the Federal Government.

So I am delighted. We have a good group of witnesses, one from Louisiana, and look forward to their testimony and working with you to see if we can improve the program. Thank you.

[The prepared statement of Senator Breaux follows:]

PREPARD STATEMENT OF SENATOR JOHN BREAUX

Thank you Mr. Chairman for holding today's hearing on the important topic of family caregiving. Two years ago this Committee held a hearing for the introduction of the National Family Caregiver Support Act, a bill that was successfully authorized as part of the reauthorization of the Older Americans Act last year.

Today we hope to hear more about the implementation of the National Family Caregiver program. The Administration on Aging has been tasked with interpreting the newly enacted legislation and seeing that Federal dollars flow to States in a timely fashion. We know that some States are further along in the development of their family caregiving plans than others.

While state-by-state family caregiving networks are being developed, we want to revisit the original intent of the National Family Caregiver Support Act. I look forward to hearing from real caregivers and those who represent them. Their message is important. We must be sure than in our haste to distribute the money that we listen to those who provide day-to-day care for their family members and that in turn, we create family caregiving support systems to provide meaningful assistance to the wives, husbands, sons, and daughters who care for their aging relatives day in and day out.

Long-term care is one of the most daunting social issues facing our country. By passing the National Family Caregivers Act, Congress has taken a step in the right direction. Much more needs to be done and this Committee will certainly continue to address long-term care needs.

I look forward to hearing from today's witnesses and working with the Administration on Aging on the implementation of one of our country's most exciting and necessary Federal programs.

The CHAIRMAN. John, thank you very much. Thank you for that valuable insight. You are right. We were making every effort to create something new and to expand the role that can be played here. Your point is very well made.

Now let me turn to my colleague from Nevada, John Ensign, for any opening comments he might have. John.

STATEMENT OF SENATOR JOHN ENSIGN

Senator ENSIGN. Thank you, Mr. Chairman. I think that anybody who has had a family member that they have had to care for, and if you haven't, you will, is really the bottom line. It is obvious this committee focuses on the elderly; but, during my last campaign, I had several kind of home meetings with families that had disabled children, and one of the bills that I am looking forward to working with you, Mr. Chairman, that our staffs have been talking together about, is the whole idea of how can we keep people out of institutions for as long as possible and keep them in their homes.

Respite care, things like that the financial burdens on so many of these families, whether they are caring for an elderly person or they are caring for somebody who is disabled. The financial burdens are huge and the question is how can we, in the most efficient manner, give them the financial help that they need, whether that is through possible tax credits, or some of the programs here I think it is very important to be able to keep families together because too often we look at just, those times where institutions are necessary.

But in our society today, we go to institutions too quickly, and so I am looking forward to working with you to keep families together as long as possible for the best quality of life. I think it helps everybody in the family and overall I think we will have a healthier nation for it.

The CHAIRMAN. Well, thank you very much, and we have got a great deal to learn, and with this new program now moving into place, it is appropriate that we monitor it very closely to see how it works and where its deficiencies might be, and how it ultimately becomes implemented.

With that, let us turn to our first panel, and let me ask Norman Thompson to come forward to the table. Norman is the Acting Principal Deputy Assistant Secretary for Aging for the Administration on Aging here at the U.S. Department of Health and Human Services. We are pleased to have you before the committee this morning. Mr. Thompson, please proceed.

STATEMENT OF NORMAN L. THOMPSON, ACTING PRINCIPAL DEPUTY ASSISTANT SECRETARY FOR AGING, ADMINISTRATION ON AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Mr. THOMPSON. Thank you, Senator. Mr. Chairman and members of the committee, thank you for this opportunity to discuss the Administration on Aging's efforts to implement the National Family Caregiver Support Program. We appreciate your leadership and look forward to working with you on this and other issues concerning older Americans and their caregivers.

Mr. Chairman, the past several months have been exciting ones for the Administration on Aging and the aging network. With your support and that of other members of this committee, the Older Americans Act was reauthorized. That reauthorization included the new National Family Caregiver Support Program.

The National Family Caregiver Support Program is the first major new component of the Older Americans Act since the establishment of the nutrition programs back in 1972. For the first time in the history of the Act, there is now a national focus on caregivers as well as care receivers.

AoA was honored that one of Secretary Thompson's first official acts at the Department of Health and Human Services was to authorize the release of $113 million to States to begin implementation of this program.

Attention to the needs of caregivers could not come at a better time. Families provide 95 percent of the long-term care for frail older Americans. Almost three-quarters of informal caregivers are women. Many are older and vulnerable themselves or are running households, employed or parenting children. Estimates for the 1994 National Long-Term Care Survey indicate that over seven million Americans are informal caregivers providing assistance to spouses, parents, other relatives and friends.

Approximately five million older adults with disabilities receive significant levels of services from these caregivers. According to the survey, if the work of these caregivers had to be replaced by paid home care staff, the cost to our Nation would be between $45 and $94 billion per year.

The assistance provided to elderly or disabled friends or relatives may range from bill payment, transportation for medical appointments, food shopping and/or preparation, to more complex personal care.

As our older population continues to grow, especially with the increased numbers expected as a result of the aging of the baby boomers, we can anticipate that the challenge of caregiving will increase as well.

AoA and the national aging network have made good progress in implementing the National Family Caregiver Support Program. This committee knows the caregiver program is based upon the review of the research on caregivers, guidance from professional caregivers and discussions with family caregivers themselves. We looked closely at programs in various States across the country, among them Wisconsin, Pennsylvania, Michigan, and Oregon, and engaged Federal, State and local leaders in our discussion.

AoA convened a series of roundtables with caregivers in more than 30 cities across the United States involving hundreds of caregivers, service providers, policymakers and community leaders. These individuals shared with us their joys in caring for a loved one, their difficulty in accessing services, their unpreparedness for this new and often scary responsibility, their loneliness and isolation, and the compromises they have had to make in juggling careers, families and finances.

As a result of this valuable input, the National Family Caregiver Support Program is designed to be as flexible as possible to meet the diverse needs of family caregivers. We have encouraged States to develop multifaceted programs as required by the statute based on their service delivery network and responsiveness to caregiver needs. We have offered guidance and technical assistance to States and the national aging network to help them understand and utilize the National Family Caregiver Support Program's flexibility to design their system of best meet the needs of their communities.

The National Family Caregiver Support Program is comprised of five service categories. The first is information about health conditions, resources and community-based long-term care services that might best meet a family's needs. Second is assistance in securing appropriate help. Third is counseling, support groups and caregiver training to help families make decisions and solve problems. The fourth is respite care so that families and other informal caregivers can be temporarily relieved from their caregiving responsibility. And finally supplemental services on a limited basis. This could include a wide range of services, designed to support the efforts of caregivers. Examples from state-funded programs include such supports as home modifications, incontinence supplies, nutritional supplements and assistive devices.

The legislation targets family caregivers of older adults and grandparents and relative caregivers of children not more than 18 years of age. It also directs that States give priority to services for older individuals with the greatest social and economic need, with particular attention to low-income older individuals and older individuals providing care and support to persons with mental retardation or who have related developmental disabilities.

The $125 million we received in fiscal year 2001 will enable State, local and tribal programs to provide services to approximately 250,000 of America's caregivers. We have distributed $113 million to States. An additional $5 million is designated to assist caregivers of Native American elders and will be released shortly in accordance with the guidance AoA received from tribal listening sessions held recently.

Very soon AoA will also announce the availability of almost $6 million for competitive innovative grants and projects of national significance. These projects, once awarded, will demonstrate and test new and diverse approaches to caregiving providing us and the aging network with knowledge that will be critical to the future success of the program.

The remaining $1 million is being used for technical assistance to the aging network to provide state and local programs with the tools to be responsive to family caregivers. These include a national technical assistance conference to be convened in Washington, D.C., on September 6 and 7; a moderated Listserv, on which expert researchers prepare monographs on specific issues related to caregiving and enter into a dialog with the aging network on how best to respond to that issue in our country; an expanded webpage with the most recent caregiver information; and other educational and public awareness initiatives.

We have also recently completed a series of bio-regional video conferences with all the States to discuss and clarify issues related to the implementation of the program. In addition, we presented promising approaches from various caregiver programs throughout the country that would be helpful to States and area agencies on aging as they design their programs.

For fiscal year 2002, the budget request for the caregiver program is $127 million, an increase of $2 million over fiscal year 2001, to help to maintain the current level of services for caregivers as our program takes hold.

Looking forward over the next year, AoA is committed to developing partnerships with our sister Federal agencies and other national organizations to further the caregiving agenda; to implementing a public awareness campaign to inform America of the importance of caregiving and to encourage caregivers to seek assistance and training as they begin their caregiving careers; and finally continuing to provide the aging network with assistance and support to better serve our caregivers.

Mr. Chairman, we appreciate this opportunity to share our progress on the implementation of the National Family Caregiver Support Program, and we look forward to working with you to meet the challenges and take advantages of the opportunities to support America's families.

I would be happy to address any questions you may have.

[The prepared statement of Mr. Thompson follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Washington, D.C. 20201

Statement of

Norman L. Thompson

Acting Principal Deputy Assistant Secretary for Aging

U.S. Department of Health and Human Services

Before the

Special Committee on Aging

United States Senate

May 17, 2001

Mr. Chairman and Members of the Committee:

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- **Respite care** so that families and other informal caregivers can be temporarily relieved from their caregiving responsibilities; and

- **Supplemental services** on a limited basis. This could include a wide range of services designed to support the efforts of caregivers. Examples from State-funded programs include such supports as home modifications, incontinence supplies, nutritional supplements and assistive devices.

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The remaining $1 million is being used for technical assistance to the aging network to provide State and local programs with the tools to be responsive to family caregivers. These include a national technical assistance conference to be convened in Washington, DC on September 6-7, 2001; a moderated Listserv, on which expert researchers prepare monographs on specific issues related to caregiving and enter into a dialogue with the aging network on how best to implement that issue in our country; an expanded webpage containing the most recent caregiver information and resources; and other educational and public awareness initiatives.

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Over the next year, AoA is committed to:

- Develop partnerships with our sister Federal agencies and other national organizations to further the caregiving agenda;

- Implement a public awareness campaign to inform America of the importance of caregiving and to encourage caregivers to seek assistance and training as they begin their caregiving careers; and
- Continue to provide the aging network with assistance and support to better serve our caregivers.

Mr. Chairman, we appreciate this opportunity to share our progress on the implementation of the National Family Caregiver Support Program, and we look forward to working with you to meet the challenges and opportunities to support America's families. I would be happy to address any questions you have.

The CHAIRMAN. Well, Norm, thank you. We appreciate that testimony. Obviously, AoA has played a critical role on formulating the new program and I am glad that you are here to give us the perspective of the current status. According to a question and answer sheet from your agency, regulations and guidance for new amendments to the Older Americans' Act to the States are to be issued in three components: initial and ongoing guidance; regulations; and technical assistance.

What are you doing currently in those three areas?

Mr. THOMPSON. We have done a number of things. At the beginning of this year, we issued initial guidance to States on the requirements of the statute, as well as information on how to apply for funds. We made the grants available in February. On an ongoing basis, we have been answering questions that States and local providers have been asking us. We have compiled the most frequently asked of those questions into a frequently asked question document that we have made available on our website.

We have held video teleconferences throughout the country to explain the requirements of the statute and to share information on the program. We do anticipate the need for regulations on the Older Americans' Act that was reauthorized last year. That reauthorization made some changes in the statute that need to be reflected in regulation. So we are making progress on that, sir.

The CHAIRMAN. Are you at a point of looking at how you will monitor the inputs that you are now putting out and the States' activity, how you will monitor outcomes? Have you talked about that?

Mr. THOMPSON. Yes, sir. We are looking at that from a variety of perspectives. We are in the process of making major improvements in our Government Performance and Results Act (GPRA) activities. We anticipated the need a couple of years ago to include caregiving as part of our GPRA measures and last year we pilot tested some caregiving related GPRA measures in five States and got very promising results from that.

We intend to expand that as this program rolls out. So we will be getting feedback that way. We are also in the process of putting out a reporting requirement to States to gather information on how the funds are spent.

In addition to that, we are in constant communication with States and local service providers and area agencies on aging, entering into dialog with them on how they are doing with the program, what problems they are finding, how can we be of assistance to them. And we think those are all very important ways to get feedback on how this program is operating.

The CHAIRMAN. In your testimony, you mentioned that conferences with the States were held to discuss issues related to the program. What were some of the specific issues brought to your attention? That would be my first question, Norm, and then whatever measures are being taken, if any, to explore the effectiveness of the National Caregiver Program or Support Program and to receive input from the States as we move?

Mr. THOMPSON. We received the types of questions that you are normally going to get when a new program comes out: questions about what does the statute actually say; what does it require; how does this program relate to other programs; questions across the board. Again, we held a number of video conferences, too, to try to answer those questions. We have packaged the most frequently asked questions on our website to make that information available to the world.

So we have tried to be very responsive and also very respectful of the fact that the statute provides States with a wide range of flexibility, which we think is very appropriate given the diverse needs of the caregiver population.

In terms of follow on to that, we have a number of activities under way. I have mentioned the conference which I think is a very important way of getting this information out to folks. We also are putting together a program handbook, parts of which will be distributed at our conference. The rest of the document will be completed by the end of this calendar year, which will put together best practices and some of the research that is available to help States and local agencies design their programs, make sure they are incorporating the latest from the research community and the scientific community in the design of their programs.

The CHAIRMAN. Norm, thank you. Let me turn to my colleague, John Breaux. John.

Senator BREAUX. Thank you, Mr. Chairman. Thank you, Mr. Thompson. You know your testimony points out something that is a very interesting statistic that I think with all of the hearings that we have and the Finance Committee on Medicare and nursing homes and home health care services, we don't realize that families still provide about 95 percent of the long-term care for seniors in this country. That is a huge number. And we spend so much time talking about nursing homes and quality of care in nursing homes, whether they are meeting new standards. That is all very important.

But yet still 95 percent of the care is provided by families to people within their family. We are part of that 95 percent. My mother-in-law lives with us and she sort of thinks she cares for me, which is just great, and it is kind of a shared responsibility there so it works out fairly well.

But that is the situation that most Americans find themselves in. Is there any Federal guidance coming from your agency with regard to how the States go about reaching their 25 percent match? Is there any guidance as to whether they can simply subtract money from other existing aging programs and use that to match the 75 percent Federal grant?

Mr. THOMPSON. There is guidance certainly in the statute, and in the departmental grant regulations that pertain to that, Senator Breaux.

Senator BREAUX. And what does that guidance say?

Mr. THOMPSON. The guidance states there is a requirement for a 25 percent match that must be either cash or in kind. In the National Family Caregiver Support Program legislation, there is a provision regarding non-supplantation of existing spending, which would have a bearing potentially on the issues you have raised.

Senator BREAUX. And what does that mean?

Mr. THOMPSON. That means basically that a State cannot take money and substitute it for preexisting State expenditures.

Senator BREAUX. Is that in the act?

Mr. THOMPSON. It is in the act, sir.

Senator BREAUX. Is it in the guidance, the Federal regs?

Mr. THOMPSON. Yes, sir. We have no regulations out at this time. The question has come up in a variety of forms in the earlier discussions I mentioned, and we have put out questions and answers relating to that issue.

Senator BREAUX. Have you addressed that issue particularly?

Mr. THOMPSON. Yes, sir.

Senator BREAUX. And what was your question and answer guidance on that?

Mr. THOMPSON. The guidance is clear that you cannot reduce expenditures in preexisting programs with respect to the Federal funds.

Senator BREAUX. Suppose a State does that, what happens?

Mr. THOMPSON. If the State does that, it would not be in compliance with the statute, and we would certainly have discussions with the State to try to remedy that situation. If the situation were to continue, it would put funding at jeopardy for the State, sir.

In addition, I might mention in other portions of the Act, for example, in the Title III, Nutrition and Supportive Services section of the statute, there are maintenance of effort requirements as well so that the reduction of funds from one section of the statute to the other would also raise some questions we would have to look at.

Senator BREAUX. I think Senator Craig and myself probably are concerned and would be generally opposed to unfunded mandates to States requiring them to do things by Federal regulation and not giving them any financial assistance to do so. How does that differ in this case?

Mr. THOMPSON. In general, most Federal programs require some form of non-Federal share. That is a fairly standard approach. It is one that we think is good government, good management. It is a way of assuring that the State or the local agencies have a vested interest in the efficiency and the effectiveness of the program. So we certainly agree with the matching requirement.

Senator BREAUX. I mean this is not a mandate on the States to do any of this.

Mr. THOMPSON. Right.

Senator BREAUX. I mean it is an option that they can take if they want to participate, but there are Federal guidelines that say, as I understand it, that you are not allowed to take money from other existing programs in order to create your match to participate in something that is not mandated.

Mr. THOMPSON. That is correct, sir.

Senator BREAUX. OK. What about the question of respite care, something that we talked about in this committee when we were writing the act that we thought was important, just the use of some type of help just to give caregivers a break? I mean this is in some cases—not mine—but in some cases people really need just to get away, whether it is for one day or one night or one evening or what have you, and the idea was to be able to provide some type of assistance so that someone may acquire somebody to come into the home and help give them a break.

First what do you think about that? Second, is it being implemented? Or third, is it being discouraged?

Mr. THOMPSON. We think that is the critical part of the statute. It is one of the five services that States must provide. There is a substantial body of research evidence that indicates that respite care combined with other services can have very favorable outcomes both for the caregiver and the care recipient. So we think that is a critical component of the program.

States are required to have multifaceted programs and provide the five services that are listed in the statute, and we believe States are doing that. We would certainly encourage that. Again, the research is very clear that there is no single approach here that works in all cases that may even work for a single individual. But you need a broad array of services to provide help to a range of caregivers.

Senator BREAUX. You mentioned, I take it, that the guidelines are not out yet. When do we expect them to be?

Mr. THOMPSON. Again, sir, we have put out what we call frequently asked questions as well as guidance to States on the basic implementation of the program, the Federal requirements that derive from the statute, and we will be putting out a program handbook that summarizes the best research and practice available to us in the country later this year.

We believe that there is sufficient guidance out now for States to plan and implement their programs.

Senator BREAUX. But more will be coming in terms of the handbook that is coming out?

Mr. THOMPSON. Yes, sir. And the guidance, again, we are looking at guidance in perhaps two different ways. We are looking at guidance on the basic requirements of the statute; what does the law require a State to do? And we believe there is sufficient guidance there, as I mentioned, for States to plan and implement their programs.

We are also very concerned, because we want this program to be just as effective as possible, so we are trying to provide guidance in a way of information on the best science, the best research results, the best practices out there, and to make that available to States on a continuous basis, because frankly we are learning about the needs of caregivers and how best to respond to those needs everyday. So we try to make that information available to States and local agencies to help them plan their programs and run their programs better.

Senator BREAUX. OK. They need the guidance, but they need the flexibility. I mean obviously what works in one State may be adaptable to another State so we need to give them the maximum flexibility within some type of a broad framework of guidance. I mean that is what I think we could all agree we need, but they need guidance because they want to make sure they are doing what is appropriate and proper, but it does not have to be a one-size-fits-all set of regulations or guidance. I mean that is what we should strive for and I am certain that you will be doing that. Thank you very much.

Mr. THOMPSON. Thank you sir.

The CHAIRMAN. Norm, thank you for your time. This committee will stay close to you and the AoA as this program develops. We will want to monitor it closely and see what kinds of trends develop in the States as to where they may choose to go with this program because I think, as John has said, we have offered reasonable flexibility in it, and I think all of us are anxious now to see if we have read the public right and where they will go or if we need to make some adjustments down the road. But once again thank you very much for being with us this morning.

Mr. THOMPSON. Thank you, sir.

The CHAIRMAN. We appreciate it.

Let me call our next panelist, Helen Hunter. Helen is the wife of the late Jim "Catfish" Hunter, member of the board of directors of the Jim "Catfish" Hunter ALS Foundation of Hartford, NC. All right. That is our first panelist of this panel.

Our second panelist will be Sandy Tatom. Sandy is a family caregiver from Boise—my home State. She is joined by her husband Dean Tatom. I understand, Dean, you are just there for moral support; is that right?

Mr. Tatom. Yes.

The CHAIRMAN. Wonderful. We are pleased to have you with us today—all three of you. Helen, if you would pull that microphone as close as is comfortable so that we and the audience can hear you and our recorder can. Please proceed.

STATEMENT OF HELEN HUNTER, WIFE OF THE LATE JIM "CATFISH" HUNTER, MEMBER OF THE BOARD OF DIRECTORS OF THE JIM "CATFISH" HUNTER ALS FOUNDATION, HARTFORD, NC

Ms. HUNTER. Thank you, Mr. Chairman and members of the committee for letting me speak today. I am here on behalf of the ALS patients and caregivers. I have a lot of people who have come to stand behind the ALS patients and caregivers today. I would like to just mention some of them. Steve Burline, Steve Garvey, Michael Gross, Steve Stone and Michael Nurry and Jay Johnston have all come to support our effort for caregivers.

My husband was diagnosed with ALS in 1998 and died from this terrible disease in 1999 in September. It is hard to see your loved one go through this stage of disease because he had always been a very independent do-everything person, and to see them lose control of not being able to feed yourself, bathe yourself, help get up in and out of bed, you do not realize how much they can't help you when you have to pull and tug on them, and you are wanting to do all you can for them, but sometimes you don't know if you are meeting all of their needs.

And I want to help all these caregivers out here and all of the ALS patients because we need your help and we need your money to do this. An ALS patient needs a trained person to help take care of them because the stages of the disease as they progress, you have to have different like nurses and different things to come in and help take care of that.

I was very fortunate, Jim and I were, to have insurance that helped take care of our things, but a lot of people do not have that. And like Rulitek, he was on that, and that cost $800 to $900 a month, and some people don't take it because they cannot afford it. And I think we should think about this disease because any one of us, myself included, could get this terrible disease. It is not just linked to any race or any one kind of person, and you need to think about this, and it could be in my family still. I am not sure because of Jimmy having it, and that worries you thinking that your own children could have it themselves.

I wanted to thank you for letting me come speak. I am a little bit nervous because I have not talked in front of a committee like this before.

The CHAIRMAN. You are doing well. Thank you, Helen.

Ms. HUNTER. But we had like a group from Blue Cross/Blue Shield who called our chapter who needed help for someone, but they didn't know about how to go about telling them, so that is a big company, and when they need help, I think it is time for the caregivers to get some more help and the ALS patients. And see my husband was 53 when he died so it is not just older people because people with ALS are getting it younger and younger it seems like, and you do not usually live but 2 to 5 years.

There are some cases where they do live longer, but it is hard to deal with when you see somebody you love, especially if it is a friend, your loved one, or a relative. If any one of them gets it, it affects you in that certain way and you become a big advocate for this disease. So I appreciate you listening to me and thank you for your time this day.

[The prepared statement of Ms. Hunter follows:]

Senate Special Committee on Aging

Hearing on "Family Caregiving and the Older Americans Act: Caring for the Caregiver"

Testimony

Presented by Helen Hunter

Thursday, May 17, 2001

9:30am, Dirksen Senate Office Building, Room 562

My name is Helen Hunter -- I am a caregiver, and a survivor. My husband Jim "Catfish" Hunter was diagnosed with ALS, more commonly known as Lou Gehrig's disease During the illness, he was unable to do the simple things for himself that we take for granted. I became his hands -- I fed him, I combed his hair and assisted him with all activities of daily living.

I am grateful to have been asked to speak at today's hearing, on behalf of The ALS Association and the Jim "Catfish" Hunter ALS Foundation. This hearing is important in that it will help raise awareness for the National Family Caregiver Support Program – one of the most important components of reauthorization of the Older Americans Act.

Being a primary caregiver is difficult as it takes its toll on the **whole** family. You worry that all the needs are met, all the while the person with ALS worries about the burden they are putting on the family. Properly trained help to assist ALS patients and caregivers is a real need that is not being met for the ALS family at this time.

(more)

More needs to be done for ALS. We need to find a cause, we need to work on a cure, and just as important, we need to assist those impacted by this fatal disease – the ones living with this dreadful disease, 24 hours a day, seven days a week.

ALS could strike any one of us. My husband died on September 9, 1999. If he were still with us he would be here to tell you the same message. Now it is **our** responsibility to speak for those silenced by this disease.

No one knows how terrible this disease is until you have a friend, loved one or relative be told "Go home, get your affairs in order, you have ALS, we don't have a cure."

We will help to give those persons a reason for hope and help them live with ALS and support those who so unselfishly give care. In reauthorizing the Older Americans Act, Congress has brought new life to those who are truly giving their lives for the lives of others. Providing grants to states to provide information and services to family caregivers is of **utmost importance**, as it will mean a great deal to those families where being the primary caregiver is NOT the only job, but one that must be done no matter what.

Thank you very much for this oppurtunity to speak to you on behalf of all person's diagnosed with Amyotrophic Lateral Sclerosis, as well as the more than 26 million caregivers who now currently need the support you are offering to sustain them, so they may continue providing relief to others.

Sincerely,

Helen O. Hunter

The CHAIRMAN. Helen, thank you. Before we ask questions of you, I want to turn to Sandy Tatom, a family caregiver from Boise, ID. Sandy, again, if you would pull the microphone as close as is comfortable, please proceed, and welcome to the committee.

STATEMENT OF SANDY TATOM, A FAMILY CAREGIVER, BOISE, ID; ACCOMPANIED BY DEAN TATOM

Ms. TATOM. Mr. Chairman and Senator Breaux, my name is Sandra Tatom and this is my husband Dean. We are from Boise, ID and we are caregivers for Dean's mom. I am nervous, too.

My 87-year old mother-in-law has not been able to live alone for approximately 10 years. She has lived with us for 6 months or more each year and other family members in her hometown the remainder of the time. This situation has changed recently.

Mom had been in the hospital in her hometown for 2 weeks when my husband went down to see her in February of this year. She had not been out of bed in those 2 weeks, and Dean got her out of bed, out of the hospital, and soon had her back in Boise. We believe this visit will be a permanent one. The family members in her hometown are not able to keep her anymore.

When mom got to our home in February, she was not able to walk without help. She was incontinent and totally confused, and Dean and I did not have a clue how to take care of her. We could have used a class in Caregiving 101. It was very difficult to do the bathing and feeding and bathroom assistance while still leaving her some dignity.

Dean is a retired school teacher and I work full time so the caregiving during the day is his. He needs a break in his caregiving and affordable quality respite care is hard to find. Often I have wished there was someone we could call to consult regarding the certain different stages mom is going through. Our community has a dial-a-nurse for medical questions. We could use a dial-a-caregiver for caregiver questions.

We realize there are activities we have to forego in order to care for mom, but we know we have years ahead to do those activities. But one of the big decisions we had to make was did we want to give up our business? It took us time to build this business, and it is not something that we can put on the shelf and pick up later. We have a motor home and a trailer and we travel to shows and pow wows on weekends and set up a booth and sell the southwestern and Native American products.

Our goal is to supplement our retirement and pay for our travels. Mom went with us last year and we always made sure our motor home was next to our booth where we could watch and help her if she needed us. Our dilemma now is will she be strong enough to travel with us this year?

If unable to do so, we need affordable weekend care for her. This care could be having someone come into our home on weekends and stay with mom or finding an affordable adult care facility where we could leave her for the weekends. Affordable is of foremost concern. We have checked around and in-home care costs approximately $150 a day. The adult care centers which will take people for short-term care costs between $75 and $150 a day. Available beds in these facilities are real limited. Our business is just getting started and we cannot afford to pay that much.

We have heard from other caregivers that occasional affordable weekend care or respite would be very beneficial for the caregiver's sanity. Employees work 40 hours a week and they have their weekends off. Caregivers work 168 hours a week and with no weekends off.

We have learned the benefit of attending support groups, but there is a problem in finding affordable care for the loved ones while attending the meetings. I have talked to people who were or still are caring for their loved ones at home. A friend of ours from Council, ID, a rural logging and ranching community, 125 miles from Boise, had taken care of her husband at home. He had Alzheimer's. My friend had her own business and had difficulty finding someone to stay with her husband during the day.

She could find no one to stay at night so she could sleep and she finally had to place her husband in a facility because she was just worn out. There are other people I know of who live in rural areas which receive little or no respite care for the caregivers.

Mom has taken care of us through the years with total unselfish love and we are glad that we are able to care for her now. She has adamantly hoped that she would never have to go into a facility, and this is the last thing we want to do for mom. We hope and we will try with all our power to keep her with us. I know there are many people who have been at this intense caregiving stage longer than we have, and they need respite and help.

We are not looking for nor do we wish to have a give-me program, but the availability of affordable respite would help us and many like us keep our loved ones at home. We believe funding of the National Family Caregiver Support Program would be less expensive than paying for facility care.

[The prepared statement of Ms. Tatom follows:]

TESTIMONY

of
Sandra Tatom
Caregiver from Boise, Idaho

Before

THE UNITED STATES SENATE SPECIAL COMMITTEE ON AGING

Regarding

Needs of Family Caregivers

Washington, DC
May 17, 2001

May 17, 2001

Mr. Chairman and members of the committee, my name is Sandra Tatom and this is my husband Dean. We are here from Boise, Idaho and we are caregivers for Dean's mom.

BACKGROUND

My 87 year old mother-in-law has not been able to live alone for approximately ten years. She has lived with us six months or more every year and with other family members, in her home town, the remainder of the year. We would have her for about three months and fly her home for a couple of months when she got tired of us. She is a woman of quiet dignity and fierce pride and she was "doing her part" by making beds and folding clothes. She always went everywhere we went and insisted on walking as far as she could before riding in the wheelchair.

This situation has changed recently. Mom had been in the hospital, in her home town, for two weeks when my husband, Dean, went to see her in February, 2001. She had not been out of bed in those two weeks. Dean got her out of bed, out of the hospital and soon had her in Boise. We believe this visit will be permanent. The family members, in her home town, are not able to keep her anymore.

NEEDS

When mom got to our home in February, she was not able to walk without help, was incontinent, and totally confused. Dean and I did not have a clue as to how to care for her. I went to the store to find diapers and was overwhelmed by the vast array of products available. We could have used a class in *Caregiving 101*. It was very difficult to do the bathing, feeding, and bathroom assistance while still leaving her some dignity.

Dean is a retired school teacher and I work full time so the caregiving during the day is his. He needs a break in his caregiving and affordable, quality respite care is hard to find. Here again *Caregiving 101* would have been beneficial. Mom has improved somewhat since she has been in our home, but she has her good and bad days. Often I have wished there was someone I could call to consult regarding certain stages she is going through. Our community has **Dial a Nurse** for medical questions, we could use a **Dial a Caregiver** for caregiver questions.

We realize there are activities we will forgo in order to care for mom, but we know we have years ahead to do those activities. One of the big decisions we had to make was; did we want to give up our side business? We hope to continue with our one year old business. It took time to build this business and it is not something we can just stop now and pick up later. We have contacts, a customer base which we are building, money tied up in inventory, and we can not just put the business on a shelf and pick it up later.

We have a motorhome and trailer and we travel to shows and Pow Wows on weekends, set up a booth and sell southwestern and Native American products. Our goal is to supplement our retirement and pay for our travels. Mom went with us last year. We always made sure the motorhome was next to our booth where we could watch and help her as needed. Mom has always been a "goer" and enjoyed last year's trips. There were times she would be confused and not know what town or state we were in, but as long as she was with us she said she was happy. Our dilemma now is will she be strong enough to travel with us this year? If unable to do so, we need affordable weekend care for her.

This care could be: having someone come to our home on weekends and stay with mom, or finding an affordable adult care facility where we could leave her for the weekends. Affordable is the foremost concern. We have checked around and in-home care cost approximately $150 per day. The adult care centers, which will take people for short term care, cost between $75 and $150 per day. Available beds in those facilities are limited. Our business is just getting started and can't afford to pay that much for her care, and we personally can not afford it either.

We have heard from other caregivers that occasional, affordable weekend care or respite would be very beneficial for the caregiver's sanity. Employees work 40 hours a week and have their weekends off. Caregivers work 168 hours a week with no weekends off.

SUPPORT GROUPS

The benefits of support groups were unknown to us. We did not realize that others were experiencing the same problems, worries and upsets we were experiencing. The first support group meeting we attended was connected to a retirement home and the members of the group had already placed their loved ones in the home. Dean went to a new support group meeting last week which was attended by people who were still in the "home-caregiving-stage." The majority of these people have been caregivers longer than us and were able to offer excellent advise in many areas. If we had a **Dial a Support Group** or Support Group 101, we might not have had to reinvent the wheel on our own.

The problem with attending and receiving the benefit of the support group meeting is finding affordable care for the loved one while attending the meeting.

OTHER CAREGIVERS' NEEDS

I have talked to friends and acquaintances who were or still are caring for their loved ones at home. A friend of ours from Council, Idaho, a rural logging and ranching community, 125 miles from Boise, had taken care of her husband, with Alzeimers, at home. My friend had her own business and had difficulty finding someone to stay with her husband during the day. She could find no one to stay at night so that she could sleep. She finally had to place her husband in a facility because she was worn out.

Another friend from Council had to drive her mother to Ontario, Oregon, (about 70 miles) every day so that she could receive dialysis. This friend worked full time which forced her to admit her mother into a facility closer to treatment.

Another care giver from Council, who takes care of her ailing husband, said she has to have someone come who could get him into the car and take him for a drive. She just wanted a few hours at home alone.

These are a few cases of people I know who live in rural areas which receive little or no respite care for the caregivers. I am sure there are many, many more such cases.

CONCLUSION

Mom has taken care of us through the years with total unselfish love and we are glad that we are able to care for her now. She has adamantly hoped she would never have to go into a facility. The people are too old and she would have nothing in common with them, she has always said. This is the last thing we want to do for Mom and we hope and will try with all our power to keep her with us. I know there are many people who have been at this intense caregiving stage longer than we have and they need respite and help.

We are not looking for nor do we wish to have a "give me program," but the availability of affordable respite would help us and many like us keep our loved one at home. We believe Funding of the National Family Cargivers Support Program would be less expensive than paying for facility care.

The CHAIRMAN. Well, Sandy, thank you very much for that testimony. I think it demonstrates what so many people are going through and the clear need for help.

Helen, thank you for being here. I know that you are in town attending an ALS meeting, commonly known I think to most of us as Lou Gehrig's disease, and I do appreciate your taking time to come and provide us with your insight today.

I think all of us, well, at least many of us, knew of your husband by his reputation as a fine ballplayer, the Oakland A's and the New York Yankees, the winning of so many games, 224 I am told, pitched in six of the ten World Series in the 1970's, and earned five World Series rings, and won the Cy Young award. Those kinds of situations that you went through with your husband are very tragic, and to have the kind of relief and help that you talk about is so very important.

As you know, I think the National Family Caregiver Support Program will hopefully provide relief and information to caregivers this year for the first time. How would this type of program have been beneficial to you most and what services or information did you most need when you were a caregiver?

Ms. HUNTER. Well, I think it would have benefited me some, but I did have insurance. Jimmy did have good insurance. And so that helped us out a lot. But there are so many who do not, and I really didn't know a whole lot about the disease when he first was diagnosed because you have to eliminate everything else. We went to so many doctors. You have to eliminate everything before they can really finally diagnose you with ALS.

And home health care did come in and help us and we had a hospital bed because it was hard for him to sleep laying just flat, and the hospital bed helped that way. He had not gotten to the later stages as a lot of people have. And they have to have a lot more things to help them out.

So I am just thankful we did have insurance, but the other people who do not really need this to help. I mean they have Hoya lifts that they have to get to lift them. They need the wheelchairs. Sometimes they have to redo their houses, get vans, you know, to take them in. We did have a van, and I was able to help, you know, get him in it, but it is just very hard for any caregiver to do all these things because I said most of the focus is on the patient and people a lot of times don't think about the caregiver, and you do not think about it either when you are doing it, because you do it because you love them and you are wanting to do it for them. But people just don't think about that person at the time, but they do need all these things.

The CHAIRMAN. Well, thank you very much. This is very valuable insight. That is right. We almost always think of the failing or ailing person and the disease that he or she may have and the infirmities of that, but it has certainly been our experience, and I witnessed it first hand, the phenomenal fatigue and oftentimes distress that occurs with that loved one who is providing the care, and that is, of course, why we have moved the way we have here.

Sandy, your being willing to be here and offer testimony is really very valuable to us as we monitor the implementation of this program. What I think I heard you saying was that both you and Dean really did need a class in Caregiver 101.

Ms. TATOM. 101, yeah. Education.

The CHAIRMAN. And I suspect that tens of thousands of Americans end up needing that on a yearly basis, and of course that is part of what we hope this program can offer. Could you tell us how you and your husband have had to adapt your daily lifestyle? I know you have talked about the frustration of the flexibility of the working and running your business, but your daily lifestyle obviously has had to change because you have chosen to become caregivers.

Ms. TATOM. Well, I think to begin with, we had to give up skiing because, you know, there was no one that she could stay with while we were up on the slope. We try to include her in as many activities as we can. Dean was going to take his little boat out on the reservoir, and I said you can't do that, you have to take care of mom. He said I am going to take her with me. She enjoyed it. She enjoyed it.

So we try and include her as much as we can, but before she was there permanently, when I would get home from work, we would go to the gym together. Well, someone has to stay home and we have to go singularly. And there are just different activities. We talk about traveling and stuff. Oh, we can't do that right now. So, you know, most of these things we can do later. I mean, you know, that is important. So it has changed a lot of the activities.

There are days that someone has to be in the room or very close by so that she does not get up and fall. So we cannot both of us go out and work in the garage or in the yard and, you know, just different activities that someone has to be on standby, but like I say, we try and take her every place we can take her and go as much as we can and we get her to push the wheelchair as far as she can and then we push her and try and keep her as active as we can.

The CHAIRMAN. Obviously, it has changed your lifestyle a considerable amount and that is a choice you have made. If you were designing a program to provide support for people like yourself, what would be the single-most important ingredient or item that you would want to see in that?

Ms. TATOM. Well, if I was designing Caregiving 101, I think a few basics to start with: what type of products to use? I mean I went to the store and was hit by a vast array of products. I am standing there saying, OK, now what? Education in different stages, different things where my husband and I can realize, you know, others have been there. We are not reinventing the wheel. We are listening to others that have been there before we have, and they can help us. Education in the different steps and stages that we are going to be facing because each one is new to us and we just do not know what we are looking at down the line.

The CHAIRMAN. Well, thank you both. Let me turn to my colleague, John Breaux.

Senator BREAUX. Thank you very much, Mr. Chairman, and Mrs. Hunter and Mrs. Tatom, and Mr. Tatom, thank you for being with us as well. Mr. Chairman, I am informed that along with Ms. Hunter, she had a group of celebrities that are with us attending, and maybe we could just ask them if I call out their names if they would stand up.

The CHAIRMAN. Well, thank you for reminding me of that. That is right.

Senator BREAUX. They are here, as I understand, also for the ALS conference in Washington. We are delighted to have them in Washington. We are particularly delighted to have them with us at the committee and if we maybe just ask them to stand so everybody can know that they are here for a very important conference.

Steve Garvey played a little baseball in his time. Good to have you here.

The CHAIRMAN. Yes, welcome.

Senator BREAUX. Steve Burline, played a little quarterback in football days. And Jay Johnston is another former great baseball player. Delighted to have him.

The CHAIRMAN. Thank you.

Senator BREAUX. And Steve Stone, another player and former Cy Young award winner as well, delighted to have him. We also got a couple of folks from the acting world we are delighted to have as well. Michael Norry from Flashdance, which I have seen. I thank him for being here. And also Michael Gross——

The CHAIRMAN. He used to be a football player, yeah.

Senator BREAUX [continuing.] From Family Ties. Michael, thank you for being here, too.

The CHAIRMAN. Oh, yes.

Senator BREAUX. Delighted to have all these people. Oh, yes, now you recognize him. Oh, yeah. [Laughter.]

Mr. GROSS. We are all a little older.

Senator BREAUX. Yeah. Delighted to have you all here. [Applause.]

I think we have all had that statement made to us: I recognize you but I don't know who you are. [Laughter.]

Delighted to have all you folks here.

The CHAIRMAN. Thank you for doing that, John. Welcome.

Senator BREAUX. To the panel, Ms. Hunter and Ms. Tatom, thank you for what you have done and thank you for sharing that experience with us. We spend so much time, I guess, in Congress and in government talking about how to extend the lives of individuals, and that is very important, and medical science is doing wonderful things with advancement of drugs and treatments and cures for diseases that in the past were thought to be always incurable, but I think that we cannot lose fact that we also have an obligation not just to get people to live longer, but also to help them live better lives.

And really when it comes to the question of caregiving, that is really what we are talking about. Medical science can extend a human's life for a very long time. The question is what is the quality of that life? And I think that whole thing we were talking about with the home caregivers program was to help families help their family members live better lives by helping to improve the care that they receive.

I was interested, Ms. Tatom, maybe out in your more rural part of America, you don't have a Council on Aging that can help provide that information, but one of the things I would expect and hope the Councils on Aging are able to do is to help families who are involved in caregiving by giving them the hints and the help and the assistance. Maybe you don't have that out in your more rural area?

Ms. TATOM. I am finding that there is information out there. It is just initially it was very difficult for me to locate and I am finding more and more. Like I said in my little talk, it would be nice to have a dial-a-caregiver that you could call like dial-a-nurse, and I have a headache and can you help me? Or my mother-in-law has this and what is going on?

Senator BREAUX. Well, there should be. That is one of the things that the council should do, I mean the aging administration, to make sure. People need information. This is not rocket science. Other people have done this before us, and we need to learn by their experiences and know what has worked for them, where they have had problems, and here are other people's experiences. So that when it happens to you, you will know how to respond to it. And I would really encourage the Administration on Aging to really make sure that some of the funds we use are for information purposes to let people know what is out there from a help standpoint.

Where can you go when you need extra help? And then provide that very important information that I think is so, so critical, but I thank both of you for sharing your experiences with us and with the rest of the country really, and so we can come up with some better ideas. So we appreciate your being here.

Ms. TATOM. Thank you.

The CHAIRMAN. Helen, Sandy, Dean, thank you all for being here and taking time to offer testimony. We appreciate it.

Ms. HUNTER. Thank you.

The CHAIRMAN. Now let us call our third panel. Suzanne Mintz, President, National Family Caregivers Association in Kensington, MD; Deborah Briceland-Betts, Executive Director, Older Women's League of Washington, DC.

My colleague, do you want to introduce——

Senator BREAUX. Oh, sure. Yeah, absolutely. And delighted to have Kristin Duke as our Executive Director of Central Louisiana Area Council on Aging from Louisiana and hear about some of our concerns from our State. And we are delighted to have her as well. Thank you.

The CHAIRMAN. Thank you all again for being here. Suzanne, we will start with you.

STATEMENT OF SUZANNE MINTZ, PRESIDENT, NATIONAL FAMILY CAREGIVERS ASSOCIATION, KENSINGTON, MD

Ms. MINTZ. Mr. Chairman, members of the committee, thank you for this opportunity to speak to you today. Written testimony has been submitted for the record. My name is Suzanne Mintz, and I am the President and Co-Founder of the National Family Caregivers Association, NFCA, and I am also a family caregiver myself.

NFCA exists to educate, support and empower family caregivers and speak out publicly for meeting caregivers' needs. NFCA reaches across the boundaries of differing diagnoses, different relationships and different life stages to address the common concerns of all family caregivers.

Our members care for spouses, children, aging parents, siblings, friends and others. Half are caring for seniors 66 or older, and most are heavy-duty caregivers meaning they are providing hands-on care on a daily basis, helping loved ones dress, bathe, toilet, et cetera. For three-fifths of these caregivers, caregiving is the equivalent of more than a full-time job.

I have been asked to talk to you about the needs of family caregivers, especially the unmet ones, and how the National Family Caregivers Support Program might meet them. If you have never been a family caregiver yourself, it is very difficult to completely appreciate the impact. Statistics from numerous studies document the impact, but it is the voice of caregivers themselves that truly tells what they are about.

Here is one such voice:

"I am on call 24 hours a day. Last night I was up for 2 hours because he, my husband, wet the bed and I had to get up to change him. I am stressed out. I have come to a point where I am just really worried all the time. Charles has dementia, too. It makes it very hard for me because I am lonesome. Caregiving is an emotional, financial and physical drain that takes up a lot of energy. If I could be selfish, I would ask to have a wee bit of time just to dress up. I look grungy all the time and seldom get to shower because there is nobody here. I can't leave him alone too long." Frances McArty, 80 years old, Champaign, IL.

This caregiver's statement speaks to the very real and unmet needs of family caregivers. It speaks to the need for an assessment of a caregiver's individual needs and circumstances, including emotional resources, physical capabilities and practical knowledge. It speaks to the need for training to help caregivers learn the skills that apply to their particular caregiving circumstances; and training to help them learn how to manage, plan and cope with their caregiving responsibilities; it speaks to the need for respect for the work that they do and peer support to validate their feelings and experiences and provide them with knowledge and tips from the trenches; it speaks to the need for one-on-one assistance and advice from those who know the system, understand the issues, and can help caregivers access needed resources; the need for assistance to help caregivers think through and manage the decisions they need to make so that in the long-run, they can be more effective caregivers and healthier human beings; the need for financial support to offset the expenses of caregiving; and last, but certainly not least, it speaks to the need for high quality respite services that meet the individual needs and circumstances of a caregiver's life.

The National Family Caregiver Support Program can begin to address many of these needs but certainly not all of them. The program is a start and provides the first national mandate for serving a portion of our Nation's family caregivers, and the committee should be proud of its role in making it a reality.

Meeting the needs of family caregivers is a complex process and I think much can be learned by looking at programs that have already been established and been successful.

In 1999, the Family Caregiver Alliance in San Francisco published a report entitled "*Survey of Fifteen States Caregiver Support Programs*." I recommend the report to the committee for reference.

It documents 33 state-funded programs serving family caregivers. Five stood out as best practice models:

California's Caregiver Resource Centers; New Jersey's Statewide Respite Program; New York's Consumer and Family Support Services Program; Oregon's Lifespan Respite Program; and Pennsylvania's Family Care Support Program.

They are all different in their way, but they all have common themes among them. They all provide respite. They all focus on consumer directed care. They have a flexible approach to service delivery and broad income eligibility.

We need more programs with these profiles, programs that are designed with input from the people who need them, so that they can really meet the needs of the community; programs that are flexible and are designed to meet a caregiver's need in creative ways rather than being so tightly prescribed that they only allow for one-size-fits-all predetermined solutions; and programs that provide services with more access to respite, and allow family and friends to provide care when appropriate. At times that might be the only way caregivers are willing to take a break and the only way care recipients are willing to accept care from someone other than the primary caregiver.

The National Family Caregiver Support Program is the first Federal program to specifically reach out to family caregivers. Even in its first year of implementation, it needs to stand as a beacon so that other programs will follow. The National Family Caregiver Support Program should focus on providing real services that make a difference in people's lives as soon as possible so that the impact can be felt.

Keeping sight of that goal, working creatively with existing service providers to maximize available dollars, and doing so all within a targeted timeframe can help ensure its early success.

Before I close, I would like to draw the committee's attention to a piece of legislation that has not yet been passed that would provide a valuable corollary to the National Family Caregiver Support Program, and that is S. 627, the Long Term Care and Retirement Security Act of 2001.

This bill would help all of us prepare for the cost of long-term care by providing a tax deduction for the purchase of long-term care insurance. And right now, it would help existing caregiving families by providing them with a $3,000 tax credit to help assuage the out-of-pocket costs of caregiving, costs that are considerable, and medical costs for these families has been estimated at 11.2 percent of income for families that have one member with a disability.

I encourage committee members to cosponsor it and want to thank Senator Breaux, Senator Collins, and Senator Lincoln for already doing so. Thank you.

[The prepared testimony of Ms. Mintz follows:]

Written Testimony
of
Suzanne Mintz, President/Co-founder
National Family Caregivers Association
Presented to
U.S. Senate Special Committee on Aging
As Part of the Hearing on Family Caregiving in the Older Americans Act: Caring for the Caregiver, May 17, 2001

Mr. Chairman, members of the Committee thank you for this opportunity. My name is Suzanne Mintz, and I am the President and Co-founder of the National Family Caregivers Association (NFCA). NFCA exists to educate, support and empower family caregivers and speak out publicly for meeting caregivers' needs. We reach across the boundaries of differing diagnoses, different relationships and different life stages to address the common concerns of all family caregivers.

Our members care for spouses, children, aging parents, siblings, friends and others. Half are caring for seniors, 66 or older and most are "heavy duty" caregivers, meaning they are providing hands-on care on a daily basis, helping loved ones, dress, bath, toilet etc. For three fifths of these caregivers, caregiving is the equivalent of more than a full-time job.

I have been asked to talk to you about the needs of family caregivers, especially the unmet ones and how the National Family Caregivers Support Program might meet them. If you have never been a family caregiver yourself, it is truly difficult, if not impossible, to completely appreciate the impact that caregiving can have. Numerous studies have shown that heavy duty caregivers, such as the ones we talk to everyday at NFCA, experience high levels of anxiety and frustration; feel isolated from other people, even other family members; don't know where to turn for help; want and need some time for themselves; and are prone to depression at higher rates than the rest of the population. This catalogue of circumstances and difficult emotions underlies the unmet needs of family caregivers but doesn't speak to them directly. This is what caregivers say:

> *"I am on call 24 hours a day. Last night I was up for two hours because he (my husband) wet the bed, and I had to get up to change him and the bed.... I am just stressed out. I have come to a point where I am just really worried all the time...Charles has dementia, too. It makes it very hard for me because I'm lonesome.... We're getting along on what we have, but if I have to buy any more medicine, it is going to be tough. Caregiving is an emotional, financial and physical drain that takes up a lot of energy. If I could be selfish, I would ask to have a wee bit of time just to dress up. I look grungy all the time and seldom get to shower because there's nobody here. I can't leave him alone too long."*
>
> Frances McArty, 80 years old, Champaign, IL

> *"My sister has cancer, is diabetic and has a colostomy, and I have to do the care for all of that.... My sister doesn't have much education, and I have to take care of practically everything for her. This past week I had a problem. I didn't want to leave my sister by herself, and I called someone but most people are afraid to stay with anyone who is sick because they're afraid something is going to happen while you're gone. But I had to get an eye exam; this place was 35 miles away. It's not like I was gone overnight or anything, but people just don't know what to do.... I do very well if I have somebody that I know I can depend on, but if I can't get a hold of someone and I don't know what to do, it excites me, it rattles me because I'm afraid I'll make a mistake. It could mean somebody's life, and you think about that a lot.*
>
> James Lassiter, 62 years old, Lepanto, AR

These two anecdotes speak to the very real and unmet needs of family caregivers. They speak to the need for:

- Assessment of a caregiver's individual needs and circumstances, including emotional resources, physical capabilities and practical knowledge,
- Training to help caregivers learn the skills that apply to their particular caregiving circumstances and training to help them learn how to manage, plan and cope with their caregiving responsibilities,
- Respect for the work they do and peer support to validate their feelings and experiences and provide them with knowledge and tips from the trenches,
- One-on-one advice and assistance from those who know the "system", understand the issues and can help caregivers access needed resources,
- One-on-one assistance to help caregivers think through and manage the decisions they need to make, so that in the long run they can be a more effective caregiver and a healthier human being,
- Financial support to offset the expenses of caregiving,
- and last but certainly not least, high quality respite services that meet the individual needs and circumstances of a caregiver's life.

The National Family Caregiver Support Program can begin to address many of these needs, but certainly not all of them. The Program is a start and provides the first national mandate for serving a portion of our nation's family caregivers, and the Committee should be very proud of its role in making it a reality. Meeting the needs of family caregivers is a complex process, and I think much can be learned by looking at programs that have already been established and are successful.

In 1999 the Family Caregiver Alliance in San Francisco, published a report entitled *Survey of Fifteen States' Caregiver Support Programs*. Thirty-three state-funded programs that serve the needs of family caregivers were reviewed. Five stood out as "best practice" models:

- California's Caregiver Resource Centers,
- New Jersey's Statewide Respite Program,
- New York's Consumer and Family Support Services Program,
- Oregon's Lifespan Respite Care Program, and
- Pennsylvania's Family Care Support Program.

Although there are obviously differences between the programs, there are also common themes among them including:

- Provision of respite care,
- A focus on consumer-directed care,
- Flexibility of program services, and
- Broad income eligibility.

I would recommend this report to the Committee for reference. Much can be learned from the experience of others. And I can tell you, as a family caregiver myself these common themes resonate with me.

If I can paraphrase the comments of state program personnel from the report, and add my voice to the chorus, we want to see:

- Programs that are designed with input from the people who need them so they can really meet the needs of their community,

- Programs that are flexible and are designed to meet a caregiver's needs in creative ways, rather than being so tightly prescribed that they only allow for a predetermined solution and,

- Programs that provide caregivers with more access to respite that allows family and friends to provide care when appropriate. At times, that might be the only way caregivers are willing to take a break and the only way care recipients are willing to accept care from someone other than the primary caregiver.

The National Family Caregivers Support Program is the first federal program to specifically reach out to family caregivers. Even in its first year of implementation, it needs to stand as a beacon so that other programs will follow. The National Family Caregivers Support Program should focus on providing real services that make a difference in people's lives, meaningful services that are available as soon as possible so that their impact can be felt. Keeping sight of the goal, actually helping more family caregivers as soon as possible, working creatively with existing service providers to maximize available dollars and doing so all within a targeted time frame can help insure its early success.

Before I close I would like to draw the Committee's attention to a piece of legislation that has not yet been passed that would provide a valuable corollary to the National Family Caregivers Support Program and that is S627, The Long Term Care and Retirement Security Act of 2001. This bill would help all of us prepare for the cost of long term care by providing a tax deduction for the purchase of long term care insurance, and right now it would help existing caregiving families by providing them with a $3,000 tax credit to help assuage the out-of-pocket medical costs of caregiving, costs that are considerable and have been measured at 11.2% of income for families in which one member has a disability. I encourage the Committee members to co-sponsor it and want to thank Senators Breaux, Collins, and Lincoln for already doing so.

Thank you for your time and attention.

The CHAIRMAN. Suzanne, thank you. Valuable testimony. We appreciate that. Now let me turn to Deborah Briceland-Betts, Executive Director, Older Women's League, Washington. Deborah.

STATEMENT OF DEBORAH BRICELAND-BETTS, EXECUTIVE DIRECTOR, OLDER WOMEN'S LEAGUE, WASHINGTON, DC

Ms. BRICELAND-BETTS. Thank you, Mr. Chairman and Senator Breaux. OWL commends you for engaging in this important discussion. OWL's 2001 Mother's Day Report, Faces of Caregiving, was released last week on Capitol Hill, and it reminds us that women provide the majority of informal caregiving work and often pay a steep price for their efforts.

Caregivers suffer reduced wages and job security, which inevitably lead to diminished retirement security. Informal caregivers also experience emotional and physical stress that can take a toll on their own health. Caregiving is a gender issue. Nearly three-quarters of informal caregivers to seniors are women. Among the men and women who are caregivers, women average 50 percent more hours of care per week than men.

Women also provide care for longer periods of time than men—in many cases, for over five consecutive years. The typical caregiver is a married woman in her mid–40's to mid–50's. She is employed full time and also spends an average of 18 hours per week on caregiving. She juggles her career with caring for a parent, a partner, a spouse, and she is still most often the primary caregiver for her children.

Increasingly, these women are primary caregivers for their grandchildren as well. Between 20 and 40 percent of caregivers are members of the sandwich generation, caring for children under 18 in addition to other family members. OWL's report indicates that women's earnings and retirement security are put at risk by informal caregiving and increasingly so the longer they provide care.

Time out of the workforce for caregiving diminishes women's earning power, which is already reduced by the wage gap and sharpened by her longer life span. In fact, estimates reveal that caregivers lose an average of $550,000 in total wage wealth, and their Social Security benefits decrease an average of $2,100 annually as a result of caregiving.

These figures would be even larger if those losses associated with childcare responsibilities were also included. The National Family Caregiver Program provides some relief from the stresses of caregiving. The direct services for caregivers are critical. Information is power, as we have heard today, to anyone struggling with a long-term care situation. And the program will provide an important one-stop shop for caregivers.

Families thrust into such situations—as we heard from Ms. Tatom—often don't know where to turn. They aren't worried about policy implications. They simply want and need accurate, timely information about services and options. The caregiver program provides an important point of entry for caregivers and their families to find out what services are available in their community.

The training piece of the program is also important, not just in its positive effect on the care provided, but for the protections it would provide the caregiver. Caregiving is physically demanding work. OWL's report indicates that 44 percent of caregivers find their routine caregiving tasks cause chronic physical pain, particularly when the caregivers lack appropriate training.

The support group and respite components of the program are also a significant step in the right direction. Older women with caregiving responsibilities often face mental, physical, and financial stresses. The OWL report points out that a substantial number of caregivers feel worried, frustrated, depressed, or overwhelmed as a result of caregiving.

This emotional stress sometimes leads to depression, which can impair a caregiver's ability to provide care and also endanger her own health. One study cited in the report found that two out of three informal caregivers are in poor health. The additional health related costs due to increased informal caregiving will further erode an already dwindled retirement income. The opportunity for caregivers to talk about these challenges with counselors and peers in similar situations can be an invaluable source of emotional support.

The program provides an opportunity to bring together community agencies to begin to address the critical needs of caregivers. This is the good news. But the bad news is that we already know the program is woefully underfunded. The lack of resources is already a problem and as the baby boomers age, it will easily become a crisis.

Last, the program was developed as an initial effort to meet the needs of only one segment of the caregiver population. It targets the caregivers of older adults as well as older individuals who are raising their grandchildren or caring for children with disabilities, but many of America's caregivers including Mrs. Hunter—"Catfish" Hunter was 52 when he died—would not be eligible for this program. A spouse caring for a spouse under the age of 60 is not eligible for these services.

OWL urges a broader definition of caregiver beyond family. Our report indicates that 29 percent of those who provide informal care are not family members. Aside from its limited funding, these eligibility restrictions represent a significant shortcoming of the program.

OWL believes that we need a new paradigm for long-term care policy that values caregiving and moreover is aimed at getting the best and more appropriate care to those who need it, without requiring women to sacrifice their economic security and retirement to achieve it. This repositioning would put caregiving on a whole new plane. Caregiving relationships are as varied as the faces of those who provide the care and motivations for providing such care are more complicated than obligation or familial love.

OWL does not believe women—or anyone else—should be expected to willingly sacrifice their own retirement security or health as a result of caring. Thank you.

[The prepared remarks of Ms. Briceland-Betts and Faces of Caregiving Report follow:]

"The National Family Caregiver Support Program"

A Hearing before the Senate Special Committee on Aging
U. S. Senate
May 17, 2001

Testimony of Deborah Briceland-Betts, J.D.
Executive Director
Older Women's League

Mr. Chairman and distinguished Members of the Committee:

I appreciate your invitation to testify today on the timely issue of caregiving and the new National Family Caregiver Support Program (NFCSP). OWL commends you and the Committee for engaging in the important discussion of addressing the critical needs of America's caregivers. My testimony today will focus on how caregiving affects women, including its long-term financial consequences. I will also highlight a few policy recommendations to address some of these consequences, with special attention paid to the NFCSP.

This past weekend the nation observed Mother's Day. Our celebrations typically praise women for the caregiving roles they play in our families and communities. One day a year, the country acknowledges the irreplaceable contributions mothers, grandmothers, aunts, sisters and daughters offer their families and friends. These celebrations are part of the rewarding side of caregiving, but its important to remember there are consequences to caregiving as well – and there is no better time to discuss them than Mother's Day.

As the Executive Director of OWL, the only national grassroots membership organization dedicated exclusively to the unique concerns of women as they age, I can assure you that our members have a very personal stake in the issue of caregiving.

OWL's 2001 Mother's Day Report, *Faces of Caregiving*, released just last week on Capitol Hill, addresses the value, scope and consequences of informal caregivers' work. "Informal caregiving" is a catch-all phrase that refers to unpaid care and financial support provided by family members or friends to people with chronic illness or disabilities. It is an irreplaceable source of long-term care and support in America.

The report reminds us that women provide the majority of informal caregiving work — and often pay a steep price for their efforts. Caregivers suffer reduced wages and job security, which inevitably lead to diminished retirement security. Informal caregivers also experience emotional and physical stress that can take a toll on their own health.

When we speak of caregiving, OWL uses a broad definition which encompasses raising children, assisting people with disabilities, and caring for frail elders. As the voice of midlife and older women, OWL stresses that caregiving truly spans the generations. We also underscore the one common denominator to all forms of caregiving -- women do the majority of caregiving work, both paid and unpaid.

I would like to begin by describing the scope of informal caregiving in America. We know that as many as 52 million Americans, or 31 percent of the adult population, are informal caregivers. Almost one quarter of American households provide care to friends or relatives age 50 or older. We also know that informal caregivers provide an irreplaceable service, estimated at nearly $200 billion annually. When formal home care expenditures are added to the $200 billion "public good" of informal care, the economic value of community-based care dwarfs the value of institutional care by a ratio of nearly three to one. In fact, informal caregivers provide more care in the home -- free of charge -- than the federal government provides in all settings combined.

And gender makes a difference when it comes to informal caregiving. Nearly three-quarters of informal caregivers to seniors are women. Women on average provide 50 percent more hours of informal care per week than men. Women also provide informal care for longer periods of time than men -- in many cases, for over five continuous years.

The typical informal caregiver is a married woman in her mid-forties to mid-fifties. She is employed full-time and also spends an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner or spouse, she may be the primary caregiver for her children and increasingly, for her grandchildren as well. Between 20 and 40 percent of caregivers are members of the "sandwich generation," caring for children under 18 in addition to other family members. Because women are more likely than men to assume caregiving roles, they are also more likely to be sandwiched by the caregiving needs of two or more generations.

So we know that caregiving is a gender issue. But OWL also sees caregiving as a retirement security issue. Women's earnings and retirement security are put at risk by informal caregiving, and increasingly so the longer they provide care.

Informal caregivers often curtail their professional opportunities and thereby imperil their financial security in retirement. These financial sacrifices can be particularly troubling for women: time out of the workforce diminishes their earning power, which is already reduced by the wage gap. As a result, women are more likely than men to face poverty in retirement.

It is estimated that caregivers lose an average of $550,000 in total wage wealth, and their Social Security benefits decrease an average of $2,100 annually as a result of caregiving. These figures would be even larger if losses associated with childcare responsibilities were also included. These economic sacrifices can be particularly devastating to older women, whose quality of life is seriously constrained by social and economic policies that are not responsive to their life patterns.

So America depends upon women as caregivers, and in many ways expects them to assume this role – that's nothing new. The important question is why? OWL would submit that the answer is deceptively simple – America depends on women because it can. As long as words like love and commitment, duty and family are used in relation to caregiving, society will always see it as "women's work." Unfortunately, women's work is consistently devalued, and too often policy solutions reflect this bias. Caregiving is a perfect case in point. Current long term care policy assumes women will continue in this role, and many of the "solutions" – while well meaning and even helpful in the short term – revolve around encouraging women to continue to do this work. Changing the way we talk and think about the work of caregiving would also lead us to focus more on the person who needs the service and the service itself. OWL is convinced that changing the focus as such would produce better long-term care policy.

Now, the challenge: there is no simple remedy in sight. Public policy and community services should be improved, but we also must confront difficult and pervasive social norms that expect women to care for others more than they care for themselves.

OWL's 2001 Mother's Day report highlights some policy recommendations that OWL feels would help to lighten some of the load for caregivers, and provide retirement security protections that are particularly critical for women. Chief among these recommendations are improvements to the National Family Caregiver Support Program.

Provide Greater Support for Public Caregiver Assistance Programs and Innovations: Funding for federal and state programs that assist informal caregivers by providing information, training, referrals and respite care should be expanded. Policy makers took an important first step last year when Congress launched the NFCSP with the 2000 reauthorization of the Older Americans Act. Under a $125 million appropriation, the program is intended to provide informal caregivers with critical information, training, counseling and respite services. It is the largest new assistance program under the Act since Congress established nutritional programs for older Americans in 1972.

The direct services for caregivers that will be implemented through the NFCSP are clearly critical to older women. Information is power to anyone struggling with a long-term care situation, and the NFCSP will provide an important one-stop shop for caregivers. Families thrust into such situations don't worry about policy implications, they simply need accurate, timely information about services and options. The NFCSP, as it is implemented across the country, will provide an important point of entry for caregivers and their families as they make these difficult choices.

The training piece of the NFCSP is also important – not just in its positive affect on the care provided, but for the protections it could provide the caregiver. This can be physically demanding work, and proper training -- lifting techniques, for example -- can avoid debilitating injuries to caregivers down the road.

The support group and respite components of the NFCSP are also a significant step in the right direction towards minimizing the negative consequences for caregivers. Older women with caregiving responsibilities often face mental, physical and financial stresses. Midlife women face these challenges while simultaneously being pinched by career responsibilities and preparing for their own retirement. Caregiving is stressful in its own right, and even more so when combined with these other demands.

In some cases, this emotional stress leads to depression, which can impair a caregiver's ability to provide care and also endanger her own health. The incidence of depression is higher among informal caregivers than in society at-large. Other common physical manifestations of caregiving stress include insomnia, indigestion, changes in appetite and increased frequency or intensity of headaches. Informal caregivers can become so overwhelmed with caregiving that they neglect their personal health until a crisis arises, and such crises are often costly. An expectation that women will bear additional health-related costs due to increased informal caregiving could have a devastating impact on their retirement security. The opportunity for caregivers to talk about these challenges with counselors and peers in similar situations can be an invaluable source of emotional support.

The NFCSP will provide an important opportunity to bring together community agencies to begin to address the critical needs of caregivers. This is the good news. But the bad news is that we already know the program is woefully underfunded. In fact, the current funding level translates to roughly $5.00 in services for every caregiver in America. This lack of resources is already a problem today. As the baby boomers age it could easily become a crisis tomorrow.

Lastly, the NFCSP was developed as an initial effort to meet the needs of only a segment of the caregiver population. This new initiative targets only the informal caregivers of older adults, as well as older individuals who are raising their grandchildren or caring for children with disabilities. As a result, many of America's caregivers cannot avail themselves of these important programs. For example, a spouse caring for a partner under the age of 60 is not eligible for these services. Aside from its limited funding, these eligibility restrictions represent a significant shortcoming of the program.

Expand the Family and Medical Leave Act (FMLA) to Make It More Inclusive and Effective: First, there should be a broader definition of immediate family member whose care qualifies as a covered event. Second, the law should be expanded to cover smaller workplaces. To the extent that small businesses express concern with such an expansion, consideration should be given to tax policies to help mitigate any adverse impact. Third, the FMLA should be amended to extend prorated benefits and protections to caregivers who work less than the current minimum of 1250 hours a year or who have worked for a particular employer for less than a year. Fourth, serious consideration should be given to wage supplementation during a period of leave to enhance utilization of the benefit. Finally, federal policymakers should expand the worker benefits that are protected under the law. Like the mandatory continuation of health benefits under current law, the FMLA should also require employers to continue any employer contributions to qualified retirement plans during a covered leave period. This requirement would ensure that caregivers do not risk their own retirement as a result of their commitments to family and community. Given their higher rates of poverty in retirement, this is a particularly critical issue for women.

Modify the Medicare Program to Support Informal Caregiving: The Medicare Program should become a reliable partner for informal caregivers. First, Medicare should be amended to allow informal caregivers who do not have access to employer-sponsored coverage, and who care for Medicare-eligible or enrolled spouses or relatives, to buy into Medicare. Women who leave the workplace early or shift from full-time to part-time jobs to be caregivers can lose access to affordable health insurance. Women without coverage will sometimes forgo preventive medical care, diagnosis and treatment, which can result in more serious and costly illness down the road. In light of the numerous emotional, physical and financial stresses caused by informal caregiving, access to affordable health insurance is crucial.

Any discussion of "modernizing" Medicare's benefit package should recognize that Medicare has a critical role to play in meeting the chronic health care needs of beneficiaries, which in turn will limit medical emergencies, prevent excess disability, and support informal caregivers. Medicare should provide a chronic care benefit and cover respite care, adult day care, and other community-based long-term care and support services.

Strengthen Social Security by Recognizing the Work of Informal Caregivers: Informal caregivers who work less than full-time or who take a leave of absence from work should be protected in retirement. There are several approaches to help ensure that benefits are not reduced in retirement due to caregiving during working years. Such reforms would help reduce the extent to which women are penalized in retirement for fulfilling caregiving responsibilities during prime earning years.

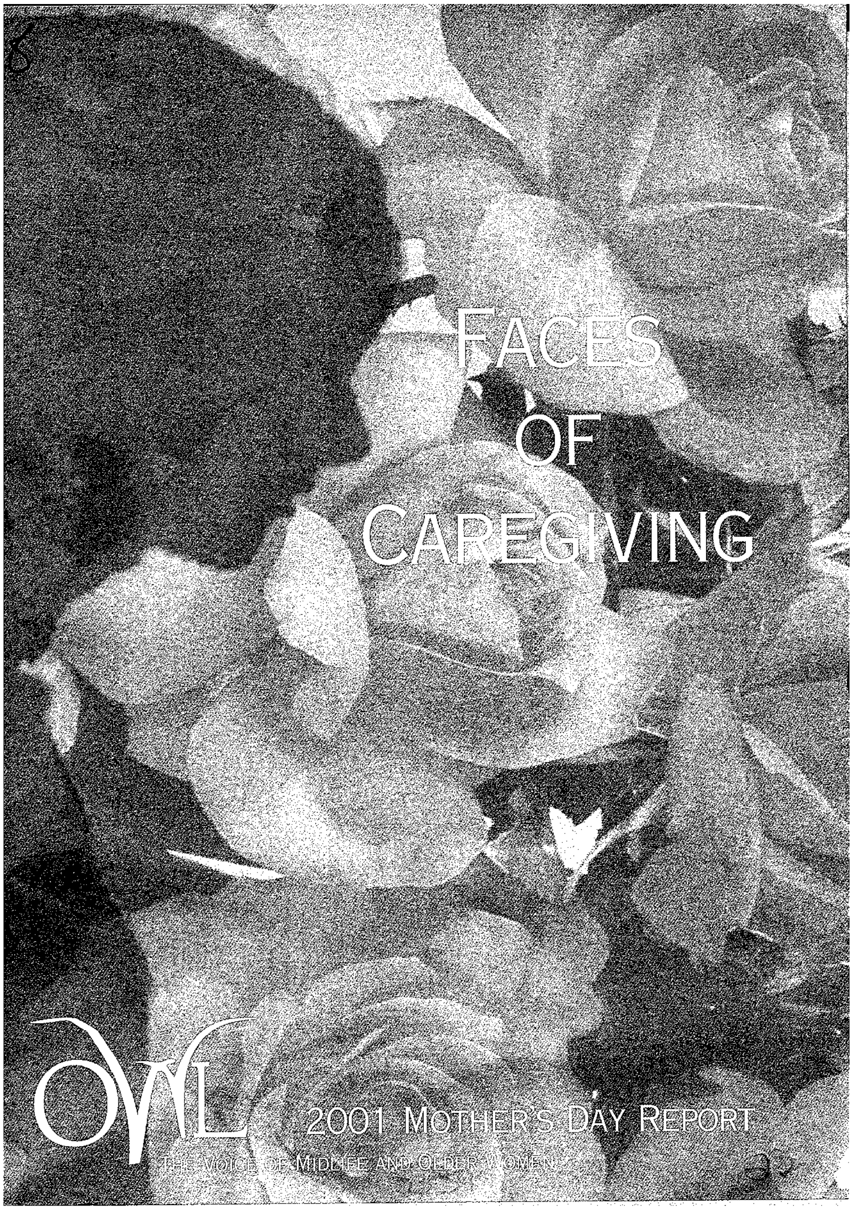
Improve Pension Coverage for Caregivers in the Paid Workforce: Federal pension law should be revised to better protect the retirement security of caregivers. While pension reform will benefit all women, it particularly resonates with the needs of women who are informal caregivers. Pension law should be amended to reduce vesting requirements from five to three years, a change which would better reflect women's work patterns. The Grassley-Baucus bill, S. 742, would implement this change if passed. However, we should take it one step further and count leave time under the Family and Medical Leave Act as service time, and it should accrue to help meet any pension vesting requirements. Such revisions would allow more women to qualify for pension coverage and would also help protect informal caregivers who move in and out of the paid workforce due to caregiving. Further, employers should not be allowed to exclude part-time and temporary workers from pension benefits or contributions as the law currently permits. Women who work part-time because of informal caregiving are particularly affected by this policy.

America lacks an effective system to address caregiving. As a result, caregivers – the majority of whom are women -- are often pushed beyond their means and suffer long-term consequences as they struggle to meet the caregiving needs of those who depend on them. The demographics are clear, and now is the time for Congress and the Administration to take the appropriate steps to head off a national caregiving crisis. The NFCSP is a very good start, but federal policymakers have a unique opportunity to make additional important reforms designed to benefit informal caregivers in the context of examining the Medicare and Social Security programs.

The aging population and increased longevity are two trends that could drain the nation's informal caregiving resources if a comprehensive long-term care and support system is not developed and implemented. Public policy responses such as those described in OWL's 2001 Mother's Day Report are critical if we are to address the emotional, physical and financial challenges facing caregivers today and to ensure that caregiving does not jeopardize their own health and retirement security tomorrow.

OWL believes we need to build a new paradigm for long-term care policy that values caregiving and, moreover, is aimed at getting the best and most appropriate care to those who need it -- without requiring women to sacrifice their economic security in retirement to achieve it. This repositioning would put caregiving on a whole new plane. Caregiving relationships are as varied as the faces of those who provide care, and the motivations for providing such are more complicated than obligation or familial love.

There are some in the long-term care community who in fact object to the use of the word "care," who prefer instead the phrase "long-term services and support." OWL supports that preference, but for us the reality is that women *do* care – emotionally, physically and financially. OWL just doesn't believe women – or anyone else – should be expected to willingly sacrifice their own retirement security or health as a consequence of caring. If we can do that, caregiving work will be truly valued -- not just on Mother's Day, but on every day of the year.



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FACES OF CAREGIVING

OWL

2001 MOTHER'S DAY REPORT

THE VOICE OF MIDLIFE AND OLDER WOMEN

30

A MESSAGE FROM LUPE SOLIS

PRESIDENT, OWL

Happy Mother's Day!

Mother's Day celebrations typically praise women for the caregiving roles they play in our families and communities. One day a year, the country acknowledges the irreplaceable contributions mothers, grandmothers, aunts, sisters and daughters offer their families and friends. These celebrations are part of the rewarding side of caregiving, but it's important to remember there are consequences to caregiving as well — and there is no better time to discuss them than Mother's Day.

OWL's 2001 Mother's Day Report, *Faces of Caregiving*, addresses the value, scope and consequences of informal caregivers' work. The report reminds us that women provide the majority of informal caregiving work — and often pay a steep price for their efforts. Caregivers suffer reduced wages and job security, which inevitably leads to diminished retirement security. Informal caregivers also experience emotional and physical stress that can take a toll on their own health.

Faces of Caregiving also spotlights the faces behind the facts. Diverse communities tackle their own unique caregiving challenges, and the experiences of Latina, African American, Asian American, lesbian and low-income caregivers are highlighted. Our population is not only aging, it is growing more diverse. In fact, Latinos are the fastest growing segment of the age 65 and over population.

The report emphasizes a broad definition of caregiving; encompassing raising children, assisting people with disabilities, caring for frail elders, and even providing paid professional caregiving. As the voice of midlife and older women, OWL stresses that caregiving truly spans the generations. In this report, we also underscore the one common denominator to all forms of caregiving — women do the majority of caregiving work, both paid and unpaid.

America depends upon women as caregivers — that's nothing new. The important question is why? OWL would submit that the answer is deceptively simple — because it can. As long as words like love and commitment, duty and family are used in relation to caregiving, society will always see it as "women's work." Unfortunately, women's work is consistently devalued, and too often our policy solutions reflect this bias. Caregiving is a perfect case in point. Current long term care policy assumes women will continue in this role, and much of the "solutions" — while well meaning and even helpful in the short term — revolve around encouraging women to continue to do this work.

OWL believes we need to build a new paradigm for long-term care policy that values caregiving and, moreover, is aimed at getting the best and most appropriate care to those who need it—without requiring women to sacrifice their economic security in retirement to achieve it. This repositioning would put caregiving on a whole new plane. Caregiving relationships are as varied as the faces of those who provide care, and the motivations for providing such care are more complicated than obligation or familial love.

There are some in the long-term care community who in fact object to the use of the word "care," who prefer instead the phrase "long term services and support." OWL supports that preference, but for us today's reality is that women *do* care — emotionally, physically, and financially. The use of the phrase long-term services and support places the policy emphasis more appropriately where it should be — on the recipient and her/his need. But OWL doesn't believe women — or anyone else — should be expected to willingly sacrifice their own retirement security or health as a consequence of caring.

Now, the challenge: there is no simple remedy in sight. Public policy and community services should be improved, but we also must confront difficult and pervasive social norms that expect women to care for others more than they care for themselves. If we can do that, caregiving work will be truly valued — not just on Mother's Day, but on every day of the year.

Lupe Solis

Lupe Solis
President, OWL

Photo by Pamela Valois

> "Is caregiving an issue of special concern of women, or is it more correctly seen as an aspect of long- term care where women happen to be the primary participants? How do the traditional roles of men and women affect the problem? How will changing roles and expectations of the sexes impact on family caregiving? And what will the future bring?
>
> From one point of view, we could logically ask, what difference does it make? Families include both sexes, and men as well as women may find themselves as the primary caregiver to an ailing spouse or parent. The agonies and ambivalences are likely to be the same no matter who finds himself or herself in that situation. Caregiving is a family matter.
>
> On the other hand, gender differences are an essential part of our social fabric. Despite sex neutrality under the law, policies reflect popular attitudes and changes in those polices are often brought about by significant shifts in public opinion. ... My thesis is that caregiving is a fundamental woman's issue of our decade.
>
> ...To see caregiving as a woman's issue is not to denigrate the contributions of men who provide whatever care and help they can for their disabled parents and spouses. Nor does the emphasis on women minimize the initiatives of health care professionals. Instead, women as a whole and women's organizations in particular should be viewed as potential allies to bring about the needed shift in national priorities to develop a viable long term care policy. But first, a great deal of consciousness raising will have to occur. That is a task for all of us."
>
> — Tish Sommers
> Founder of the Older Women's League
> From "Caregiving: A Woman's Issue," *Generations*, Fall 1985

HIGHLIGHTS

- "Informal caregiving" is a catch-all phrase that refers to unpaid care and financial support provided by family members or friends to people with chronic illness or disabilities. It is an irreplaceable source of long-term care and support in America.
- As many as 52 million Americans, or 31 percent of the adult population, are informal caregivers. Almost one quarter of American households provide care to friends or relatives age 50 or older.
- Gender makes a difference when it comes to informal caregiving. Nearly three-quarters of informal caregivers to seniors are women. The typical informal caregiver is a married woman in her mid-forties to mid-fifties. She is employed full-time and also spends an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner or spouse, she may be the primary caregiver for her children and increasingly, for her grandchildren as well.

- Between 20 and 40 percent of caregivers are members of the "sandwich generation," caring for children under 18 in addition to other family members. Because women are more likely than men to assume caregiving roles, they are also more likely to be sandwiched by the caregiving needs of two or more generations.

- Women on average provide 50 percent more hours of informal care per week than men. Women also provide informal care for longer periods of time than men — in many cases, for over five continuous years. As a result, women's health, earnings and retirement security are put at risk by informal caregiving, and increasingly so the longer they provide care.

- Older Americans have the greatest need for long-term care and support, including informal caregiving. Population trends forecast an increase in the need for informal caregiving. By 2030, one in five Americans will be age 65 or older. By 2040, there will be nearly four times as many Americans over age 85 as there are today, with one in nine baby boomers expected to reach age 90. This aging population will also be increasingly diverse, with minority populations projected to represent 25 percent of the elderly population in 2030, up from 16 percent in 1999.

- Despite the enormous value of informal caregiving to society, most informal caregivers face substantial stresses with limited public support. Prolonged caregiving takes a toll on the emotional, physical and financial health of informal caregivers.

- Informal caregivers curtail their professional opportunities and thereby imperil their financial security in retirement. These financial sacrifices can be particularly troubling for women: time out of the workforce diminishes their earning power even beyond the impact of the wage gap. As a result, women are more likely than men to face poverty in retirement.

- It is estimated that caregivers lose an average of $550,000 in total wage wealth, and that their Social Security benefits decrease an average of $2,100 annually as a result of caregiving. These figures would be even larger if losses associated with childcare were also included. These economic sacrifices can be particularly devastating to older women, whose quality of life is seriously constrained by social and economic policies that are not responsive to their everyday experiences and life patterns.

- Concerns about maintaining personal health or missing work as a result of caregiving are common. Women worry about their ability to retire comfortably, particularly in the course of forgoing paid employment for informal caregiving. A recent survey of women aged 25 to 55 found 41 percent are worried they will live at or near the poverty level during retirement because they cannot adequately save during their working years.

- The value of informal caregiving provided each year is estimated at nearly $200 billion. Even those who are enrolled in Medicaid, who have public or private insurance coverage, or who can afford formal care often prefer to receive care and support at home where they can maintain some autonomy and independence. Over 80 percent of adults who receive long-term care and support reside in the community.

- When formal home care expenditures are added to the $200 billion "public good" of informal care, the economic value of community-based care dwarfs the value of institutional care by a ratio of nearly three to one. The value of informal caregiving is underscored by the fact that 50 percent of older

Americans with long-term care needs who lack an informal caregiving option reside in a nursing facility. Only seven percent of older Americans who have a family caregiving option reside in a nursing facility.

- Informal caregivers provide more care in the home — free of charge — than the federal government provides in all settings combined.
- Informal caregiving is valuable as a matter of public health. Researchers who have examined the value of relationship-centered care and support have noted that significant interaction with family, friends and the community correlates with better health status. On the flip side, the adverse impact of caregiving work on the health of caregivers is a critical public health concern.
- One-third of informal caregivers consider themselves to be in fair to poor health. Routine caregiver tasks can cause acute and chronic physical strain, particularly when caregivers lack appropriate training. Forty-four percent of informal caregivers report physical strain as a result of their caregiving activities. Stress imposed by daily caregiver tasks may also render informal caregivers more susceptible to illness. One study found chronic stress in informal caregivers can weaken the caregiver's immune system. Because the majority of informal caregivers are over age 50, their risk of experiencing health problems already is relatively high.
- Since most informal caregivers work in the paid labor force, informal caregiving is an important issue for employers. While employer costs associated with informal caregiving are high, the societal costs to replace the unpaid care with formal care would be staggering — about $200 billion per year.
- Some large employers have responded to the important issue of informal caregiving by offering flexible scheduling, information clearinghouses, and counseling or support groups. Flexible scheduling and family leave are particularly popular.
- The use of family leave by workers between ages 50 and 64 has increased steadily in recent years. The reasons for taking leave have shifted from personal health to caring for a spouse, child or parent.
- In the absence of a comprehensive program offering long-term care and support, caregiving responsibilities will eventually touch nearly all workers' lives, male or female. Employers who fail to respond to informal caregivers' needs will face unnecessary costs and be at a competitive disadvantage in tight labor markets.
- Limited federal programs supplement and support informal caregiving. The Family and Medical Leave Act ensures a federal minimum floor of protection for certain workers who need time off from work to care for a family member. The National Family Caregiver Support Program focuses most of its support on informal caregiving to older Americans, and the Social Services Block Grants provide additional support. Each of these policies is helpful but would be even more valuable with specific modifications and additional funding.

"INFORMAL CAREGIVING IS THE BACKBONE OF LONG-TERM CARE AND SUPPORT IN THE UNITED STATES."

INTRODUCTION

"Informal caregiving" — a catch-all phrase that refers to unpaid care and financial support provided by family members or friends to frail and elderly people with chronic illness or disabilities — is the backbone of long-term care and support in the United States. As many as 52 million Americans (31 percent of the adult population) are informal caregivers.[1] Across the generations, women and men act as informal caregivers to friends and family members with chronic illness or disabilities.

This report presents a profile of informal caregivers and explains the value, scope and consequences of their unpaid work. It then offers a number of policy recommendations that if implemented would better value and support informal caregiving. Although the report gives a great deal of attention to caregiving for older relatives, spouses and partners, caregiving arrangements span the generations and go beyond "traditional" notions of family. Friends, neighbors and domestic partners all give and receive informal care. Grandparents care for children and grandchildren. Mothers and fathers care for sisters and brothers, daughters and sons. Wives care for husbands, uncles, friends and cousins. Caregiving relationships are as varied as the faces of those who provide care, and the motivations for providing such care are more complicated than obligation or familial love.

> *"CAREGIVING RELATIONSHIPS ARE AS VARIED AS THE FACES OF THOSE WHO PROVIDE CARE, AND THE MOTIVATIONS FOR PROVIDING SUCH CARE ARE MORE COMPLICATED THAN OBLIGATION OR FAMILIAL LOVE."*

COMMON CAREGIVING TERMS

Activities Of Daily Living (ADLs): Basic personal care tasks to be performed daily such as dressing, bathing, eating or toileting.

Care Recipient or Consumer: The person receiving care who typically has a condition such as Parkinson's disease, cancer, Alzheimer's disease, traumatic brain injury, AIDS, muscular dystrophy, paralysis, multiple sclerosis, frailty attributed to old age, or other chronic illness.

Caregiver: Anyone who provides assistance to another in need.

Family Caregiver: Used interchangeably with informal caregiver and can include family, friends or neighbors.

Formal Caregiver: Paid professionals and paraprofessionals within a service system who provide care at home, in community agencies, or in institutions or residential facilities.

Informal Caregiver: Anyone who provides care without pay and who usually has personal ties to the care recipient. Examples include family, friends and neighbors. The caregiver can be a "primary" or "secondary" caregiver, can provide full- or part-time help, and may live with the care recipient or separately.

Instrumental Activities Of Daily Living (IADLs): Personal tasks such as meal preparation, grocery shopping, remembering to take medication, making telephone calls, and money management.

Long-Term Care and Support: Long-term care and support refers to a broad and highly variable range of rehabilitative, restorative and health maintenance services that assist people with ADLs, IADLs, and the emotional aspects of coping with illness or disability.

Sources: Family Caregiver Alliance, *Survey of Fifteen State's Caregiver Support Programs* (October 1999); H. Komisar and J. Feder, *The President's Proposed Long-Term Care Initiative* (The Commonwealth Fund, July 1999).

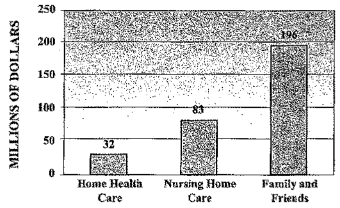
PART ONE:
INFORMAL CAREGIVING — IRREPLACEABLE WORK

AMERICA RELIES ON INFORMAL CAREGIVING

The current demand for some form of long-term care and support is acute. It is estimated that 100 million Americans today have a chronic illness or disability that can give rise to a need for formal or informal long-term care and support.[2] This number is expected to rise to 160 million by 2040.[3] Of the 100 million Americans with chronic conditions today, 41 million are limited in their ability to perform routine activities (ADLs and/or IADLs) as a result of the condition.[4] Many are older Americans who rely on informal caregivers to assist them with their daily needs.

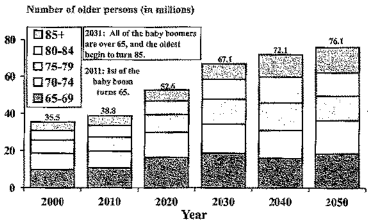
Informal caregiving is unpaid work valued at nearly $200 billion per year.[5] The value of informal caregiving to society will increase in the foreseeable future. Aging baby boomers will bring unprecedented growth and diversity to the senior population, with the greatest growth expected between the years 2010 and 2030. The population of seniors in America is projected to more than double its current size over the next 30 years, rising from 34 million in 1997 to over 69 million by 2030.[6] At that time, one in five Americans will be age 65 or older.[7] Moreover, minority populations are projected to represent 25 percent of the elderly population in 2030, up from 16 percent in 1999. Between 1999 and 2030, the minority population of those aged 65 years and older is projected to increase by 291 percent, compared to 81 percent for Caucasians. This projection includes an increase of 328 percent for Hispanics, 131 percent for African Americans, 147 percent for American Indians, and 285 percent for Asian/Pacific Islanders.[8]

Chart A: The Value of Care



Source: P. Arno, C. Levine and M. Memmott, *The Economic Value of Informal Caregiving*, in Health Affairs. Vol. 18, No. 2 at pp. 182-188 (March 1999).

Chart B: The Aging of the U.S. Population, 2000-2050



Source: *The Long-Term Care Financing Model.* Prepared by The Lewin Group, Inc. for the Office of the Assistant Secretary for Planning and Evaluation (OASPE), DHHS, 2000.

In addition to being larger, the next generation of seniors will be older than previous generations. This projection is significant considering the demand for long-term care and support, including informal caregiving, increases with age.[9] It is expected that by 2040, there will be nearly four times as many Americans over age 85 as there are today, with one in nine baby boomers expected to reach age 90.[10] The same advances in medical science and technology that will allow seniors to live longer will lengthen the life expectancy of the non-elderly with disabilities as well.

FORMAL LONG-TERM CARE DOES NOT REPLACE INFORMAL CAREGIVING

At present, formal sources of long-term care and support do not meet the needs of many Americans.[11] Depending on the severity of an individual's impairment and the degree of assistance required, care and support is available in nursing facilities or from other formal service providers. Medicare coverage for long-term care and support provided by nursing facilities and home care agencies is limited, as is coverage by private health insurance.[12] Although Medicaid provides the broadest coverage for long-term care and support, eligibility is restricted to those with extremely limited financial resources.[13] Most people who need long-term care and support must purchase long-term care insurance, pay for the care out-of-pocket, or obtain care from informal sources.

> *"WHEN FORMAL HOME CARE EXPENDITURES ARE ADDED TO THE $200 BILLION "PUBLIC GOOD" OF INFORMAL CARE, THE ECONOMIC VALUE OF COMMUNITY-BASED CARE DWARFS THE VALUE OF INSTITUTIONAL CARE BY A RATIO OF NEARLY THREE TO ONE."*

Even those who are enrolled in Medicaid, who have private insurance coverage, or who can afford formal care often prefer to receive care and support at home where they can maintain some autonomy and independence.[14] Over 80 percent of adults who receive long-term care and support

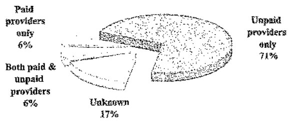
PUBLIC FUNDING FOR LONG-TERM CARE

Contrary to popular belief, public resources devoted to long-term care and support are scarce and only available in limited contexts.

The Medicaid program generally provides coverage for nursing home care to individuals whose income and assets fall beneath stringent limitations. Medicaid can also cover home health and personal care services to individuals living in their homes. Some, but not all state Medicaid programs assume the long-term care expenses of the "medically needy," who "spend down" their assets to the specified level as a result of large medical bills. People in institutions spend down to Medicaid eligibility more frequently than those who remain in the community using long-term care and support services. Medicaid enrollees may receive either institutional care or community based care, but if they have reduced their income and assets to become eligible for Medicaid, they have little left for all of their non-medical needs including food and housing. In an institution, these expenses would be covered by Medicaid, but those who wish to remain in the community must maintain themselves. For all of these reasons, many people have noted with irony that Medicaid payment for long-term care and support is biased toward institutionalized care — the most expensive and often least preferred setting.

Benefits under ***the Medicare program*** are even more limited than under Medicaid. Medicare provides coverage for short stays in skilled nursing facilities (limited to 100 days of coverage per episode of illness) that are based on a hospital stay just prior to entry into the skilled nursing facility. A treating physician must prescribe the stay. The majority of skilled nursing facility residents either exhaust Medicare coverage during the course of their stay, or fail to qualify for the benefit at the outset. Medicare's home health benefit is similarly restrictive and is intended to cover care related to a medical condition requiring some level of medical care or monitoring.

Chart C: Reliance on Paid and Unpaid Caregivers Among Non-Instituionalized Persons Age 18-64



Source: 1994 NHIS-DS, from W. Spector, J. Fleishman, L. Pezzin, and B. Spillman, *Characteristics of Long-Term Care Users*. Prepared for the Committee on Improving Quality in Long-Term Care, Institute of Medicine, 1998.

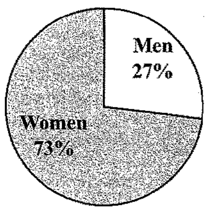
reside in the community.[15] In 1997, federal payors spent $83 billion on skilled nursing facility care, and $32 billion was spent on formal home care. When formal home care expenditures are added to the $200 billion "public good" of informal care,[16] the economic value of community-based care dwarfs the value of institutional care by a ratio of nearly three to one. As a matter of public health and public policy, resources for in-home care and support should be made available. Families and individuals should have options regarding the most appropriate setting of care. Researchers have examined the value of relationship-centered care and support and have noted that significant interaction with family, friends and the community correlates with better health status.[17]

FAMILIES AND INFORMAL CAREGIVING

Informal caregivers make great sacrifices to keep friends and family members with disabilities or chronic illness at home for as long as possible. It must be acknowledged that families provide caregiving for a variety of reasons, ranging from commitment, duty and obligation to financial constraints and social expectations. Describing caregiving responsibilities as an "act of love" oversimplifies what can be very complicated motivations, and describing care recipients as "loved ones" implies a single, all-consuming motive for giving care; both can be problematic for informal caregivers and muddies the water on policymaking.

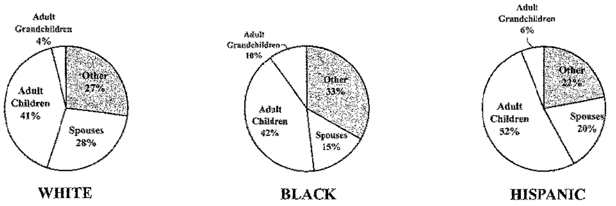
Families often are confronted with unexpected disability or disease and have no other option. For some, individual economic and personal circumstances allow them to provide informal care willingly and with good grace. Others may struggle economically, emotionally and physically with caregiving that is done with reluctance and perhaps even with anger or resentment. Gaps in the long-term care and support system often require informal caregivers to do more than is reasonable, including compromising their own health and retirement security. While many caregivers do step in and take personal responsibility, the motivations and consequences of this decision are complex and should not be taken lightly. By and large, however, family members do not express unwillingness to provide care.[18] In some cases, an individual's care needs increase to the point that formal care, including placement in a nursing home, is required. Informal caregivers, however, remain an invaluable and often irreplaceable provider of long-term care and support.

Chart D: Informal Caregivers to Family and Friends Age 50 and Older, 1997



Source: National Alliance for Caregiving, 1997.

Chart E: Caregiving Patterns by Racial and Ethnic Groups



SOURCE: National Academy on an Aging Society analysis of data from the 1993 study of *Assets and Health Dynamics Among the Oldest Old.*

PART TWO: THE SECOND SHIFT — THE CHALLENGE OF WORK/FAMILY INTEGRATION

GENDER MATTERS

As in many other facets of life, gender makes a difference when it comes to informal caregiving. Nearly three-quarters of informal caregivers to seniors are women.[19] The typical informal caregiver is a married woman in her mid-forties to mid-fifties — a baby boomer who is herself aging and increasingly likely to need long-term care and support.[20] She is employed full-time and also spends an average of 18 hours per week on caregiving.[21] In addition to juggling her career with caring for a parent, partner or spouse, she may be the primary caregiver for her children and increasingly, for her grandchildren as well.[22] Women with significant caregiving responsibilities often face mental, physical and financial stresses. Midlife women face these challenges while simultaneously being pinched by career and preparing for their own retirement. Multiple caregiving roles create even more pressure.

Caregiving is stressful in its own right and more so when combined with other demands. Emotional, physical and financial stresses are especially threatening to women, who are still assuming the primary caregiving role. Women on average provide 50 percent more hours of informal care per week than men.[23] Women also provide informal care for longer periods of time than men — in many cases, for over five continuous years.[24] As a result, women's health, earnings and retirement security are put at risk by informal caregiving, and increasingly so the longer they provide care. When combined with years out of the paid labor force for childrearing, caregiving can be an economic disaster for women.

> "WOMEN ON AVERAGE PROVIDE 50 PERCENT MORE HOURS OF INFORMAL CARE PER WEEK THAN MEN."

ACROSS THE GENERATIONS: INFORMAL CAREGIVING IN THE AFRICAN AMERICAN COMMUNITY

The prevalence of informal caregiving among African Americans is higher than the national average. While an estimated 23 percent of all U.S. households undertake informal caregiving, 29 percent of African American households have informal caregivers. Within African American households, 77 percent of caregivers are women, representing the highest proportion of female caregivers within any racial group.

Older African American women play a special role in their families. Nearly 12 percent of African American children reside with their grandmothers (compared to six percent of Hispanic and four percent of white children). Some researchers estimate that as many as 70 percent of African American children who live with their grandmothers live in urban, low-income areas. African American grandmothers undertake these caregiving efforts with little outside support. Sixty-two percent of African American households with grandparents raising grandchildren are headed by the grandmother only. In contrast, 63 percent of white households with grandparents raising grandchildren are headed by both grandfather and grandmother.

African Americans are particularly vulnerable to financial hardship resulting from informal caregiving, with a median annual household income of only $28,000. One-third of African American women who are informal caregivers have average incomes below $15,000 each year. This trend is likely in part due to the fact that women of color continue to experience severe pay inequities. In 1999, African American women earned only 65 cents for each dollar earned by a white man. The gap may result in part from legitimate differences in education, experience or time in the work force. A significant portion of the inequity cannot be explained by any of these factors, however, and would appear to result from discrimination. In other words, certain jobs might pay less simply because they are held by women of color. If these women are also informal caregivers, their chances of a secure retirement are even more compromised.

Sources: National Alliance for Caregiving, "Family Caregiving in the U.S." (1997); OWL, "The State of Older Women in America" (2001); University of South Carolina Institute for Families in Society, "Fact Sheet: African American Families" (1998).

EMOTIONAL AND PHYSICAL CHALLENGES OF INFORMAL CAREGIVING

Informal caregiving can have emotional and physical health consequences for caregivers. Although the overwhelming majority of adults who provide informal care to a parent age 65 or older say they feel loved, appreciated and proud of the care they provide, a substantial number feel worried, frustrated, sad, depressed or overwhelmed.[25] These emotional stresses can be accompanied by physical impairments as well. One-third of informal caregivers describe their health status as fair or poor.[26] In reality, the situation is worse. A 1992 study found that two out of three informal caregivers were in ill health.[27] Although most caregiving is short term, prolonged responsibilities take a toll on the emotional and physical health of caregivers.

Approximately one-third of informal caregivers are "very" or "somewhat concerned" about juggling caregiving with other aspects of life.[28] Caregivers worry about not having enough time to spend with their spouse, partner and children, or by themselves. Concerns about maintaining personal health or missing work as a result of caregiving are also common. Women worry about their ability to retire comfortably, particularly in the course of forgoing paid employment for informal caregiving.[29] A recent survey of women ages 25 to 55 found that 41 percent are worried they will live at or near the poverty level during retirement because they cannot adequately save during their working years.[30]

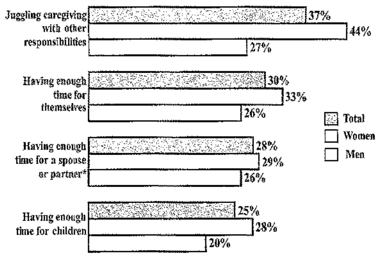
The loss of control over one's life that comes with caregiving in some cases leads to depression, which can impair a caregiver's ability to provide care and also endanger her own health.[31] The incidence of depression is higher among informal caregivers than in society-at-large.[32] Other common physical manifestations of caregiving stress include insomnia, indigestion, changes in appetite, or intensity of headaches.[33] Informal caregivers can become so overwhelmed with caregiving that they neglect their personal health until a crisis arises, and such crises are often costly. Women spend as much as 20 percent of their annual retirement income on out-of-pocket health care costs.[34] An expectation that they will bear additional health-related costs due to increased informal caregiving could have a devastating impact on their retirement security.

Attentive healthcare providers who consistently moniter the impact of caregiving work on their patients may be able to alleviate some of the emotional stress associated with informal caregiving.[35] While some physicians are now making concerted efforts to monitor the impact of this work on caregivers' emotional health, the cumulative stress of caregiving frequently goes unnoticed until an acute health condition arises.[36]

Health care providers similarly could help prevent some of the physical injuries experienced by informal caregivers, but current payment

Chart F: Emotional Stress Among Informal Caregivers

Percent of adults with a parent 65+ who are concerned about:



*Differences by gender are not statistically significant at p<.05

Source: Family Circle/Kaiser Family Foundation National Survey on Health Care and Other Elder Care Issues, 2000.

EL DERECHO DE LOS HIJOS SON LOS PADRES
THE SPECIAL STORY OF INFORMAL CAREGIVING AMONG LATINOS

Latinos are the fastest growing segment of the age 65 and over population. Projections indicate there will be 12.5 million Latinos age 65 or older by 2050, and that 4.5 million of those will have long-term care and support needs. Latinos face unique barriers to accessing formal services. In cases where adequate translation is not available, the inability to read or speak English may inhibit the dissemination of social services information to the Hispanic community. In other cases, negative experiences with the American healthcare industry may generate a lack of trust in long-term care and support providers. Finally, geography can be a significant barrier. As a result, informal caregiving is of particular importance to Latinos in America.

Family, friends and neighbors provide most informal care to older Latinos. From childhood on, Latinos are instilled with the importance of the duty to care for their elders. The common phrase "*el derecho de los hijos son los padres*" emphasizes that adult children should care for their older parents. The strong respect for informal caregiving among Latinos also has spiritual roots. Religious faith, or *fe*, helps many Latinos to trust that family, the community and a superior being will care for them during times of need.

Despite strong social support, older Latinos need more care than their informal networks often provide. Networks are being degraded as increased mobility disrupts Hispanic *barrios*. Despite the need for services beyond those provided by family and friends, older Latinos are more hesitant to ask for public assistance than their white, non-Hispanic counterparts. Thus informal caregiving is the system of long-term care and support for most Latinos in America.

Sources: M. Sotomayor and A. Garcia, *La Familia: Traditions and Realities* (1999); M. Sotomayor, *In Triple Jeopardy: Aged Hispanic Women* (1994).

> *"CAREGIVING DOESN'T JUST IMPINGE ON THE COURSE OF A CAREGIVER'S CAREER; IT CAN OFTEN PRECLUDE HER FROM WORKING AT ALL."*

systems do not reward them for doing so. Routine caregiver tasks such as heavy lifting and moving, changing of bedding, dressing, bathing and helping with the toilet can cause acute and chronic physical strain, particularly when caregivers lack appropriate training.[37] Forty-four percent of informal caregivers report physical strain as a result of their caregiving activities.[38] Stress imposed by daily caregiver tasks also may render informal caregivers more susceptible to illness. One study found that chronic stress in informal caregivers can weaken the caregiver's immune system.[39] Because the majority of informal caregivers are over age 50, their risk of experiencing health problems already is relatively high.[40]

THE VULNERABLE CARING FOR THE VULNERABLE: FINANCIAL CONSEQUENCES OF CAREGIVING

Informal caregivers often curtail their professional opportunities and imperil their financial security in old age. Fifty-four percent of caregivers in the paid labor force report their career is affected in some way by caregiving, which may require them to arrive for work late, leave work early, take unscheduled leave days or have intermittent absences during the workday.[41] Seven percent of informal caregivers who are employed report they moved from full-time to part-time work or took a less demanding job in order to accommodate their caregiving work.[42]

A DIFFERENT LENS: THE IMPORTANCE OF INFORMAL CAREGIVERS TO THE GAY, LESBIAN, BISEXUAL AND TRANSGENDER COMMUNITY

Gay, lesbian, bisexual and transgender (GLBT) individuals are particularly sensitive to the policy issues surrounding informal caregiving. Most caregiving is performed by family members, particularly spouses, daughters and daughters-in-law. Yet GLBT individuals are less likely to have these sources of support. They are more likely to live alone, less likely to have a partner, and less likely to have children. Access to informal caregiving is also restricted because the AIDS epidemic has dramatically increased the population of adults who need long-term care and support, while sadly reducing the number of people who might otherwise be available to provide care. For all of these reasons, it is especially important that public policy strengthens and supports informal caregiving in the GLBT community.

Currently, caregivers for GLBT individuals who do not fit into the heterosexual conception of "family" may encounter obstacles to obtaining information as well as appropriate acknowledgement from hospital and nursing home staff. In addition, caregivers for GLBT individuals are typically excluded from government and employer assistance policies, such as the Family and Medical Leave Act. Inclusive federal reforms are needed to better protect the health of GLBT informal caregivers and their care recipients.

Source: S. Cahill, K. South and J. Spade, *Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual and Transgender Elders* (2000).

In preparing for their retirement, Catherine and her late husband did everything right. Both had good jobs, and their peak earning years were ahead of them. They both had IRAs, they had their home, and they could count on a strong pension income from her husband as well as their Social Security benefits. What they didn't count on was Alzheimer's disease.

Catherine's husband was diagnosed with Alzheimer's in his 50's. Her husband subsequently retired after nearly 30 years with the same company—much earlier than either of them had expected and with a pension that was much smaller than they had planned.

For 18 years, Catherine was her husband's primary caregiver. Although they needed the money, she eventually left her job. "I couldn't do it all," said Catherine. "I had to stop work to give all of my time to Howard's care." In order to meet their needs, Catherine exhausted both their savings and IRAs, had to take her and her husband's annuity in a lump sum, and refinanced their home. Catherine now pays large monthly payments on a 30-year mortgage.

Soon after Catherine's husband died, she was diagnosed with breast cancer. At the time of her diagnosis, she had not had a mammogram in seven years. She was so consumed by caregiving and under such stress that she hadn't taken adequate care of herself. When you are caregiving, "everything else goes on the back-burner." Fortunately, Catherine's prognosis is good. She works full-time despite her illness in order to keep her health coverage and to meet the considerable out-of-pocket expenses of a cancer diagnosis. Catherine still feels like she is recuperating from that period of her life. "I would love to be thinking about retirement right now, but it is not in my foreseeable future," she said.

It is extremely difficult to balance caregiving with a career given society's reluctance to value informal caregiving and paid employment equally. Yet informal caregivers are expected to find this balance.

Caregiving doesn't just impinge on the course of a caregiver's career; it can often preclude her from working at all. Six percent of caregivers who were previously employed reported they stopped working because of caregiving, 11 percent took a temporary leave of absence, and another four percent took early retirement.[43] All told, roughly a quarter of caregivers who were previously employed stopped working for an extended period of time because of their caregiving roles.

The sacrifices that informal caregivers routinely make during midlife — a peak earning period — reduce lifetime earnings and retirement savings. A recent survey of caregivers estimated that caregiving caused an average loss of over $550,000 in the lifetime wage wealth of each respondent.[44] The same study estimated that respondents' Social Security payments decreased an average of $2,100 annually as a result of caregiving.[45] These figures would be even larger if losses associated with childcare were also included.

These economic sacrifices can be particularly devastating to older women, whose quality of life is seriously constrained by social and economic policies that are not responsive to their everyday experiences and life patterns. Retirement plans, both private pensions and Social Security, were designed in the first half of the twentieth century and thus mirror a set of cultural values that no long represent the reality of working peoples' lives. These policies often reward male work patterns and perpetuate traditional conceptions of family: a paid worker (usually the husband), an unpaid homemaker and caregiver (usually the wife), and children. The persistence of such stereotypes has helped to justify workplace segregation, lower wages for women workers, and place other restrictions on employment opportunities for women.

Income disparities continue to disadvantage women and are particularly harmful to informal caregivers in the paid workforce. More than 35 years since the passage of the Equal Pay Act, the wage gap still persists, especially for women of color. In 1999, Hispanic women earned 52 cents for each dollar earned by a white male, while African American women earned 65 cents on the dollar.[46] Overall, women earned only 72 percent of what white men earned.[47] These financial constraints constitute another stressor as women struggle to meet the financial demands imposed by informal caregiving. These wage inequities also are directly related to high poverty rates among women aged 65 and older.

While pay inequities are of real concern, it is the time away from work that negatively affects a caregiver's earning power today as well as her retirement security tomorrow. As traditional family constructions continue to shape pension and wage policies, women living alone who have spent several years as a caregiver are significantly vulnerable to poverty in retirement. Although recent census bureau data demonstrate the percentage of people in poverty age 65 and over has reached an all time low of 9.7 percent, women in the 65 and over age group are more likely than men to live in poverty.[48] In 1999, 12 percent of older women were poor, compared to seven percent of older men.[49] As the number of women who provide informal caregiving increases — and if caregiving continues to negatively impact women's earning power — the number of poor older women will inevitably increase as well.

For 54 years, Dorothy has cared for her son Clayton. He has cerebral palsy and has always required significant care. He needs assistance with bathing, feeding, and using the restroom. Clayton can't stand on his own and needs help in and out of the wheelchair, bed, cars, and chairs. And Dorothy has always been there to help him. Now 75, she has spent the majority of her life as a caregiver, not only caring for Clayton but also raising her two daughters.

In order to deal with the financial pressure of caregiving, Dorothy has worked part-time over the years. Until her husband died in 1979, Dorothy worked nights in office and retail jobs, never making more than $5.00 an hour. Dorothy now relies on her $1100 Social Security check to cover the monthly bills, and depends on Clayton's $800 in Social Security benefits to pay for food and some savings for his future.

But, the financial stress is still significant. The medicine Clayton requires, to prevent seizures and for other health problems, is paid for out-of-pocket every month. "Medicare doesn't cover the cost of his prescriptions and our health insurance only covers a portion of the cost as long as it is a generic brand," said Dorothy. "Only one of his prescriptions is generic."

According to Dorothy, she has always felt an obligation as a parent to care for Clayton and to do whatever possible to make his life better. Still, she is quite aware of the value of her caregiving. "Somebody is getting a good deal," she said, "if Clayton was in an institution, it would cost upwards of $3000 a month, but I do it for $800."

Dorothy continues to care for her son, while coping with the emotional and financial impact it has on her life. "We can't get out as often as we used to—maybe twice a week—and we're thankful for the help of our family," said Dorothy. "To keep my sanity, I do a lot of reading, have faith in God, and a sense of humor."

IN A PINCH: CLUB SANDWICH GENERATION CAREGIVERS

Between 20 and 40 percent of caregivers are members of the so-called "sandwich generation," caring for children at home in addition to older family members.[50] Others who care for a partner or older relative, a child or a grandchild may also be caught in the "club sandwich generation," with three or more layers of caregiving responsibilities. These subgroups of informal caregivers may be

GRANDPARENTS RAISING GRANDCHILDREN

- 5.4 million children live in households maintained by grandparents or other non-parent relatives (parents may also be present).
- Half the 5.4 million children being raised by grandparents are under the age of six.
- 1.4 million children live with grandparents in households with no parents present.
- 44 percent of the 1.4 million children are white, 35 percent are African American and 18 percent are Hispanic (all races).
- 27 percent of children living with grandparents live in poverty and 33 percent are uninsured.
- If even half of the children being cared for informally by grandparents and other relatives were to enter the formal foster care system, it would cost the nation an additional $4.5 billion annually.

Source: Generations United (2000).

Josephine, a 67-year-old African American woman, knows first-hand what it means to be sandwiched by the caregiving needs of three generations. She has simultaneously cared for her mother, her adult daughter, and her two grandchildren while struggling with the impact it had on all of their lives.

When her daughter was diagnosed with breast cancer, Josephine was already caring for her mother with Alzheimer's disease and her grandson who lost his father (Josephine's son) in a car accident. In addition to now caring for her daughter, she became responsible for her daughter's child as well. As the primary caregiver and sole provider for her family members, she has coped with great emotional, physical, and financial stress.

Like many informal caregivers, Josephine left her job in order to care for her family, greatly affecting her standard of living and her own retirement security. With the exception of her mother's $400 monthly Social Security benefit, Josephine has been the sole financial provider for her family. In order to supplement her fixed income and meet their needs, she enrolled in a food subsidy program. To pay for her daughter's medication, Josephine participated in a medical indigent program administered by a pharmaceutical company.

For years, Josephine took care of her mother, daughter, and grandchildren. She bathed and fed her daughter while also meeting the individual needs of her mother and grandsons. "As a result of the cancer, my daughter had become paralyzed and could not do these things for herself," said Josephine. And there wasn't any support to help Josephine care for her daughter or other family members. It took eight months for Josephine to find home health care for her daughter. "Help arrived one week before my daughter died, and SSI went into affect three weeks after her death," she said. Josephine's mother and daughter died within eight days of each other.

Josephine remains the primary caregiver and guardian for her two grandsons, 11 and 13. She simply cannot afford to retire. In order to supplement her limited income from Social Security, Josephine works as a home nursing consultant – a paid caregiver.

> *"AS THE NUMBER OF WOMEN WHO PROVIDE INFORMAL CAREGIVING INCREASES — AND IF CAREGIVING CONTINUES TO NEGATIVELY IMPACT WOMEN'S EARNINGS POWER — THE NUMBER OF POOR OLDER WOMEN WILL INEVITABLY INCREASE AS WELL."*

even more susceptible than informal caregivers generally to the emotional, physical and financial stresses of informal caregiving. Because women are more likely than men to assume caregiving roles, they also are more likely to be sandwiched by the caregiving needs of two or more generations. Members of the sandwich generation tend to be midlife and have additional challenges ranging from adapting their professional skills to a changing work environment to planning for a secure retirement.

The sandwich and club sandwich generations are expected to grow as a result of increased longevity and greater numbers of women having children later in life. Whereas previous

With one son in elementary school and another in high school, Donna, now age 58, never anticipated she would also be caring for her mother. But when her mother had a stroke in 1986, Donna's life situation changed dramatically.

Donna's mother was given three months to live when Donna first decided to take care of her at home. That was fifteen years ago, and Donna continues to care for her 87-year-old mother, who now needs 24-hour care. Donna's mother cannot walk or stand, is both bowel and bladder incontinent, is fed through a tube, and does not speak. With the exception of part-time assistance from an adult day care agency and some help from an aide, Donna is her mother's primary caregiver. Taking care of her mother has become a significant part of Donna's life. "I always try to make her as comfortable as possible," said Donna, "I also think about her dignity. This is my mom and I have to bathe her and change her briefs. I don't want to make her uncomfortable." According to Donna, it has been a labor of love.

Donna's health has been affected by caregiving. "Even if you've been told how to move a person, if they start to slip and slide, you don't think about the proper way to hold them," said Donna. She suffers from chronic low-back pain and has also sustained acute injuries. Two years ago, Donna injured her knee while helping her mother out of her wheelchair;the injury required surgery.

For years, Donna cared for her mother while also raising two children. Donna and her husband made every effort to keep their family life as stable as possible while balancing everyone's needs. Donna's mother sometimes would get agitated when her son's friends were over or if their music was too loud. "I told her that it was their house too," said Donna. "Everyone had a space in the house to pursue what they wanted, and I would move my mother to another room if needed."

Since her mother could not be home alone, Donna often brought her along on errands and to school-related events for her youngest son, Chris. Donna said that even at a young age, Chris understood that just as he had been cared for by grandma, it was their turn to care for her. According to Donna, her children have experienced both the difficult and the good times of caring for her mother. "No matter how stressful the day had been, I made a conscious choice when to tell my family different things," she said. "I didn't want my kids thinking about my awful day and holding it against their grandmother, because not all days are difficult—some are great. It's been my secret to survival."

generations lamented the "empty nest" feeling in midlife when their children left the home, members of today's sandwich and club sandwich generations are increasingly likely to have dependent children and/or grandchildren at home well after age 50. This trend, coupled with increasing life expectancies for seniors, suggests that caregivers will be sandwiched at record rates in the years to come. Demographic trends also suggest that caregivers themselves will be older, which will only increase the health and financial risks of caregiving.

As a young mother, Lynn planned on pursuing a professional career. But when her daughter was born with severe mental retardation and needed extensive care, Lynn put her career on hold.

For eight years, Lynn managed the substantial caregiving needs of her daughter at home, while caring for her other two children as well. Her daughter's condition was severe and eventually Lynn could no longer provide adequate in-home care. Lynn subsequently placed her daughter in a children's medical facility where her daughter could get the level of care she needed.

However, this transition only exaggerated the financial pressure the family was already facing. At the time, financial assistance was not available, and all of Lynn's daughter's medical bills were paid out-of-pocket. One year, Lynn and her husband earned $4500 while medical bills mounted to $2800. "Eventually, this extreme circumstance took its toll on my marriage, and I was left alone to care for my two sons and my daughter," said Lynn. In order to take care of her children, she worked three part-time jobs and hired babysitters. Lynn raised and cared for her children on her own, while dealing with the intense financial hardships that would undermine her retirement security.

At the age of 52, Lynn decided to pursue that professional career. She returned to college, earned both a Bachelors and Masters degree, and began teaching. And once again, she became a primary caregiver, caring for her mother until she died.

Now 64, Lynn continues to teach and would like to retire next year, but she struggles with how her caregiving has affected her retirement security. She worries she will not be able to keep her house and that her fixed income will place her close to the poverty level. "This kind of interruption of earning is a woman's phenomenon, as we are usually the caretakers," said Lynn.

Even today, the number of grandparents who are primary caregivers for their grandchildren has increased dramatically. The number of households with a grandparent raising grandchildren without a parent present increased by 53 percent between 1990 and 1998.[51] Given that over 60 percent of these grandparents are baby boomers between the ages of 45 and 65, their likelihood of at some point also caring for an older relative, an aging partner or both, is great.

Part Three: Employer-Based Caregiver Policies

The aging population and increasing demand for informal caregiving also present significant challenges in the workplace. These challenges will grow as baby boomers age and the proportion of informal caregivers in the workforce rises. Given that nearly 75 percent of informal caregivers and 46 percent of the workforce are women, employers have a vested interest in developing creative policies that allow informal caregivers to succeed in their dual and often competing roles.[52]

Some policy experts have suggested that informal caregiving may in fact be inconsistent with full-time employment and preparation for a secure retirement.[53] Women who provide two or more hours per week of informal care work 43 percent fewer hours over the course of a year than women in the paid workforce overall.[54] And while the hours of male caregivers are also reduced, there is a gender disparity: caregiving men work 28 percent fewer hours than working men overall.[55] Employers have sound economic reasons to adopt policies that assist working caregivers with their daily balancing act.

WHAT'S GOOD FOR THE CAREGIVER IS GOOD FOR THE EMPLOYER

Informal caregiving subjects both caregivers in the paid workforce and employers to a variety of stresses. Studies have attempted to quantify the cost to employers of disrupted full-time work and turnover caused by the demands of informal caregiving on employee time. One study estimated that U.S. employers spent at least $11 billion in one year on workforce costs associated with informal caregiving.[56] Almost $5 billion of that amount was attributed to the cost of replacing workers who quit or retired early due to informal caregiving demands.[57]

Informal caregivers in the paid workforce also lose financially. They are often forced to curtail professional opportunities and commitments, which typically result in lost wages and promotions as well as diminished earning potential. Further, their retirement savings are significantly reduced by penalties for early retirement. The costs of informal caregiving to employers and employees are expected to increase with each baby boomer retirement in the years ahead.

In addition to workforce replacement costs, employee absenteeism (leave time, late arrival or early departure from work) can be costly for employers and their workers. Total employer costs related to employee absenteeism are estimated to be almost $900 million a year. The time supervisors spend arranging coverage for absent caregiving workers is estimated to be over $800 million a year.[58] In addition to these employer costs, the wages of employees who are informal caregivers are reduced. Time spent away from paid employment for informal caregiving translates into lost wages and savings potential for caregivers, and in many cases, caregivers' occupational choices are limited by the need for scheduling flexibility.

In the absence of a comprehensive program offering long-term solutions, caregiving responsibilities will eventually touch nearly all workers' lives, male or female. Employers who fail to respond to informal caregivers' needs will face unnecessary costs and will be at a competitive disadvantage in tight labor markets.

A TREND TOWARD ACKNOWLEDGING INFORMAL CAREGIVING

Some American businesses have emerged as leaders in recognizing informal caregiving. Labor unions also have contributed to the progress by negotiating contract language that addresses childcare and eldercare needs, or by offering informational resources, referrals or direct services to members and retirees.[59] Flexible scheduling of work hours (including flextime, telecommuting options, job sharing and

> "THESE ACTIVITIES DO PROVIDE MORE TIME FOR CAREGIVERS AND CERTAINLY EASE THE IMPACT OF CAREGIVING ON THE EMPLOYER, BUT THEY CAN STILL LEAVE CAREGIVING WOMEN ECONOMICALLY SHORT-CHANGED IN RETIREMENT."

compressed workweeks) is an example of a common workplace policy designed to address the needs of workers who are informal caregivers. These activities do provide more time for caregivers and certainly ease the impact of caregiving on the employer, but they can still leave caregiving women economically shortchanged in retirement. Job sharing, for example, is sometimes just a euphemism for going part-time. It glosses over the potential consequences such as a loss in pay and seniority, and the decrease or elimination of employee benefits such as pension coverage, health insurance, and protections under the Family and Medical Leave Act.

A DIFFERENT VOICE: SOME FACTS ON INFORMAL CAREGIVING AND ASIAN AMERICANS

Characteristics of Asian American informal caregivers are unique in several respects:

- Asian American men and women do a better job of sharing caregiving work than the national average. Of all Asian American caregivers, 48 percent are men, and 52 percent are women. Among caregivers nationwide, 72.5 percent are women.
- Asian American caregivers tend to be younger. The national average age of caregivers is 46, while the average age of Asian American caregivers is 39.
- Asian American caregivers have a median annual household income of $45,000, compared to $35,000 nationally. As a result, Asian American caregivers are more likely to purchase formal respite or adult day care services to supplement their unpaid work.
- The income disparities may in part be attributed to a greater percentage of Asian American caregivers being employed outside the home (77 percent vs. 65 percent nationally), which in turn may be attributed to the fact that Asian Americans spend an average of 15 hours per week (as opposed to 18) on caregiving activites.

Source: National Alliance for Caregiving, *Family Caregiving in the U.S.* (1997).

Another workplace alternative includes making financial assistance available to caregivers, with or without an employer subsidy. For example, some employers offer flexible benefit spending accounts and cafeteria plans. Employees can channel up to $5,000 in pre-tax wages to an employer-established account, which can be used to pay for eligible caregiving services. The accounts are most useful for dependent childcare expenses because the uniform federal definition of "dependence" applies more readily to children than to parents or other adults.

Additionally, direct care services, such as adult day care, are targeted benefits that may not fit the needs of all caregivers and care recipients. For example, the care recipient may be homebound or may resist enrollment in an adult day care program. Given the often-changing needs of care recipients, a program that provides only a single service may be of limited use to a caregiver at any particular moment in time.

PART FOUR: PREPARING FOR THE FUTURE — FEDERAL EFFORTS TO ASSIST INFORMAL CAREGIVERS

A patchwork of state and federal policies to assist informal caregivers has emerged in recent years, but even when considered collectively, they fall short of meeting the increasing needs of informal caregivers. At the federal level, the Family and Medical Leave Act, the National Family Caregiver Support Program, and the Social Services

Block Grants are the primary sources of help for informal caregivers.

THE FAMILY AND MEDICAL LEAVE ACT

The Family and Medical Leave Act (FMLA) was enacted in 1993 in response to changes in the American workforce. By the early 1990s, when the most recent census data were released, over 60 percent of U.S. women were in the workforce compared to just 30 percent in 1950.[60] Nearly 60 percent of mothers of young children were in the workforce in 1990, and a substantial number were single parents.[61] Women in the paid workforce also were caring for ill family members — and in some cases, cared for the ill in addition to their children.

Women and men in the paid workforce risked losing their jobs and important workplace benefits like health insurance if they took significant leave around the birth or adoption of a child or to care for a sick family member. The FMLA attempted to respond to this dilemma by ensuring workers up to 12 weeks of unpaid leave each year for these purposes. The FMLA was an important step forward and has aided many working informal caregivers. The law is only a federal minimum floor of protection, however, with significant limitations.

First, the law applies only to firms with at least 50 employees. Employees also must work slightly more than part-time (1250 annual hours) to be eligible for leave. The Department of Labor estimates that approximately 40 percent of the workforce is employed by firms that are not covered by the law.[62] This requirement leaves nearly half the workforce ineligible for FMLA-covered leave.

Second, the leave guaranteed by statute is unpaid leave, which has caused some to advocate for an amendment requiring paid leave for covered

By the time she was 15 years old, Roz was already a caregiver. Roz's mother had schizophrenia and depended on Roz for help and care. As a young adult, Roz was constantly working and constantly being fired as a result of the time off she needed to take care of her mother. "I thought everyone lived this way and cared for their mothers when they were ill," said Roz.

Roz didn't just care for her mother; she cared for her brother as well. Roz's brother also had schizophrenia and desperately needed care. Just as she cared for her mother, she cared for her brother, even as it impacted her own financial and emotional health. "It was not convenient, to say the least, for the both of us to cut ourselves off from the world, but there was no alternative," she said.

Because of her brother's needs and his condition, Roz took care of him at home. Roz's brother had only a small income provided by the state of Florida, and he had a minimal work history as a result of his illness. They did receive some support from Medicaid, but not enough to significantly relieve the financial pressure. "For six years, we lived in abject poverty, just barely able to pay for his medications," said Roz.

Since her brother passed away, Roz has not been able to fully recover from the impact caregiving has had on her life. She has yet to recuperate especially from her financial collapse. And she still struggles emotionally, often wrestling with a sense of guilt that she didn't do enough. "At this stage in life, I don't have the strength to care for anyone anymore," said Roz. "I find myself running away from people, rather than gravitating towards them," said Roz."

"If we have enough money as a nation to build up our military and to consider giving a tax break for the rich, we must show some humanity to helping those young people who haven't gotten started in life," said Roz.

employees. Because the median income for working caregivers is $35,000 a year, it may not be realistic financially for an informal caregiver to take 12 weeks of unpaid leave. The Department of Labor reported earlier this year that of all employees in the paid workforce (regardless of eligibility for FMLA), 3.5 million workers who needed leave for an FMLA-covered event did not take it.[63] Of those 3.5 million workers, 78 percent reported they could not afford to take unpaid leave.[64] Among those who did use leave, almost 60 percent reported that it was "somewhat" to "very difficult" to make ends meet during the period of leave.[65] These concerns may be particularly strong for women, who on average earn only 72 percent of men's earnings for comparable work.[66] Reforming the FMLA to require a minimum amount of paid leave for covered events would address these barriers.

The FMLA allows unpaid leave only to care for a specific group of family members: self, a child, a spouse or a parent. It notably does not cover domestic partners, in-laws, siblings, grandparents or grandchildren. It also does not cover friends, to whom 29 percent of informal care is provided.[67] A recent study examining the tendencies of employees to take time off work to care for new children or ill family members found that employees between ages 50-64 have taken time off with increasing frequency in recent years.[68] The reasons for taking time off have shifted from personal health to caring for a spouse, child or parent.[69] The FMLA is a strong starting point for reform, but its benefit is not an adequate answer for many informal caregivers in the paid workforce.

In addition to the shortcomings of the law itself, workplace culture can make it difficult for women in the paid workforce to fully avail themselves of the FMLA's protections as a practical matter. While employers generally accept childcare and maternity or paternity leave as important family issues, supervisors and managers may be less inclined to allow leave and flexibility for family caregiving issues other than childcare. In many fields, job success is dependent on performance as well as time spent in the workplace. "Face time" with a supervisor or maintaining long hours can be an important factor in success, regardless of productivity or efficiency. Workers who aspire to professional advancement – and the payoff in higher compensation — may be reluctant to use the full benefit of the FMLA (or any other employer leave policy) for fear their career potential or earning power may be compromised. In fact, recent research highlights employee concerns with the negative impact of using leave for FMLA-covered events. Among employees who

THE FAMILY AND MEDICAL LEAVE ACT AT A GLANCE

FMLA Applies to:

- Employers with 50 or more employees
- Employees who have worked for at least 12 months
- Employees who work at least 1250 hours per year

FMLA Provides:

- Up to twelve weeks of unpaid leave each year
- Guranteed employment and health benefits for the duration of the leave
- Leave available upon the birth or adoption of a child, or to care for self, a spouse, a child or a parent during illness

"THE FMLA ALLOWS UNPAID LEAVE ONLY TO CARE FOR A SPECIFIC GROUP OF FAMILY MEMBERS: SELF, A CHILD, A SPOUSE OR A PARENT. IT NOTABLY DOES NOT COVER DOMESTIC PARTNERS, IN-LAWS, SIBLINGS, GRANDPARENTS OR GRANDCHILDREN. IT ALSO DOES NOT COVER FRIENDS, TO WHOM 29 PERCENT OF INFORMAL CARE IS PROVIDED."

reported not taking needed leave, over 40 percent felt their career advancement would be compromised.[70]

THE OLDER AMERICANS ACT

The Older Americans Act of 1965 (Act) provides essential home and community-based services for seniors.[71] The Administration on Aging (AoA) within the Department of Health and Human Services (HHS) administers a wide variety of services under the Act, including nutrition programs, transportation services, senior centers, health promotion programs, a nursing home ombudsperson, legal services, public benefit outreach and counseling, and elder abuse prevention. The AoA also has recruited approximately 500,000 volunteers who assist in delivering services under the Act.

Congress launched the National Family Caregiver Support Program (NFCSP) with the 2000 reauthorization of the Act.[72] President Clinton originally

Edith, 71, and her partner, 69, have been together for 36 years. Thirteen years into their relationship, Edith's partner was diagnosed with chronic progressive Multiple Sclerosis. For many years, Edith has cared for her partner while struggling with the emotional, physical, and financial impact it has had on her own life.

Shortly after her partner's diagnosis, Edith made the decision to leave her 16-year career with IBM so that she could move in with and take constant care of her partner. "It was important that my partner, who is a clinical psychologist, still be able to work, even though she is confined to a wheelchair and needs round-the-clock care," explained Edith. "I left my job to help care for her and so that she could continue working."

After years of caring for her partner alone, the physical stress became too great. Edith suffered chronic pain, constantly hurting her back and arms as a result of moving her partner. "It got to be too much, especially after I suffered a heart attack in 1996 that required emergency bypass surgery," said Edith. In order to relieve some of the pressure, Edith hired a home health aide to assist during the day.

Since hiring the aide, Edith and her partner's private life has been greatly affected. "For 12 hours a day we are 'in the closet'," said Edith. "When the aide goes home at 8:00p.m. it feels like we have been let out of prison. Since my partner is handled a great deal—she needs catheterized 5 times a day—we feel that we can't risk exposing our sexuality to people's ignorance and worry about potential mistreatment. If it comes to a point where we need help 24 hours a day, that's the end of our privacy."

In addition to the emotional and physical stress, Edith and her partner struggle with significant financial strain. Even though Edith and her partner have saved and invested, and continue to earn an income, annual out-of-pocket prescription costs nearing $14,000 and the costs of home health care continue to drain their resources. In order to better secure their financial stability, Edith returned to work part-time for three years. "We've got our investments lined up and as an emergency comes up, I deal with it," said Edith. "But by the time everything is alright, I am ready to collapse."

proposed NFCSP in 1999 as part of a broader long-term care initiative.[73] Under a $125 million appropriation, the program is intended to provide informal caregivers with information, training, counseling and respite services. It is the largest new assistance program under the Act since Congress established nutritional programs for older Americans in 1972.

HHS approved the release of $113 million in grants to state Agencies on Aging in February 2001 to fund programs that assist informal caregivers providing care for older Americans or grandparents raising grandchildren. The grants will be distributed to states through a congressionally mandated formula. Allocations range from $564,300 for states including Alaska, Delaware, District of Columbia, Hawaii, Idaho, Maine, Montana, New Hampshire, South Carolina, Vermont and Wyoming, to $11.3 million for California. State Agencies on Aging are expected to work with local Agencies on Aging to deliver services to informal caregivers. Up to 10 percent of the funds can be used to provide supportive services to grandparents raising grandchildren.

> *"INFORMAL CAREGIVERS PROVIDE MORE LONG-TERM CARE AND SUPPORT IN THE HOME — FREE OF CHARGE AND WITH LIMITED SUPPORT — THAN THE FEDERAL GOVERNMENT PROVIDES IN ALL SETTINGS COMBINED."*

The NFCSP also authorizes "competitive innovative grants" to assist in the development of caregiver assistance systems. A special program to assist informal caregivers of Native Americans will also be developed under the NFCSP. Finally, in addition to the funding elements of the NFCSP, training and technical assistance will be made available to state Agencies on Aging.

While the informal caregiver assistance community has shown mixed reaction to the NFCSP, especially with regards to its rather modest funding, it provides an important opportunity to bring together community agencies to meet the needs of caregivers, and broadens the role of the aging network.

SOCIAL SERVICES BLOCK GRANT PROGRAM

The Title XX Social Services Block Grant (SSBG) program is a third federal resource available to assist informal caregivers and care recipients.[74] The program was enacted in 1981 and gives states great latitude in providing services to their most vulnerable citizens. Services provided by states with SSBG funds include transportation, meals-on-wheels, and home-based services for older Americans and people with disabilities. Many states distribute SSBG funds to local nonprofit agencies, which contribute additional resources to the delivery of social services.

The degree of assistance available to informal caregivers through the SSBG program is limited in two important respects. First, the funding available under the program is limited and dwindling. Fiscal year 2001 funding for the SSBG program is significantly lower than the fiscal year 2000 funding level. Second, most of the programs made possible by SSBG provide support to care recipients but not to their caregivers. While such services can indirectly assist informal caregivers by reducing the amount of assistance requested of them, additional programs aimed directly at informal caregivers would be extremely helpful.

LONG-TERM CARE INSURANCE: A RED HERRING

Lacking a sufficient public source of support for long-term care and support, some individuals have turned to private insurance to meet their needs. The long-term care insurance industry reports that insurance policy sales increased an average of 22 percent per year between 1987 and 1996. While most policies are sold in the individual market, a growing number of employers are providing access to policies through the workplace. By 1998, 800,000 of the policies sold were obtained through 2,100 employers. Although most employers do not contribute to premium costs, employer-offered policies tend to be more affordable because agent commissions are eliminated, administrative costs are reduced, and underwriting can be limited or eliminated.

Despite market growth, there are several important limitations to long-term care insurance. For example, many policies offer fixed benefits, and pay a set dollar amount per day for the type of service used. It is not clear that fixed-benefit policies purchased today will reflect the cost of long-term care and support many years from now when a policyholder may need the coverage. Second, policies may have limited portability when employees move or change jobs. To the extent a current employer contributes to insurance premiums, it is not clear whether a policyholder will maintain coverage if she changes jobs. Finally, purchasers are not well protected from large premium increases over the life of a policy, which may make the policy unaffordable after the purchaser has paid in for a number of years. While there are provisions in many policies to pay some minimal benefit in the event a policy lapses, the protection offered is often inadequate.

Long-term care insurance policies may be an option for some segments of the population, but they do not provide a complete answer to the nation's growing long-term care and support needs.

PART FIVE: POLICY RECOMMENDATIONS

On many levels, society depends on women to meet the needs of older Americans, people with disabilities, and people with chronic illness. The economic value of informal caregiving is substantial, and the social value is incalculable. Researchers estimate that the value of caregiving responsibilities regularly assumed by friends and family members was almost $200 billion in 1997.[75] In comparison, federal spending for formal home care in the same year was only $32 billion, with an additional $83 billion for nursing home care.[76] Informal caregivers provide more long-term care and support in the home — free of charge and with limited support — than the federal government provides in all settings combined.

In addition to the real dollar value of unpaid care, in most instances individuals in need of long-term care and support prefer to remain at home and in the community for as long as possible, rather than receive care in an institutionalized setting. In the absence of a reliable source of informal caregiving, or in the face of particularly intensive care needs, individuals in need of care are left with few choices but to seek care in an institutionalized setting. While current public policy supports institutional care — the type of care that those in need typically do *not* prefer — society relies almost exclusively on informal caregivers to provide the type of care desired by most care recipients.

The public sector could take a variety of steps to support informal caregivers. In the context of considering proposals to reform the Medicare and Social Security programs, Congress has an opportunity to evaluate how those programs could better assist and support the informal caregiving provided by all caregivers, whether or not they are in the paid work force. Other public sector policies are more indirect and could help the private sector respond better to the needs of informal caregivers in the paid workforce.

PUBLIC POLICY RECOMMENDATIONS TO SUPPORT INFORMAL CAREGIVERS

Expand the Family and Medical Leave Act (FMLA) to Make It More Inclusive and Effective: The Family and Medical Leave Act should be revised in a number of ways to overcome many of the current limitations. First, there should be a broader definition of immediate family member whose care qualifies as a covered event. Second, the law should be expanded to cover smaller workplaces. To the extent that small businesses express concern with such an expansion, consideration should be given to tax policies to help mitigate any adverse impact. Third, the FMLA should be amended to extend prorated benefits and protections to caregivers who work less than the current minimum of 1250 hours a year or who have worked for a particular employer for less than a year. Fourth, serious consideration should be given to wage supplementation during a period of leave to enhance utilization of the benefit.

Finally, federal policymakers should expand the worker benefits that are protected under the law. Like the mandatory continuation of health benefits under current law, the FMLA should also require employers to continue any employer contributions to qualified retirement plans during a covered leave period. This requirement would ensure that caregivers do not risk their own retirement as a result of their commitments to family and community. Given their higher rates of poverty in retirement, this is a particularly critical issue for women

Modify the Medicare program to Support Informal Caregiving: The Medicare Program should become a reliable partner for informal caregivers. First, Medicare should be amended to allow informal caregivers who do not have access to employer-sponsored coverage, and who care for Medicare-eligible or enrolled spouses or other Medicare-eligible or enrolled relatives, to buy into Medicare. Women who leave the workplace early or shift from full-time to part-time jobs to be caregivers can lose access to affordable health insurance. Women without coverage will sometimes forgo preventive medical care, diagnosis and treatment, which can result in more serious and costly illness down the road. In light of the numerous emotional, physical, and financial stresses caused by informal caregiving, access to affordable health insurance is crucial.

Second, the Medicare program should be amended to provide a comprehensive prescription drug benefit. Prescription drugs are a critical component of health care for older Americans and people with chronic illness or disabilities. A Medicare prescription drug benefit is of vital importance to people in need of informal care as well as to those who care for them. Affordable prescription drugs help individuals maintain their health and functioning, which could reduce the need for informal care and perhaps prolong their ability to provide such care.

In addition to an outpatient prescription drug benefit, there is a growing consensus that the Medicare benefit should be modified in other ways to better reflect the evolving needs of the senior population and the changing health care delivery system. Any discussion of "modernizing" Medicare's benefit package should recognize that Medicare has a critical role to play in meeting the chronic health care needs of beneficiaries, which in turn will limit medical emergencies, prevent excess disability, and support informal caregivers. Medicare should provide a chronic care benefit and cover respite care, adult day care, and other community based long-term care and support services.

Create a Dependent Care Tax Credit Building on the Childcare Tax Credit: The existing childcare income tax credit is designed to compensate in a small way for the childcare costs of working parents, but it does not offset broader dependent care costs. For example, unemployed parents are eligible only if they have more than two children, and the credit is non-refundable. This tax credit has a number of shortcomings, including a restrictive definition of "dependence." The test of "dependence" should be made less restrictive in terms of the dependent care reimbursement account and patterned more closely after the California informal care tax credit law. The credit should also be refundable. The proposed caregiver tax credit is a good start, but the requirement that a doctor certify that a care recipient needs assistance with three or more ADLs may be overly restrictive.

Strengthen Social Security by Recognizing the Work of Informal Caregivers: Informal caregivers who work less than full-time or who take a leave of absence from work should not be penalized in retirement. There are at least two approaches to help ensure that benefits are not reduced in retirement due to caregiving during working years. One approach is to disregard up to five years of lower income when calculating Social Security retirement benefits if income has been reduced due to unpaid caregiving. For example, a worker who moves from full-time to part-time work or who leaves the workforce temporarily to provide care should not have that period of lower income included in a Social Security base year computation. Alternatively, a worker could receive credits in the Social Security system for up to five years of work for unpaid caregiving. Either of these revisions to the Social Security Act would help reduce the extent to which women are penalized in retirement for fulfilling caregiving responsibilities during prime earning years.

Provide Greater Support for Public Caregiver Assistance Programs and Innovations: Funding for federal and state programs that assist informal caregivers by providing information, training, referrals and respite care should be expanded. For example, the National Family Caregiver Support Program should be expanded.

Improve Pension Coverage for Caregivers in the Paid Workforce: Federal pension law should be revised to better protect the retirement security of caregivers. While pension reform will benefit all women, it particularly resonates with the needs of women who are informal caregivers. Pension law should be amended to reduce vesting requirements from five to three years, which better reflects women's work patterns. Leave time under the Family and Medical Leave Act should count as service time and should accrue to help meet any pension vesting requirements. Such revisions would allow more women to qualify for pension coverage and would also help protect informal caregivers who move in and out of the paid workforce due to caregiving. Further, employers should not be allowed to exclude part-time and temporary workers from pension benefits or contributions as the law currently permits. Women who work part-time because of informal caregiving are particularly affected by this policy.

PUBLIC POLICY RECOMMENDATIONS TO AID COMMUNITIES AND BUSINESSES

Create Incentives Through Tax Policy: Tax policy should provide incentives to the private sector to develop programs that assist women in the paid workforce who provide informal care. While there should be tax incentives for the whole range of caregiver assistance services that employers might provide, the incentives should provide the greatest benefit for employer policies that promote the development of eldercare programs and services made available to the entire community.

Build a Larger Workforce of Formal Caregivers: Federal policy should be designed to improve the quality and quantity of the formal caregiving workforce such as home health workers. Formal caregivers assist and supplement the work of informal caregivers and play an important role in providing comprehensive care to individuals requiring long-term care and support. Public program reimbursement should be adequately targeted to formal caregivers. Additionally, public policies and programs should be designed to provide low-wage health care workers with access to affordable health insurance when their employers do not provide such benefits. Low wages and lack of benefits create high turnover among portions of the health care workforce, adding to the work of informal caregivers.

Make Dependent Care Spending Accounts Applicable to Eldercare: Dependent care spending accounts offered by employers to employees have been successful in offsetting childcare expenses but have been less successful with expenses related to eldercare. They would be useful to workers with eldercare costs if federal tax policy were changed to allow more claims for eldercare. For example, the definition of "dependence" should be modified so that adult family members would not be required to spend eight hours a day in the home of the worker in order to qualify.

Current rules also require that any unused portion of the spending account revert to the employer at the end of a year. Allowing unused funds to roll over at year's end would permit greater flexibility for eldercare costs, which, unlike childcare, can vary significantly from year to year. Additionally, employees should have at least two opportunities during the course of a year to establish and fund a dependent care spending account. Current law permits only one opportunity per year.

CONCLUSION

America lacks an effective system to address caregiving. As a result, caregivers – the majority of whom are women — are often pushed beyond their means and suffer long-term consequences as they struggle to meet the caregiving needs of those who depend on them. The demographics are clear, and now is the time for Congress and the Administration to take the appropriate steps to head off a national caregiving crisis. Federal policymakers have a unique opportunity to make important reforms designed to benefit informal caregivers in the context of examining the Medicare and Social Security Programs. The aging population and increased longevity are two trends that could drain the nation's informal caregiving resources if a comprehensive long-term care and support system is not developed and implemented. Public policy responses such as those described in this report are critical if we are to address the emotional, physical and financial challenges facing caregivers today and to ensure that caregiving does not jeopardize their own health and retirement security tomorrow.

> *"NOW IS THE TIME FOR CONGRESS AND THE ADMINISTRATION TO TAKE THE APPROPRIATE STEPS TO HEAD OFF A NATIONAL CAREGIVING CRISIS."*

RESOURCES FOR INFORMAL CAREGIVERS

A number of resources exist to help informal caregivers balance their multiple responsibilities. For example, adult day care services and respite care can offer some relief from the daily strain of informal caregiving. Training in body mechanics by health professionals could mitigate some of the physical stress imposed on informal caregivers by daily tasks such as helping the care recipient in and out of bed, bathing or changing clothes. Finally, knowledge is power in most challenging situations, and informal caregiving is no exception. A number of initiatives at the federal, state and local level provide informal caregivers with access to credible information on particular diseases and conditions, available social services, and financing options for formal long-term care. Listed below are just a few of the many resources available to informal caregivers and care recipients:

WEBSITES

- **OWL**
  www.owl-national.org
- **Alzheimer's Association**
  www.alz.org
- **Caregivers.com**
  www.caregivers.com
- **Caregivers Count**
  www.caregiverscount.com
- **Caregiver Zone**
  www.caregiverzone.com
- **Children of Aging Parents**
  www.careguide.net
- **Elder Care On-Line**
  www.ec-online.net
- **Elder Web**
  www.elderweb.com
- **Family Caregiver Alliance**
  www.caregiver.org
- **Generations United**
  www.gu.org
- **Grand Parent Again**
  www.grandparentagain.com
- **GrandsPlace**
  www.grandsplace.com
- **Interfaith Caregivers Alliance**
  www.interfaithcaregivers.org
- **National Alliance for Caregivers**
  www.caregiving.org
- **National Family Caregivers Association**
  www.nfcacares.org

GOVERNMENT RESOURCES

- **Eldercare Locator**
  (800) 677-1116 (available weekdays, 9:00 a.m. to 8:00 p.m. EST)
- **National Association of Area Agencies on Aging**
  www.n4a.org
- **U.S. Administration on Aging, National Aging Information Center Website**
  www.aoa.dhhs.gov/naic
- **U.S. Administration on Aging, Caregiving Resources for the Aging Network**
  www.aoa.gov/carenetwork.default.htm
- **U.S. Administration on Aging, Elderpage: Information for Elderly People and Their Families**
  www.aoa.gov/elderpage.html

- **U.S. Administration on Aging, Office of Public Affairs, "Because We Care: A Guide for People Who Care"**
  www.aoa.gov/wecare
- **U.S. Department of Health and Human Services Healthfinder**
  www.healthfinder.gov
- **U.S. Health Care Financing Administration, Information on the Health Insurance Portability and Accountability Act**
  hipaa.hcfa.gov
- **U.S. Health Care Financing Administration, nursing home quality**
  www.Medicare.gov/nhcompare

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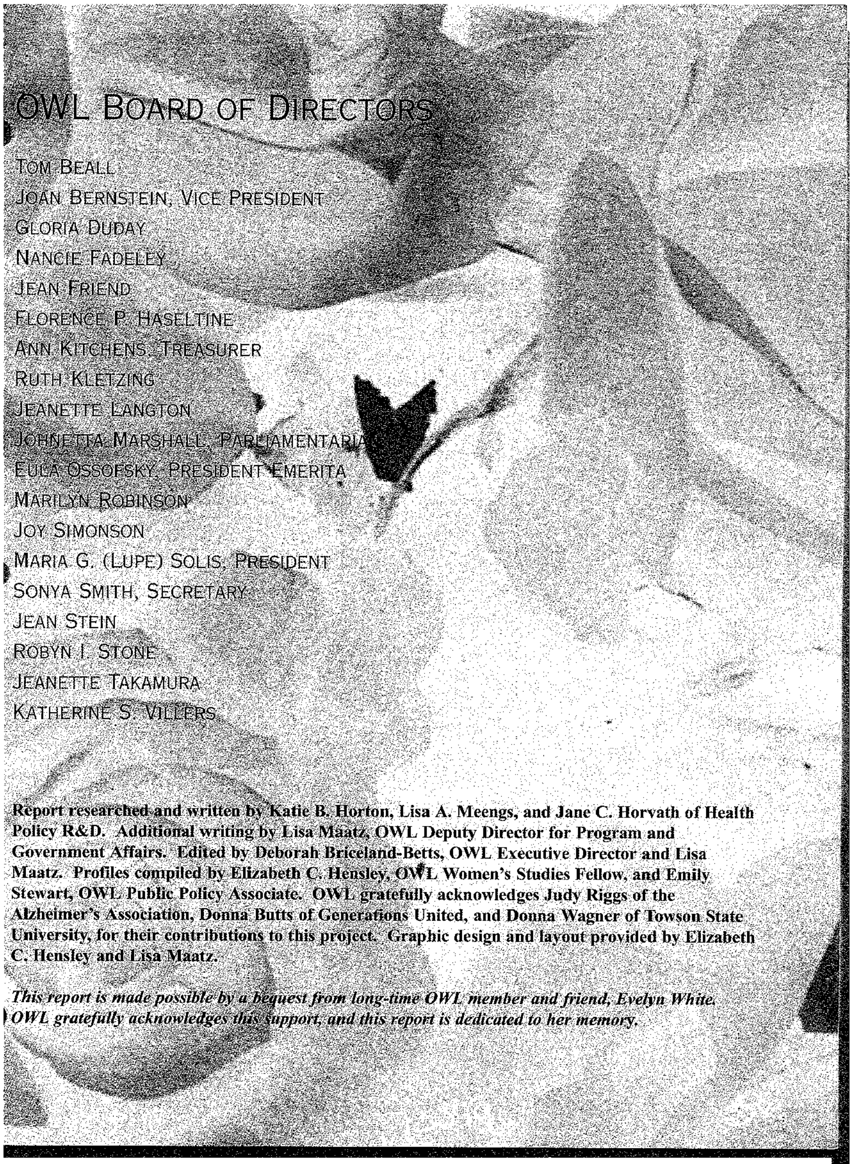

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This report is made possible by a bequest from long-time OWL member and friend, Evelyn White. OWL gratefully acknowledges this support, and this report is dedicated to her memory.

As the only national grassroots membership organization to focus solely on issues unique to women as they age, OWL strives to improve the status and quality of life for midlife and older women. OWL is a non-profit, non-partisan organization that accomplishes its work through research, education, and advocacy activities conducted through a nationwide chapter network. Now in its 20th year, OWL provides a strong and effective voice for the more than 58 million women age 40 and over in America. Membership in OWL is $25 annually. For additional information, contact OWL at 666 11th Street, NW, Suite 700, Washington, DC 20001, call (800) 825-3695 or (202) 783-6686, or visit OWL's website at www.owl-national.org.

The CHAIRMAN. Deborah, thank you very much. Now, let me turn to our last panelist, Kristin Duke, Executive Director, Cenla Area Agency on Aging, Alexandria, LA.

STATEMENT OF KRISTIN DUKE, EXECUTIVE DIRECTOR, CENLA AREA AGENCY ON AGING, INC., ALEXANDRIA, LA

Ms. DUKE. That is why we call ourselves AAAs.

The CHAIRMAN. Yes, I see. Thank you.

Ms. DUKE. Good morning, Chairman Craig——

The CHAIRMAN. That is easier.

Ms. DUKE [continuing.] And Senator Breaux. My name is Kristin Duke. I am the Executive Director of the Cenla Area Agency on Aging in Alexandria, LA, and a member of the board of directors of N4A, the National Association of Area Agencies on Aging. Thank you, Senator Breaux, for the opportunity to appear today at this important hearing on the National Family Caregiver Support Program.

N4A and area agencies share a common goal with the new Family Caregiver Support Program: to help older Americans stay in their own homes and communities with maximum dignity and independence as long as possible. Since the mid–1970's, area agencies have demonstrated an extraordinary record of achievement in stretching a limited amount of Federal money to help hundreds of thousands of older people avoid costly nursing home placement and remain independent in their communities.

The Older Americans' Act is a prime example of Federal, State and local partnerships that work. There is widely varying capacity across the country to serve caregivers, and area agencies face unique challenges as we begin to implement the Family Caregiver Support Program. I would like to share with you some of the particular challenges that area agencies in Louisiana face.

Because the Older Americans' Act requires that we serve the neediest elderly first and because there are so many older persons without anyone nearby to provide help of any kind, the seniors we reach now with in-home Older Americans' Act programs tend to live alone. The Family Caregiver Support Program gives us our first opportunity to concentrate on caregivers' needs.

My advisory council are very excited about the new program and early this year determined the caregiver support services they would like for us to provide. In Louisiana, however, we have met with both time and money problems implementing the new program. The guidelines proposed by the State office in late March are more restrictive than we had hoped, and allow for little direction from caregivers about preferred services.

But they do stress that respite for caregivers is the program's goal. Because of the lengthy process for State regulations, area agencies will not be able to issue contracts soon; funds will not be available before October 1. With regard to money, rather than identify a new source of funds, Louisiana has transferred existing State funds that were used for other critical aging services to meet the 25 percent match requirement for the Family Caregiver Support Program.

So, although Louisiana will receive new Federal funds for the caregiver program, existing aging services such as home delivered meals, transportation and senior center activities in my area will be decreased. Surely, it was not Congress' intent to begin a new program at the expense of existing aging services.

So, as much as I wish I could, I cannot offer you a success story from Louisiana, at least not yet. I support the Federal goal to allow States flexibility to design new programs for family caregivers, but in Louisiana, time for development of strict State regulations and difficulty raising the match mean that those services will not be available before the last quarter of this year.

As a member of the N4A board of directors, I have spoken with other board members and area agency directors across the country. All share my excitement about this program's potential. Some also share my frustration with slow implementation processes. But it is not possible to institute new programs overnight, particularly serving an entirely new constituency.

State agencies are proceeding cautiously in designing programs and area agencies face the difficulty of maximizing funding and balancing multiple local needs. I cannot offer much tangible information because few States have a full-fledged operational program yet.

States that already had a caregiver support program funded locally seem to be moving most successfully. Thanks to the Administration on Aging's list-serve program which links State units and area agencies to discuss caregiver issues, I have learned from the experience of those States, and I am sure that with resources and guidance available in Louisiana, we can do a great deal for our caregivers.

I know that the Family Caregiver Support Program will be a resounding success. I have personally done my time in the sandwich generation. And I assure you that a program that helps family caregivers will make a tremendous difference in the lives of both caregivers and those they love. It is vital that we maintain an increased funding for family caregiver services, and N4A has already established a broad-based advocacy effort to keep caregiver support high on the agenda of the new administration and Congress.

We look forward to an opportunity to sit before you again soon and present documented evidence of the success of the Family Caregiver Support Program and to let you know how we have improved the lives of caregivers and the seniors they maintain in the community. With this evidence of success in hand, we will ask you for additional funds to expand this program. Thank you again for your interest in the Family Caregiver Support Program and the national aging network.

[The prepared statement of Ms. Duke follows:]

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STATEMENT OF KRISTIN DUKE
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SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

HEARING ON
"Family Caregiving and the Older Americans Act: Caring for the Caregiver"
May 17, 2001 at 9:30 a.m.
562 Dirksen Senate Office Building
Washington, D.C.

Good morning Chairman Craig and distinguished members of the Special Committee on Aging. My name is Kristin Duke, and I am the Executive Director of the Cenla Area Agency on Aging in Alexandria, Louisiana, and a member of the Board of Directors of N4A, the National Association of Area Agencies on Aging. Thank you Senator Breaux for inviting me to this important hearing on caregiving and the National Family Caregiver Support Program. My local Board of Directors wants me to convey their appreciation for your interest in this much-needed program to help those caring for seniors at home.

The Mission of N4A and AAAs

N4A and AAAs share a common goal with the National Family Caregiver Support Program — to help older Americans stay in their own homes and communities with maximum dignity and independence for as long as possible. Uncompensated care by family members makes it possible for millions of older adults with long term care needs to avoid costly and often unnecessary and unwelcome placements in formal care settings. We were very pleased that the Congress recognized the tremendous contributions of families and included the National Family Caregiver Support Program in last year's reauthorization of the Older Americans Act.

The Older Americans Act (OAA) joins together 655 AAAs and 232 Title VI Native American aging grantees across the country, providing a support structure for planning, service coordination, oversight, and advocacy. Since the mid-1970s, AAAs have demonstrated an extraordinary record of achievement in stretching a limited amount of federal money to help hundreds of thousands of older people remain independent in the community. OAA funds make it possible for AAAs to leverage millions of non-federal dollars, such as local government, foundation, private sector, participant and volunteer contributions. The OAA is a prime example of federal, state, and local partnerships that work.

N4A and AAAs throughout the country are extremely pleased that the Older Americans Act was recognized as the natural vehicle for expanding home and community-based services. The National Family Caregiver Support Program was designed to channel funds from the Administration on Aging through State Aging Offices to AAAs, whose infrastructure and role in the community make it the ideal place to provide intended services, such as providing families with information on caregiver resources, including respite care, and offering counseling, training and peer support to families involved in caregiving.

National Need for Home and Community-Based Services and Caregiver Support

As the people who are implementing the Family Caregiver Program at the local level, AAA directors and our staffs have our work cut out for us. The need is great and expectations are high. An estimated 8.7 million Americans over the age of 65 need assistance with tasks of daily living including eating, dressing and bathing. Only about two million of these people reside in nursing homes.

Over 80% of people who have long term care needs rely on family members and friends for uncompensated care, at an estimated annual value of $196 billion. In Louisiana this uncompensated care is estimated at $3.2 billion annually. These individuals live at home, either in their own homes, with or without a spouse, or in the home of a close relative or friend. Nationally the estimated number of individuals providing informal care ranges from 7 to 25 million, depending on the level of care provided.

Because local needs and resources differ, OAA programs in each community are tailored to meet the specific needs of older adults in that community. This also holds true for the Family Caregiver Support program. AAAs around the country are experiencing unique challenges in implementing this program. I would like to share with you some of the challenges that AAAs in Louisiana face in implementing the new program in our state.

Cenla AAA Programs and Services

The Cenla agency serves seven mostly rural parishes in central Louisiana. There are about 50,000 persons 60 and over in that area. We hailed the reauthorization of the Older Americans Act with its Family Caregiver Support Program as an opportunity to reach new constituents who desperately need our assistance, but who go largely unserved by our current programs. Because the Older Americans Act requires that we serve the "neediest elderly" first, and because there are so many older persons without family nearby to provide help of any kind, the seniors we reach now with in-home Older

Americans Act programs tend to be very frail and live alone; most are women, many are rural, and most are very poor.

With funds earmarked for caregivers, we will be able to serve additional people who are struggling to maintain their own lives as they care for their loved ones. Our Advisory Council is very excited about the new program, and early this year we determined the caregiver support services we would like to provide under the new program. Our Board adopted priorities, and we have been waiting for guidance from our state unit on aging.

In Louisiana we have met with both time and money problems in trying to implement the program. In late March, the state convened a "focus group" on the Family Caregiver Support program and issued draft guidelines. The guidelines proposed by the state office are more restrictive than we had hoped and allow for little direction from caregivers about preferred services, but do stress that respite for caregivers is the goal of the program. Because of the lengthy process for state regulations, AAAs will not be able to advertise the availability of funds, receive proposals, and issue contracts for some time, possibly as late as the start of next year; funds will not be available until October 1.

Despite these delays, we continue to mount efforts to identify potential participants. With regard to funding, rather than identifying a new source of funding, Louisiana has chosen to transfer existing state funds that were used for other critical aging services to meet the 25% match requirement for the Family Caregiver Support Program. So, although Louisiana will receive new federal funds for the caregiver program, existing aging services (such as home delivered meals, transportation and senior center activities, in my area) will be decreased. Surely it was not Congress's intent to begin a new program at the expense of existing aging services.

As much as I would like to, I do not have a success story from Louisiana to tell you--at least, not yet. I support the federal goal to allow states flexibility to design new programs for family caregivers, but in Louisiana the lack of federal regulatory guidance that has often accompanied other OAA programs, coupled with slow responses by the state office and difficulties raising the 25% match requirement, have combined to leave us in a position where caregiver support services will not be available until October, at the earliest.

Implementation in other states

As a member of the Board of Directors of the National Association of Area Agencies on Aging, I have spoken with other Board members and AAA directors across the country. I have found that all share my excitement about the potential of the new program, but some also share my frustrations with its drawn-out implementation.

The states that are moving ahead are generally those that have already developed caregiver support programs with state funding. However, because the Family Caregiver Support Program focuses on primarily a new constituency, many states are proceeding cautiously in designing programs. Some state agencies and AAAs are obtaining input directly from caregivers and community stake-holders, a process that takes time and which reveals a myriad of needs. My peers and I face the difficulty of balancing multiple service needs within our local communities.

I cannot offer much tangible information, because few states have a full-fledged operational program. Thanks to the Administration on Aging (AoA) list-serve program, which links state agencies and AAAs in discussions on caregiver support, I have learned from the experience of those states where caregiver services are already in place. And, I know that once resources and guidance become available in Louisiana, we can do a great deal for our state's caregivers.

I believe that the Family Caregiver Support Program will be a resounding success. I have led Cenla AAA for over twenty-six years, and have personally done my time in the "sandwich generation," when my children were still at home and my husband and I were losing our parents and grandparents. I assure you that a program that helps family caregivers will make a tremendous difference in the lives of both the caregivers and those they love.

The Family Caregiver Support Program provides an excellent opportunity to increase awareness and visibility of home and community services and the crucial role they play in providing older adults with a good quality of life in their later years. It is vital that we maintain and increase funding for family caregiver support services. As we begin to design local programs, we see how great the needs are. While $125 million may sound like a lot of funding to some, it only translates to about $5 per current caregiver. N4A and local agencies have already established a broad-based advocacy effort to keep caregiver support high on the agenda of the new Administration and Congress.

We look forward to the opportunity to sit before you again soon and present documented evidence of the success of the Family Caregiver Support program, and to let you know how many caregivers we are helping and how many seniors are still living in their communities because of it. With evidence of success in hand we will be asking you for additional funds to expand the program to other relative caregivers not yet served by the program. Thank you again for your interest in the Family Caregiver Support program and the national aging network.

Senator BREAUX [presiding.] Thank you very much. Senator Craig, Chairman Craig, will be back in just a moment and we can start with questions, and we are delighted that we are joined by Senator Carnahan as well.

Let me ask Ms. Duke, obviously the question I am really concerned about is that we created a program, we really intended it to be a new program, and that was going to be funded 75 percent by the Federal Government, and the States were going to have to come up with the 25 percent match.

This is not a mandatory program. It is an optional program to the States. If they want to do it, they can participate, but they have to show support for it on a local level and that support is intended to be shown by coming up with a 25 percent match. I take it from what you are telling me is that in Louisiana, my State, that I represent, that we did not do that, that the 25 percent that the State came up with in matching money was achieved not by adding additional dollars, but merely taking other monies away from existing aging programs——

Ms. DUKE. That is correct.

Senator BREAUX [continuing.] to come up with a match.

Ms. DUKE. That is right. In Louisiana, the legislature is very good to aging programs, and for over 20 years parish councils on aging, which are service providers, have received discretionary State funds that must be used for aging services, but can be used wherever the local council determines the most need exists, and these funds have gone up and down over the years and most recently have been at least $20,000, even for the smallest parishes.

Senator BREAUX. So the result of the new program on a Federal level is that you created a new program, but you really did not get additional money in the Council of Aging to fund the program from the State?

Ms. DUKE. That is correct. The State unit chose to take the matching amount from those parish discretionary funds which are entirely State funds and transfer that as the match for the Family Caregiver Support Program.

Senator BREAUX. So the net result was no increase in funding for the new program?

Ms. DUKE. Well, the Family Caregivers Support dollars are new, but existing programs that had been shored up by those parish discretionary funds have been decreased.

Senator BREAUX. Now, the area where the money has been decreased would be programs such as what?

Ms. DUKE. In my area, I ran a survey. It includes home delivered meals, senior center activities and transportation.

Senator BREAUX. So as a result of the program on a Federal level, you actually lost money on those programs that the State used to put into the new program that we created up here?

Ms. DUKE. That is correct.

Senator BREAUX. Now you probably heard when I asked the first witness——

Ms. DUKE. Mr. Thompson.

Senator BREAUX. Yeah, Mr. Thompson. Excuse me—the question about whether the guidelines were clear enough that that was not something that should be done? I mean have you gotten any or has our State gotten the information that they are not supposed to be doing that?

Ms. DUKE. My local level interpretation of the Federal regulations is that what Louisiana has done probably did not violate the Federal guidelines because that was the money they transferred, although it has been used as overmatch for the Federal programs, was State dollars that they used to supplement. And I believe that the attitude of the State unit is that that is money they can put wherever they need to put it.

Senator BREAUX. I am always concerned about technical niceties and how you get these things done and still, you know, be within the legal parameters, but certainly the policy is very clear that this was not intended. I mean we do not make the program mandatory. The States don't have to do it, but what Congress has said that if you want to do it, we want to encourage you to do it, we are going to fund three-fourths of it, and you are going to have to fund 25 percent of it.

And it was certainly not the intent of the Congress to say you can get your 25 percent by cutting Meals on Wheels or transportation programs or other programs in order to do this, because those programs are important. Obviously, the intent was to create new dollars, both on a Federal level and on a State level. So I am delighted that you have taken the time to come—I know it has been difficult—to be up with us. But we appreciate very much what you have had to say and it is obviously something that needs to be looked into further.

Ms. Betts, thank you very much. Ms. Mintz, your testimony was right on target. We appreciate it very much. Thank you, Mr. Chairman.

The CHAIRMAN. John, thank you. Suzanne, in your testimony, you stressed that caregiver programs should be flexible enough to accommodate the varied needs of caregivers and differing needs in different regions. As you may know, it was Congress' intent to provide just such flexibility in the legislation that is now law, that is now being implemented, the Family Caregiver Program. At least as much as you understand about it now, did we succeed in that flexibility?

Ms. MINTZ. It is my understanding that there is flexibility built into the program, but I don't know that the implementation is far enough along in order to know exactly what is going to happen. I think it is very important that we get the input of consumers and caregivers in designing the programs and that is one way of ensuring flexibility to meet the real needs of real people.

The CHAIRMAN. Well, we may ask you back a year from today or something like that because you are right, that question is probably a bit premature. As these programs get into the field and on to the ground on a State by State basis, but with your national organization, I trust you will be watching and monitoring, as will we, and we will have you back to ask that question again, because we want to create that kind of flexibility and at the same time respond to these very real needs.

Caregiver speakers—I should say caregivers speak urgently of the needs of respite help, education and support. Recognizing that States and situations vary, what do you believe are the most urgent two of three needs that family caregivers in this program should have at this moment?

Ms. MINTZ. Each family is so different and what each family needs at any given time is different, and so I think it is a really important to begin with an assessment of each family's need, and within the guidelines of the program, there is the possibility for care coordination services, helping people actually access services, and in the process of assessing someone's needs, we would be able to find out exactly which ones are most appropriate at that given moment in time.

It may be respite. It may be training. It may be transportation, but for each family it is going to be so different that working with a counselor to help each family I think is really critical.

The CHAIRMAN. And establishing, at least doing that initial assessment——

Ms. MINTZ. Yes.

The CHAIRMAN [continuing.] through that council to determine the primary needs?

Ms. MINTZ. Absolutely.

The CHAIRMAN. OK. Deborah, we are not only pleased to have you here today, but I am glad you made reference to the report that the Older Women's League released last week. I think, you know, those are tremendously valuable findings to help better understand the profile of a caregiver. In your testimony you mentioned quite a large number of ways the Federal Government could help family caregivers.

However, within the limited context of the particular family caregiver program being examined here today, what do you believe are the two or three most pressing needs of women caregivers that this program can be effective in addressing?

Ms. BRICELAND-BETTS. Certainly, if we listened to the testimony that was presented today by the caregivers who are here with us, Ms. Tatom and Mrs. Hunter, when families are thrust into caregiving situations, frequently they tend to think of it as a kitchen table issue. Families are sitting there trying to figure out how our family can deal with this issue. And information, as I said in my statement, is a source of power for families. To think about this as a community issue, a social issue, and that there may be services in their community to supplement what they as individuals are able to bring to this situation.

And certainly the second thing we heard is training, and how is it that we can perform this task within the scope of this particular program. Those two things would probably be most effective for women.

The CHAIRMAN. OK. Well, I concur with what we understand that knowledge of where to go to get it, of course, is going to be key, and is it available, and hopefully this program will begin to advance that.

You observed correctly that the burden of family caregiving falls disproportionately on women. Do you believe this imbalance can or will change over time? Or is it a matter that women seem to more readily accept that responsibility and therefore our job is to focus the resources not just to women but certainly to the dominant caregivers?

Ms. BRICELAND-BETTS. Well, you know, I think it is a culturalization. I think we see some change. We have. There was a point in time 20 years ago when 90 some percent or 89 percent—I think OWL's last caregiving report said 89 percent of caregivers are women. So we see some change.

I think we will continue to see it as predominantly an issue for women. I don't know that we should focus public policy particularly on the caregiver. I think a point we were trying to make is that if we could look at the needs of the individual and figure out how to meet those needs in a way that some day, Senator, I would be sitting in front of you and he decides to stay home and take care of his mother-in-law, because there is no economic or other threat, we will have achieved what we need in terms of the fact that we have created an environment where care, as Susan said, can be given, you know, in terms of what the family needs, what the individual needs, and not necessarily a societal expectation.

The CHAIRMAN. Well, I think you are absolutely right, Deborah. I have a son right now who is a Mr. Mom stay-at-home. That is going on in our society today, and it was fascinating to me when he approached me to suggest that that was what he and his wife might do and could I live with that? [Laughter.]

He was obviously responding to the cultural difference.

Ms. BRICELAND-BETTS. Yes.

The CHAIRMAN. And, of course, I have. In fact, I have enjoyed that young grandson with him. But that young man may someday be sitting in front of this committee talking about the needs of caregivers because that seems to be his inclination and it has certainly worked well, and we do see those kinds of changes going on out there.

Ms. Duke, of the various eligible services identified in the caregiver program, which do you believe to be the most important from your perspective?

Ms. DUKE. I think that what will prove to be the most important services are the information and assistance piece, which at least in Louisiana we are viewing as the access piece to get caregivers into the system, and we are in the process of increasing the amount that the State will allow us to spend on the counseling and education piece so that people like the Tatoms can come to us and we can give them that help, and then we plan to put the rest of it into various respite services so that caregivers can get the break that the program wants them to have.

The CHAIRMAN. How do you make that service available or allow the public to be aware of it? A website? A 1–800 number? What type of outreach so that Mrs. Tatom, Mr. Tatom would know where to go and find it relatively easy to find that information?

Ms. DUKE. Remembering that the program is not operational in Louisiana yet——

The CHAIRMAN. Right.

Ms. DUKE [continuing.] but we have begun our efforts, we have a 1–800 number at the area agency regional level and we have a publicity program in the planning stages that includes brochures, speaking engagements, fliers, whatever it takes.

The CHAIRMAN. In your role as a board member of the National Association of Area Agencies on Aging, could you identify unmet caregiver needs on a national basis and discuss how these new caregiving programs will or will not address those needs? In other words, what have we missed? Where are we missing?

Ms. DUKE. I think that the flexibility that Administration on Aging has given us has really enabled nationwide the State units and the area agencies to go out and truly attempt to find out what caregiver needs, and I think what we are finding out is, as so many people come to you and say, there is not enough money. Once programs begin to receive coverage in the media, there is an overwhelming response, and what we are also learning is that there are so many levels of caregiving; like everything else there is a continuum.

There may be the next door neighbor that takes someone to the doctor when necessary and to the grocery store every week, and that is a form of caregiving, but we are also finding the people with family members at home who do 24 hour care. And we are going to have to concentrate on that most concentrated of caregiving, but we want to be able to provide help all along the continuum because the more we can help at the lower end, the less help we may need one day at the more concentrated end. But there is a broad spectrum of caregivers out there.

The CHAIRMAN. A point that Suzanne was making. Very true. Well, thank you all for your time. As you know, this is a work in progress and now that the legislation has been passed, the money has been appropriated, we will monitor it very closely in the coming year or years as it gets to the ground and begins to shape itself based on the flexibilities that the States offer.

So we thank you, and we have been joined by Senator Carnahan, who I would ask to make any opening statement, comments, and/or questions of this panel if you wish, Senator.

Senator CARNAHAN. All right. Thank you, Mr. Chairman. I will just submit my comments for the record and move on to asking some questions.

[The prepared statement of Senator Carnahan and Senator Bayh follows:]

PREPARED STATEMENT OF SENATOR JEAN CARNAHAN

Caring for a loved one who is sick is a 24-hour, seven day a week job. It is exhausting, it can be frustrating, it can be thankless, it can be lonely.

So, why do you do it? How do you do it? You do it because that person is your mother or father. You do it because that person is your husband or wife. You do it because that person is your sister or brother. You do it because that person is your best friend.

You do it because you love them. It is not even a question.

It is one of the most important jobs you will ever do.

I would like to thank each of today's witnesses for being here to share your personal stories. I could be sitting on your side of the table, too. For nearly eight years, I cared for my own father in my home. My father was diabetic and asthmatic and needed help with the most basic tasks of daily living. I know what it is like to have to balance your family's daily activities with caring for someone else. I had to make sure that each of his meals was prepared for him before I left the house. While those years were difficult, I would not have traded them for anything.

Just because we choose to care for a loved one doesn't mean we don't need help, too. Caring for the caregiver is critical for all those involved. I thank Chairman Craig for calling this hearing today. I also applaud my colleagues for recognizing the needs of family caregivers and passing the National Family Caregiver Support Program last year. Allocating $125 million for the program is a good first step. But we must do more. I support an increase for this important program in next year's budget.

The purpose of today's hearing is to examine how states are implementing the new National Family Caregiver Program. While the Federal funds were just made available to states on February 15, I am pleased to report in Missouri, the new law is moving forward smoothly and thoughtfully. The State Division on Aging, in coordination with the local Areas on Aging (AAAs), is working to ensure that the use of the funds reflects the true needs of caregivers. In addition, they are aiming to coordinate new services with existing services that the State already funds.

To begin receiving the new funds, AAAs have to develop a plan on how the money will be spent. In Missouri, funds will be used to services like respite care, counseling, and information about the availability of services. Each of Missouri's ten AAAs is creating its plan based on the needs of its local community. At least three AAAs are set to begin providing the new services in May or June 2001.

I look forward to learning from the panelists and would like to recognize them for the important work they are doing. It truly makes a difference.

Thank you.

PREPARED STATEMENT OF SENATOR EVAN BAYH

Thank you Chairman Craig and Senator Breaux for holding this important hearing on the implementation of the National Family Caregiver Support Program. As we all know, our nation is aging, and if we do not seriously evaluate how to make long-term care more affordable in the next few years we will find ourselves in the midst of a long-term crisis.

Caring at home for a family member is a responsibility that many Americans want desperately to meet. In my state of Indiana, there are more than a half million Hoosiers who provide informal caregiving in their homes. Additionally, three out of every five individuals in Indiana in need of long-term care receive their assistance from their family.

Because of the heroic efforts of caregivers, American taxpayers save billions of dollars each year. According to a study released by the Alzheimers Association caregivers provide $196 billion a year in services free of charge to the government.

The National Family Caregiver Support program was designed to provide information to caregivers about available services, assist caregivers in gaining access to services, individual counseling, support group services, respite services to families for temporary relief, and supplemental services such as home care and adult day care. Hoosiers who provide at-home care will receive much-needed support through this program. The state of Indiana has received $2.3 million through the National Family Caregiver Support program and is in the process of implementing the program.

During a field hearing I held in Indianapolis, called "Making Long-Term Care Affordable," I learned about the challenges associated with caring for loved ones with Alzheimers. Caregivers are heroes, often caring for their loved ones before they care for themselves. During that hearing, it became evident that caregivers needed both financial assistance and emotional support.

There are emotional strains that come with caring for a loved one. I hear about the challenges associated with caregiving each day when constituents visit my office. To share one example with you, a women from Indiana visited my office to discuss Huntington's disease. She cares for her husband who was diagnosed with the disease several years ago. In conversation, she mentioned that the few days she was away from her husband for her trip to Washington would mark the first weekend she was not at home caring for him in the last six years. I am hopeful that successful implementation of the National Family Caregiver Support Program will provide caregivers like her with necessary relief.

In addition to services provided by this program, we need to remember there is still a need for financial relief for caregivers to make it an economically viable option for American families. I have authored a bipartisan bill, S. 464, along with Senator Gordon Smith to provide caregivers a $3,000 tax credit. I know that there is support for this and similar proposals and urge the Senate to make legislative strides in this area this year.

I thank Senator Craig and Senator Breaux for holding this hearing and allowing the committee to focus on the needs of caregivers. I look forward to learning about the next steps needed in the proper implementation of the program.

Senator CARNAHAN. I want to thank you for the very important job that each of you do. I feel like I could be sitting on that side of the table with you as an advocate for caregiving. I took care of my own father for 8 years in our home. He was diabetic and also had asthma and so I had to learn how to balance caregiving with the other duties as a mother and a wife.

I had to make sure that he had his meals ready before I left the house each day, and although it was a difficult time for us at times, I would not trade those years for anything. They were very precious years as I look back. But just because we choose to care for a loved one does not mean that we don't need help too. And certainly you are aware of that very well.

Mrs. Duke has answered this question, but I wanted to address it to our other panelists as well. What are your suggestions on how States can get the word out to family caregivers on the new assistance that is available?

Ms. MINTZ. Family caregivers do not easily reach out for help. Many programs have shown that it takes several years in the caregiving process before people reach out, and so I think information can't be given out at one point. It needs to be continuous. It is like the concept of advertising, you hear it over and over again, and so I think information that goes out in as many public ways as possible, whether it is PSAs, potentially free ads in local newspapers, but I think we have to be creative and continuous about how the information does get out, because unless that happens the caregivers, except for those who find it, are not going to know that it is out there and know that it is OK to ask for the help because that is a big issue, getting over the fact that you think you are only supposed to do this by yourself.

Ms. BRICELAND-BETTS. I think this is one of the areas, the point that Suzanne made about understanding the variety of people who are caregivers. Our report talks about how caregiving is pretty dramatically different by culture. So knowing the culture of the area you are serving and knowing what Hispanic and Latino families are feeling about duty and caring or reaching out through churches, the difference in the Asian population, and even the variety of dialects within Asian languages.

Certainly we can talk about the need for information and getting information out, but assuming that we can do some PSAs or broadcasts or a website, that doesn't address the cultural variety in a given community; it really isn't getting information to probably some of the segments of that population who need that information most critically. So it also has to go to addressing culture.

Senator CARNAHAN. OK. Thank you. One other question and either one of you could answer this if you would. If there is any one thing that you think it would be important for government to do in behalf of caregivers, what would that be?

Ms. DUKE. We need more money. [Laughter.]

Now you know if you give me a chance to say that, it is true. We need more money.

Ms. MINTZ. We need to recognize the value of the work of caregiving. American society does not tend to value work that goes on in the home and in caregiving much of the work goes on in bedrooms and bathrooms. And unless we value the work that is done by families and by the paid workforce that does provide care, I don't see that we are really going to be able to begin to address this problem in a significant way.

Senator CARNAHAN. In a sense, you are both saying the same thing.

Ms. BRICELAND-BETTS. That is right, I would like to see it called unvalued work, both in the paid arena in terms of how nursing home and home care aides, their work is incredibly undervalued, and there are very few benefits for those women who are paid caregivers, but also the informal caregiving that we are talking about here today, and in valuing what it is that goes on in that home, we are going to be able to create a different environment for her down the road when we start as policymakers and advocates talking about our retirement system; we won't with such affirmation look at her and say you didn't plan for your retirement and that is why you don't have as much as you should. She was doing unvalued work and we need to figure out how to value that.

Senator CARNAHAN. Thank you all very much. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, and I mean that most sincerely. You bring valuable testimony. As I said, we will follow this program and see where we can broaden it, improve it. It is a fascinating dimension of our culture and an important one. And, of course, as this committee knows, we have an aging country. A good many more citizens will live better lives longer, but that also means there will be more responsibilities out there in the levels of care that they will need, and most of those responsibilities as we already know will fall on families.

So where we can assist, we not only lower the overall cost to society, but we probably, for those who can stay in their homes longer, provide the kind of life that they would want to live, or assist them in the kind of life that they would want to continue to live. So we thank you very much and appreciate your time here.

Ms. MINTZ. Thank you.

Ms. BRICELAND-BETTS. Thank you.

Ms. DUKE. Thank you.

The CHAIRMAN. The committee will stand adjourned.

[Whereupon, at 11:25 a.m., the committee was adjourned.]

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Statement of the

National Association of State Units on Aging

Submitted to

The U.S. Senate Special Committee on Aging

Hearing on the Older Americans Act

National Family Caregiver
Support Program

May 17, 2001

STATES UNITED FOR ACTION IN AGING

Introduction

The National Association of State Units on Aging (NASUA) is pleased to present this statement to the Senate Special Committee on Aging on the implementation of the National Family Caregiver Support Program (NFCSP) under the Older Americans Act (OAA). State Units on Aging are charged with implementing all the major reforms of the Older Americans Act Amendments of 2000 pertaining to Title III and Title V, which were enacted by the 106th Congress. These changes include implementing the new caregiver program.

We appreciate the role the Senate Special Committee on Aging played last year in shaping and passing this important legislation. The hearing today demonstrates the Committee's continued interest in the success of Older Americans Act and the new caregiver program.

Need to support caregivers

The majority of older people with chronic disabling conditions rely on friends or family members as their primary source of assistance with activities of daily living, such as dressing, bathing, eating and toileting. Sixty-five percent rely exclusively on friends and family, while 30 percent use a combination of paid caregivers and family or friends. Only about five percent of older people who need care rely exclusively on paid care, mostly in institutional settings.

These informal caregivers are the backbone of the long-term care system in this country, and are the primary source of dependable and reliable care for those in need. If the work of these unpaid caregivers were replaced by paid home care providers, estimates show this could cost between $45 billion to $95 billion per year.

Research had shown that caregivers need a variety of services to support them in their caregiving role. If supported properly, they can remain in the caregiving role for longer periods of time, often delaying or circumventing the need for more costly institutional care. Therefore, it is essential that we provide support to these informal caregivers.

Under the Act, states receive grants to provide caregivers with a menu of services and supports, which may include:

1. Information about services that are available to caregivers
2. Assistance in gaining access to services
3. Individual counseling, support groups, and caregiver training
4. Respite care
5. Other supplemental services

NASUA support for caregiver program

NASUA and its 57 member state agencies on aging played a pivotal role in working with federal policy makers to design and enact the new National Family Caregiver Support Program. We are pleased that the new program uses the existing infrastructure within the aging network to provide services to caregivers. State Units on Aging (SUAs) have taken the lead over the last two decades in developing state-funded programs to support caregivers. These existing state programs were a model on which the National Family Caregiver Support Program was based.

NASUA applauds the Congress for recognizing the great need that exists to support caregivers and reaching a bipartisan agreement on OAA reauthorization that enacted the caregiver program. We congratulate the Administration on Aging for its vision in designing the program and the valuable assistance it has provided to states in the past three months as the caregiver program has been implemented at the state and local level.

State progress in implementing the new caregiver program

In the last three months since federal grants were awarded to states (February 2001), SUAs have made extraordinary progress in facilitating rapid implementation of the caregiver program at the state and local level. They have made great strides in areas including planning, funding, evaluation, coordination, training, and technical assistance. The specific steps states have taken to implement the program include:

- Obtaining advice and guidance from caregiver consumers, area agencies on aging, providers and others stakeholders at the state and community level.

- Working with state legislatures to secure funding for the required 25 percent state match and to enact any state authorizing legislation that may be necessary.

- Developing plans and guidance on statewide implementation.

- Evaluating statewide allocation formulas to target the caregiver funds to those most in need, including the low-income elderly.

- Designing caregiver programs so they will be responsive over the years to the growing and changing needs of older people and their families.

- Evaluating the need and strategies to provide support to older relatives and grandparents raising children or grandchildren.

- Transferring the lessons learned from other state and federal programs on the importance of providing consumer-centered, consumer directed services.

- Developing outcome measures and quality standards, as required under the Act, and working with the Administration on Aging to test their effectiveness.

- Coordinating efforts with existing state-funded caregiver programs to ensure proper expansion of services to caregivers.

- Coordinating efforts with other state agencies and local governments that provide similar services to caregivers of other populations, such as adults with disabilities.

- Integrating caregiver services into the existing state home and community-based service system.

- Providing training and technical assistance to area agencies on aging and service providers on the design and implementation of the program.

- Developing tools to help area agencies on aging and providers assess the needs of caregivers.

- Working with the research and academic communities to measure the efficiency and effectiveness of caregiver programs.

- Developing outreach plans to find caregivers that are eligible for services, enlisting support from churches, community colleges, senior centers, and local civic organizations.

- Revising reporting systems in order to provide accurate information on services delivered, clients reached and use of program funds to state and federal policy makers.

Conclusion

We are pleased to report that states have made exceptional progress in the last three months in implementing the new National Family Caregiver Support Program at the state and local level. States have risen to the challenge of implementing this program on a fast track and getting services to caregivers as soon as possible.

NASUA looks forward to working with the Congress and the new Administration to assess the success of the program and make any appropriate changes to the program, as measures of quality and outcomes become available over the next year. We hope the program will continue to receive bipartisan support as Congress makes future decisions about funding this important new federal/state partnership

Generations United

Statement Submitted to

The U.S. Senate Special Committee on Aging

Hearing on the Older Americans Act

National Family Caregiver Support Program

May 17, 2001

Introduction

Generations United (GU) thanks the Special Committee on Aging for the opportunity to provide this statement concerning the National Family Caregiver Support Program (NFCSP) of the Older Americans Act. GU particularly appreciates the Committee's dedication to the success of this program as demonstrated by its May 17, 2001 hearing.

This statement focuses on the NFCSP's inclusion of grandparents and older relatives who are relative caregivers of children and their need for supportive services. Only ten percent of NFCSP funds can be used to assist these caregivers and, as a result, they may continue to be occasionally overlooked in the program's implementation efforts.

GU encourages the Committee to consider these caregivers in its monitoring activities. Specifically, GU asks that the Committee ensure that grandparents and other relatives be included in all federal government press releases, educational and outreach materials concerning the NFCSP. Grandparents and other relatives are keeping families together, while saving the country billions of dollars. The NFCSP is an important first step in supporting them.

About Generations United

GU is the only national nonprofit membership organization whose mission is to promote intergenerational public policies, strategies, and programs. GU was founded in 1986 by the Child Welfare League of America, the National Council on the Aging, the Children's Defense Fund, and AARP and now includes over 100 national, state, and local organizations representing more than 70 million Americans.

One of GU's core initiatives is its grandparents and other relatives raising children project, which publishes and disseminates publications, tracks state laws and programs, educates federal policy makers, and provides technical assistance and training to direct service providers and other professionals working with the families. The project also partners with the Brookdale Foundation Group to establish KinNET, a national network of support groups for relatives caring for kin in foster care, and to replicate Brookdale's Relatives As Parents Program in eight mental health agencies around the country. GU is receiving funding from the Children's Bureau of the U.S. Department of Health and Human Services (DHHS) for KinNET, and from the Center for Mental Health Services at DHHS for the replication program.

Generations United and the National Family Caregiver Support Program

In spring 1999, when the NFCSP was originally introduced in Congress, it did not include grandparents and other relatives raising children. Instead, it was designed solely to provide services to family caregivers of individuals aged 60 and older. GU was supportive of the NFCSP and thought it was important to help these caregivers. GU, however, also thought it was important to acknowledge older individuals not only as the receivers of care, but also as the givers of care, which they so often are. As a result, GU met with several Members of Congress about including grandparents and other relatives in the NFCSP. In June 1999, Senator Mike DeWine (R-OH) invited GU to testify regarding the inclusion of these caregivers. Donna Butts, GU's Executive Director, testified before the Subcommittee on Aging of the Senate Health, Education, Labor and Pensions Committee. The testimony was well received and resulted in an invitation to GU to provide language for inclusion in the Program. GU submitted the language and worked for its inclusion. As a result, grandparents and other relatives raising children are included in the final version of the NFCSP that became law in November 2000.

Grandparents and Other Relatives Raising Children

There are currently 5.4 million children living in grandparent or other relative-maintained households, 2.1 million of whom are being raised solely by their grandparents or other relatives with no parents present. (U.S. Bureau of the Census, 1998). The majority of these children are being raised by their grandparents and in the last twenty-five years, there has been dramatic growth in the number of grandchildren being raised by grandparents in all types of grandparent-maintained households. The largest increase, however, has occurred in those households without either parent present. Since 1990, these families have increased by 53 percent (Casper & Bryson, 1998).

These national data are from sample surveys done in 1997 and 1998 by the U.S. Census Bureau and many observers suspect that the numbers are low. In July 2001, the Census Bureau will be releasing new numbers from the Census 2000, which, for the first time, included a three-part question about grandparents raising grandchildren. Prior to this Census, the Bureau had to extrapolate data from existing questions. The new question, which was required by Congress, asked if the grandparent has a grandchild under age 18 living in the grandparent's home; whether the grandparent is responsible for the grandchild's basic needs; and for how long the grandparent has been financially responsible for the grandchild. The resulting data should be very helpful to Congress and other policymakers. However, data on other relative caregivers, such as aunts and uncles, remain limited.

Of the 2.1 million children living with grandparents or other relatives with no parents present, approximately 150,000 of them are in the formal foster care system. The 150,000 children make up more than a fourth of the entire foster care population of 568,000 children (U.S. Department of Health and Human Services, AFCARS, October 2000 estimates). The remaining 2 million children are being cared for outside of the system and their caregivers often do not have access to any support services or financial assistance. If even half of these 2 million children were to enter the foster care system, it would cost taxpayers $4.5 billion a year and completely overwhelm the system. (Calculated based on a $373 monthly payment, which was the 1996 national average for basic maintenance payments to foster parents for a nine-year old). Alternative services, such as those provided through the NFCSP, need to be available in each community where these families live.

Factors causing the increase in the number of grandparents and other relatives raising children include parental drug and alcohol abuse, incarceration, death, teenage pregnancy, and HIV/AIDS. Because of the omnipresent societal nature of these factors, anyone can find him or herself raising related children. U.S. Census Bureau statistics prove the geographic and ethnic diversity of these families. Many grandparent families live in the South and in non-metropolitan areas. Fifty-one percent of the grandparents raising grandchildren are married couples (Bryson & Casper, 1999). 44 percent of the grandchildren are white, 35 percent are black, and 18 percent are Hispanic (U.S. Census Bureau, 1998). 65 percent of the grandparents are between ages 45-64, whereas 21 percent are over age 65, and 15 percent are under 45 (Bryson & Casper, 1999). Although the NFCSP is an important first step, given its age restriction to relative caregivers aged 60 and older, numerous caregivers are still not being reached.

Many of these diverse families are raising children informally, meaning outside of the formal foster care system and without a legal relationship, like legal custody or guardianship. They do not want to sue their adult children or other relatives, the parents, in court for legal custody or guardianship. To do so, the relative caregivers must prove that the parents are unfit, which often tears families apart, rather than keeping them together. Furthermore, to adopt the children, parental rights and responsibilities must be severed and the relative becomes the parent in the eyes of the law. This is a step that many grandparents and other relatives are unwilling to take. However, access to services, such as medical treatment and private and public health insurance, on behalf of the children can be severely limited if the relatives have not adopted the children or lack legal custody or guardianship. GU applauds the Congress for including "informal" caregivers among those eligible for services. Under the NFCSP, caregivers are not required to prove a legal relationship in order to access supportive services. Many existing services, however, still pose a problem and cause challenges for the relative caregivers.

These challenges vary depending on the relatives' legal relationship to the children and the families' needs. Some relative caregivers, for example, may need only a support group whereas another caregiver may need respite, counseling, and information and referral services. U.S. Census Bureau statistics, however, demonstrate that many families headed by grandparents need help. One in five children living in homes maintained by their parents live in poverty, whereas one in four are impoverished in grandparent-maintained homes. One in five children in homes maintained by their parents have no health insurance, whereas one in three in grandparent-maintained homes lack health insurance (Bryson & Casper, 1999).

In addition to greater incidences of poverty and lack of health insurance, both the grandparents and grandchildren in these families face physical and mental health issues to a greater degree than the general population. According to the U.S. Census Bureau, many of the caregivers self-rate their health quite low. Grandmothers in all grandparent-maintained families self-reported their general state of health as follows: a sizeable 33.6 percent rated themselves poor or fair, 31.2 percent rated good, 21.9 percent rated very good, and only 13.3 percent rated excellent. 28.7 percent of grandfathers in all-grandparent maintained families self-reported their health as fair or poor, 33.9 percent as good, 22 percent as very good, and 15.4 percent as excellent (Bryson & Casper, 1999).

Grandparents and other relatives raising grandchildren are often unable to attend to their own health needs due to a lack of childcare, respite care, or adequate medical insurance. A survey conducted by GU in 1998 of practitioners working with relatives raising children elicited many responses concerning the need for respite care (Generations United, 2000). Grandparent caregivers are frequently stressed because they are caring for children at a time in their lives they did not expect to be and they are often socially isolated from their peers. They may feel a sense of shame and guilt about their own adult children who are unable or unwilling to parent. These grandparents have been found to frequently suffer health problems like depression, diabetes, hypertension, insomnia, and gastric distress (Minkler, 1999).

Unlike the several studies concerning grandparent caregivers, there have been very few about the overall well being of children in grandparent care. The existing findings show that these children exhibit a variety of physical, behavioral and emotional problems to a greater degree than the general population of children, often due to the difficult situations that caused them to be placed in a grandparent's care. They have frequently been exposed to drugs or alcohol in utero and many of the children have special needs (Altshuler, 1998, Pruchno, 1999). Because of the children's needs and the caregiver's advanced age, many caregivers need and benefit from supportive services.

Supportive services have been shown to help alleviate caregivers' stress and improve their health. There is a lack of national studies showing how these services help relatives raising children, but anecdotally it is known that support groups, respite, counseling, and information and referral help these families tremendously. GU has been working with the Brookdale Foundation Group to replicate Brookdale's Relatives As Parents Program in eight mental health centers around the country. Through this partnership, counseling, support groups, respite, and information and referral have been provided to the caregivers. GU has been told repeatedly that the support groups in its collaboration reduce caregiver's stress through the sharing of resources, joys, and problems. Many caregivers express the thought that "just knowing that there are others in the same situation" is helpful. A great grandmother who is raising five grandchildren summed it up when she said, respite care "makes me a better person and a nicer person to be around."

Area Agencies on Aging

Many AAAs around the country have already been providing services to grandparents and other relatives raising children and can serve as a model to those AAAs who would like to provide such services. AAAs have been providing services often with limited financial resources and through creative collaborations with other local human resource providers. Consider, for example, the largest AAA in Michigan – AAA1-B -- which has been working to help these families since 1993. Among the supports it helps provide, it published and disseminated 8,500 copies of two county resource guides specially targeted towards relatives raising children. Thanks to the new funding, it is planning on creating resource guides for the four remaining counties the AAA covers. The thirteen AAAs in Illinois are also planning on expanding services for grandparents and other relatives raising children by using NFCSP funds. Other AAAs, including ones in Delaware, Indiana, Nebraska, Ohio, Oklahoma, Tennessee, Virginia, and Washington, have been providing supportive services such as information and referral, respite, counseling, and/or support groups. Many of these AAAs are planning on using NFCSP funds in conjunction with other state and federal funds, because the new program funds alone are often not enough. However, thanks to the new funding, these AAAs will be able to reach and serve more caregivers.

Generations United is creating a guide that will highlight existing AAA programs so that other AAAs may replicate these successful models. It will be published by early fall 2001 and is designed to complement the Administration on Aging's implementation materials.

Conclusion

The inclusion of grandparents and older relatives in the NFCSP is an important first step towards supporting these caregivers. More is still needed. The required age of the relative caregivers needs to be lowered and funding needs to be increased so that more services can be provided to both relatives raising children and family caregivers.

GU asks that the Committee continue to include relative caregivers of children when monitoring implementation of the NFCSP. These caregivers should be included in all NFCSP educational and outreach materials issued by the federal government. It is critical that they not be overlooked, as they occasionally have been. These grandparents and other relatives' role in keeping families together is saving the country billions of dollars and they must be supported.

GU looks forward to assisting and complementing the government's efforts in its implementation and monitoring of this new program. Thank you.

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