

**NATIONAL FAMILY CAREGIVER SUPPORT  
PROGRAM: GETTING BEHIND  
OUR NATION'S FAMILIES**

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**HEARING**

BEFORE THE

SUBCOMMITTEE ON AGING

OF THE

COMMITTEE ON HEALTH, EDUCATION,  
LABOR, AND PENSIONS  
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

ON

EXAMINING THE IMPLEMENTATION OF THE ADMINISTRATION ON  
AGING'S NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

MAY 7, 2002

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**NATIONAL FAMILY CAREGIVER SUPPORT  
PROGRAM: GETTING BEHIND  
OUR NATION'S FAMILIES**

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**TUESDAY, MAY 7, 2002**

U.S. SENATE,  
SUBCOMMITTEE ON AGING, OF THE  
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,  
*Washington, DC.*

The subcommittee met, pursuant to notice, at 2:35 p.m., in room SD-430, Dirksen Senate Office Building, Senator Mikulski, (Chairwoman of the Subcommittee), presiding.

Present: Senators Mikulski, Hutchinson.

OPENING STATEMENT OF SENATOR MIKULSKI

Senator MIKULSKI. The Subcommittee on Aging of the Health, Education, Labor, and Pensions Committee will come to order.

We are going to focus today on an oversight issue of the National Family Caregivers Support Program, essentially getting behind our Nation's families and giving help to those who practice self-help.

I want to thank my colleague Senator Tim Hutchinson. When he chaired the subcommittee, we were able to get The Older Americans Act authorized after it had languished for a number of years, and of course, his predecessor Senator DeWine was very helpful in laying the groundwork, as well as on this Family Caregivers Act.

So we thought that in this month that celebrates The Older Americans Act and aging, we would hold a hearing on one of the most pressing issues, which is caregiving, to see how something that we did is doing and what we can do to be of assistance.

I believe that honoring our father and our mother is not only a good commandment to live by but a good policy to govern by. My own dear father suffered from Alzheimer's disease, and our family watched him go through that terrible, terrible long goodbye. I know what families live through when a loved one ages and needs more care, and eventually, more than one family alone can provide.

My colleagues and I created the National Family Caregiver Support Program almost 2 years ago to help families who need some support and to help them get the services they need. We are here today to find out how that caregiver program is doing. Is it meeting the day-to-day needs of family caregivers and the long-range needs of our Nation? Is the program doing well? What can it do better? And when we say is the program doing well, we mean not only administratively and fiscally, but in terms of putting families first.

What are the gaps, what are the glitches, and what are the successes?

Our families are the backbone of the long-term care system of the country. One out of every four households is involved in providing care to an older adult. That is 22 million families. America is getting older. Baby boomers are becoming seniors. The number of families caring for an older adult will reach 39 million in the next 5 years.

Most caregivers would say it is a rewarding part of their lives, but caregiving can take a significant toll. Workers who take care of older relatives lose several hundred thousand dollars in wages, Social Security, and pensions. Caregivers experience enormous stress and enormous strain. Families are often overwhelmed with questions about where to go and what to do to care for their relative. Families often call our offices, asking what are the programs that can help them; how do they find out about available services; where do they go, and can they afford it.

The list of questions is endless, and the answers may not be easy. Caregiving is not one-size-fits-all.

The predominant number of caregivers are women, and it can be the “sandwich” generation or even the “club sandwich” generation. The “sandwich” generation is where an adult under the age of 60 is helping to provide care to someone over age 60 or 65. The “club sandwich” generation is where somebody age 70 is taking care of somebody age 90. And if it is the “club sandwich” generation, we have got to make sure we put the bacon there to help them out.

Our colleagues created this program, and we want to make sure it provides a one-stop shop to get information and referral, to provide counseling, training, and support, and also to provide respite care.

I have been fighting for double funding for this program to get it to \$250 million, and I have been pleased that it has been on a bipartisan basis. You know, those millions of caregivers work three shifts—raising children, working a full-time job, and caring for an elderly parent, or one elderly parent caring for their parent.

So we are going to work very hard to make sure this bill works well and is funded properly. May is Older Americans Month, and I can think of no better way to honor our older Americans than to help them stay independent and in their communities.

So we look forward to hearing our witnesses—Assistant Secretary Carbonell, Sue Ward, John Skirven, and Barb McSweeney.

[The prepared statement of Senator Barbara Mikulski follows:]

#### PREPARED STATEMENT OF SENATOR MIKULSKI

I believe that honoring your mother and father is not only a good Commandment to live by, but also good public policy to govern by. I know what families live through when a loved one ages and needs more care, eventually more than you alone can provide. My colleagues and I created the National Family Caregiver Support Program almost two years ago to help families like mine that need some support and to help them get the services they need.

We’re here today to find out how well the Caregiver Program is meeting the day-to-day needs of family caregivers and the long range needs of the Nation: what the program is doing well, what it can do better, what are the gaps and glitches, and what are the great successes.

Our families are the backbone of the long-term care system in this country. One out of every four households is involved in providing care to an older adult. That’s 22 million families! America is aging, and baby boomers are becoming seniors. The

number of families caring for an older adult could reach 39 million in the next 5 years.

Most caregivers would say it is a rewarding part of their lives, but caregiving can take an enormous toll. Workers who take care of older relatives lose \$659,139 in wages, pension benefits, and Social Security over a lifetime. Caregivers experience depression at three times the rate of others in their own age group.

Families are overwhelmed with questions about where to go and what to do to care for their relative. If you're a family: What are the programs that can help you? How do you find out about available services? Where do you go for services? Who helps you put together the right package of services to meet the needs of the person you are caring for? There is adult day care, respite care, home-delivered meals and more. How do you know what your mom or dad needs? How do you pay for services? Does Medicare or Medicaid cover anything? Where do you go to hire help, like a respite care worker? Is this person properly trained?

The list of questions is endless and the answers may not be easy to find. Caregiving is not "one-size-fits-all." You have to shop around to find the best fit.

The National Family Caregiver Support Program is one of the solutions to the long term care crunch facing America's families. My colleagues and I created this Program in 2000. The Caregiver Program gets behind our Nation's families and gives help to those who practice self help.

What does the Caregiver Program do? It gives families a one-stop shop to get information and referrals to help caregivers get answers to their questions. It provides counseling, training, and support groups to help people cope with the stresses and strains of caregiving. And it provides respite care so that caregivers can run errands or just relax briefly without having to worry about a relative not being cared for during that time.

I'm fighting to double funding for this program to \$250 million, to redouble our commitment to the women and men of this country that care for a loved one. Millions of caregivers work 3 shifts: raising children, working a full-time job, and caring for an elderly parent or other family member at home. I'm going to work just as hard to make sure our Federal law books and our Federal checkbook get behind these families.

May is Older Americans Month. I can't think of a better way to honor older Americans than to help seniors stay independent and in their communities. I look forward to hearing from our witnesses today: Asst. Secretary Carbonell, Secretary Sue Ward, John Skirven, and Barbara McSweeney.

Senator MIKULSKI. Senator Hutchinson, do you have any remarks? You have been so active in this.

#### OPENING STATEMENT OF SENATOR HUTCHINSON

Senator HUTCHINSON. Thank you, Chairwoman Mikulski.

I am very pleased that you have scheduled today's hearing to assess the current implementation and impact of the National Family Caregiver Support Program.

Contrary to popular belief, families generally do whatever is necessary to keep their elderly family members at home rather than in a nursing home or an institution. Nearly one out of every four households is involved in caregiving to older persons, and over two-thirds of those caregivers are, as Senator Mikulski pointed out, women.

Because Arkansas ranks among the top 10 States in terms of the percentage of its population over the age of 65, the family caregiver program is very important to our State and has provided a much-needed boost to caregiving families in Arkansas.

The journey a caregiver must go through to help improve the life of a loved one is not always easy. Stress, frustration, and often depression are all feelings that caregivers may experience along the way. The wide variety of services being offered and planned in Arkansas I think illustrates the flexibility of the National Family

Caregiver Support Program in providing support to these families who are doing such noble work.

Many of the State's Area Agencies on Aging, our State organization through which The Older Americans Act is implemented, are participating in a program called Arkansas Caregivers, which seeks to meet the needs of spouse caregivers and adult child caregivers. Each region in the State of Arkansas has taken steps to meet the unique needs of caregivers in their communities.

For example, some of the Area Agencies on Aging have established training for caregivers. Classes on 20 different topics have been taught to 460 families. The most popular classes were on depression, spiritual care for homebound people, and home safety and security for seniors.

Over 3,000 hours of adult day care and in-home respite care have been provided thus far in my State. Support groups and caregiver libraries stocked with disease and resource information are also being established in Arkansas as a result of this caregiver program.

The National Family Caregiver Support Program is the first step in supporting family caregivers in their attempts to keep their family members in the community. I think the flexibility of the National Family Caregiver Support Program gives aging programs an opportunity to develop innovative solutions for caregiver support.

The experience in Arkansas I think has been very positive and shows great potential for this program to meet our rapidly growing needs.

So I appreciate this opportunity for us to hear a report on how this is going, and I thank you, Madam Chairman, for scheduling the hearing today.

Senator MIKULSKI. Thank you.

We would like now to call to the table the Assistant Secretary for Aging at the Department of Health and Human Services, Ms. Josefina Carbonell. She comes to us with a great deal of hands-on background.

Before joining HHS as the Assistant Secretary, she was president of the Little Havana Activities and Nutrition Center in Dade County, FL, the largest aging health and nutrition project in Florida and the largest Hispanic geriatric health and human service organization. So she understands what it is like to administer the program and across very broad, diverse lines.

She attended Florida International University and is a graduate of the Kennedy School of Government at Harvard, and she oversees a budget of over \$1 billion, 57 State agencies, 27,000 local providers, and lots of things that we created to help seniors be independent.

We welcome you. This is the first time you are testifying before the committee, and we look forward to both your testimony and also, Madam Assistant Secretary, to getting better acquainted.

So why don't you just go ahead with your testimony, and then we will engage in some questions.



**STATEMENT OF HON. JOSEFINA G. CARBONELL, ASSISTANT  
SECRETARY FOR AGING, U.S. DEPARTMENT OF HEALTH AND  
HUMAN SERVICES**

Ms. CARBONELL. Thank you, Senator Mikulski and Members of the Subcommittee.

Thank you for this wonderful opportunity to testify today on the Administration on Aging's efforts to support America's caregivers and our implementation of the Family Caregiver Support Program—a really appropriate time, as May is Older Americans Month, as the Senator mentioned earlier.

I appreciate this subcommittee's commitment to America's families, and I am grateful for the support you have shown to ensure that the caregiver program remains strong and effective.

Today I am pleased to report that after one year, the National Family Caregiver Support Program is a total success. I would like to share with you some examples of the great strides we are making in the program.

This year, HHS Secretary Tommy Thompson released \$138 million to States and Territories, and the community services and resources made available by this funding are easing the burden of approximately 250,000 caregivers all across this Nation.

I am proud that the States and localities are using these funds in a number of creative ways. For instance, caregiver resource centers have been established in public libraries; donated computers have been retrofitted and used to establish an online support group staffed by a registered nurse; retirees have received training and are providing respite care to caregivers across this Nation, and States are bringing adult day care to rural communities by creating mobile day care programs in which staff travel from 25 to 45 miles a day to offer respite for caregivers. So it is "respite-on-wheels" sort of like Meals-on-Wheels.

These are just some of the many innovative activities we are hearing about the States, but let me focus particularly on some of the States represented here in this committee.

For instance, in Maryland, during the first quarter of 2002, over 17,000 caregivers were served, including information and assistance services to over 10,000 individuals. Counseling, support group, and training support activities were provided to over 1,200 caregivers, respite care services to over 300 seniors, and supplemental services to over 18 persons.

If we look at, for instance, the uniqueness of some of the National Family Caregiver Support Programs, they have paid for in-home aid to care for man with ALS in Maryland, allowing his wife time to shop for food and run other errands. He is on continuous oxygen, in a wheelchair, incontinent, needs suctioning, and is dependent for most of the ADLs. Other Maryland families have received assistance with the cost of medications for their loved ones. A daughter with a husband and six children and an infant grandchild assumed care for her elderly mother with diabetes, CHF, hypertension, incontinence, and was severely obese. There was no room for her mother in her townhouse, and the family caregivers program paid for a small security deposit and first month's rent to enable them to avail themselves of another unit in which the daughter, the mother, and the grandchild moved.

So these are some examples of the flexibility of the services that we are hearing about.

In New Jersey—

Senator MIKULSKI. Madam Assistant Secretary, we are lost in your testimony. Is that an addendum to the testimony?

Ms. CARBONELL. Yes. I decided to bring a little bit of the exact examples of what is happening in some of the States. If you would like me to remain within the testimony—

Senator MIKULSKI. No; go ahead, but we are a little bit pushed for time.

Ms. CARBONELL. Okay. So we are seeing some innovative services across all of the States. We also are very enthused about the kind of pooling together that many of the AAAs are doing to establish caregiver information and caregiver websites throughout many States.

At least 18 States have established either a voucher system or a caregiver reimbursement system that allows the freedom and the choice of the caregiver to purchase services that they might need.

We have also funded six projects of national significance, and we have worked to address issues—for instance, with caregivers of relatives with mental retardation and developmental disabilities, including the investigation of the provision of services to caregivers of MRDD relatives who are between the ages of 19 and 59 years of age in three particular grants that we have given, including also the AHCRQ grant.

Challenges—where do we go from here? First, I believe we need to heighten public awareness. We need to continue to work on ensuring that caregiving is given top priority in the information and assistance networks. Caregiving is a public health issue, and it needs to be realized as such. Caregiving takes its toll on caregivers, jeopardizing their health and emotional well-being.

Many of the millions of caregivers are aged themselves. All too often, they assist loved ones at a considerable cost to themselves. Frequently, caregivers do not seek medical care or engage in preventive health practices. It is important that we work to educate all sectors of the health care community about the importance of treating the caregiver as well as the care recipient.

A second challenge and a primary concern of mine is that caregivers often are not aware that they are caregivers or that services really exist in their communities. All too often, a caregiver seeks help only when a crisis occurs or pretty late. So I want all caregivers to be aware that help is available through the National Family Caregiver Support Program.

Any one of us at any time may be a caregiver. I am one, and I know that there are many others like me here today in this room. I am taking several steps to address these challenges.

First, we have invested in a public service campaign which will be aired more than 100 times on PBS series. It will focus on the caregiver program and how caregivers can access services.

Second, we are forming grassroots community caregiver coalitions to complement an upcoming PBS caregiver documentary which is designed to make more Americans aware of help available through this caregiver program.

Third, we are working with a coalition of States, area agencies, Tribal organizations, and service providers to develop a national public awareness campaign which is very much needed.

Our objective, obviously, is to reach out to caregivers with critical information about local resources and to also recruit volunteers to support programs like Meals-on-Wheels and caregiver respite.

We need to be more responsive to caregivers and their families by providing services that meet their needs. I am committed to working with you to support America's families. One of the greatest strengths of this country is that we are a compassionate Nation with a strong spirit of generosity and with a commitment to help people of all walks of life now and to pave the way for a better future for our children and grandchildren. The National Family Caregiver Support Program embodies this very compassionate spirit.

I would be happy to address any questions that you might have.

Thank you.

[The prepared statement of Hon. Josefina Carbonell follows:]

PREPARED STATEMENT OF HON. JOSEFINA G. CARBONELL

Thank you for the opportunity to testify today—a most appropriate time as May is Older Americans Month—on the Administration on Aging's (AoA) efforts to support America's caregivers and implement the National Family Caregiver Support Program. I appreciate this Subcommittee's commitment to America's families and I am grateful for the support you have shown to ensure that the caregiver program remains strong and effective.

Today, I am pleased to report that after one year the National Family Caregiver Support Program is a total success. I would like to share with you some examples of the great strides we are making in the program.

Last year, HHS Secretary Tommy Thompson released \$113 million to States and territories. The community services and resources made available by this funding is easing the burden of approximately 250,000 caregivers all across the Nation. This year, an additional \$128 million was awarded to States. I am proud that States and localities are using these funds in a number of creative ways. For instance, we have seen new tele-health technology using computers to link caregivers to support networks. Caregiver resource centers have been established in public libraries. Donated computers have been retrofitted and used to establish an online support group staffed by a registered nurse. Retirees have received training and are providing respite care. States are bringing adult day care to rural communities by creating "mobile day care programs" in which staff travel from 25 to 45 miles a day to offer respite for caregivers by providing day care. These are just some of the many innovative initiatives we are hearing about from the States.

Caregiver funds are also being used to form new partnerships, to improve access to services, and to reach out to special populations. Let me give you just one example from each of these categories.

First, States are forming new partnerships. "Faith-in-Action" is an inter-faith initiative that recruits volunteers from faith-based communities to assist the elderly, and those with disabilities and their caregivers. States are collaborating with these existing projects and establishing additional programs in underserved areas.

Second, they are improving access to services. The area agency on aging in Seattle is implementing caregiver training and skills building. The program is designed to help caregivers maintain their own health and increase their confidence in handling difficult situations, emotions and decisions. While attending training courses, these caregivers can access services. This training program has also been successfully introduced to other States, as well.

Third, we are reaching out to special populations. Virginia, for example, is providing specialized services to male caregivers, particularly retired military personnel and men who live in rural and farming communities. Although it is true that most caregivers are women, significant contributions are made every day by husbands, brothers and sons.

In the first year of the caregiver program, the aging network made great strides in designing responsive support systems. Two keys to this success are flexibility and consumer input. AoA, State and area agencies, tribes and providers solicited the input of caregivers in shaping programs through town meetings, focus groups, advi-

sory boards with caregiver representation, new partnerships with the faith community and businesses, and outreach to special populations. AoA has been in the forefront of this movement by conducting listening sessions across the country to hear first-hand from America's caregivers about their own unique needs.

#### NFCSP ASSISTS CAREGIVERS BY PROVIDING THEM WHAT THEY NEED

I would like to share with you how we are contributing to helping America's caregivers. Through information assistance, many caregivers have been helped to determine if their loved one is eligible for Federal programs such as Medicaid, and are assisted with paperwork. Also, caregivers of veterans are learning that their spouses may be eligible for benefits from the Department of Veterans Affairs such as medication assistance. AoA is working both within and outside the Department of Health and Human Services to help those we are entrusted to serve. I am proud to say that AoA is part of what we call "One Department." We all work together to reduce barriers to participating in programs so that the customer always comes first.

I would like to share with you some real life examples of how this program is helping caregivers. A caregiver in North Carolina was involved in an automobile accident and was hospitalized. She was caring for her mother with Alzheimer's disease and her stepfather who had multiple physical problems. Caregiver program funds were used to temporarily place her mother and stepfather in a long-term care facility during the duration of her hospitalization.

South Carolina assisted an 80-year-old great-grandmother who is caring for her 23-year-old granddaughter with end-stage AIDS and her three young children. Funds are used to purchase diapers and related supplies for the babies and respite care for the great-grandmother to allow her to go to medical appointments.

In Missouri, a grab bar and bath bench assisted an 80-year-old gentleman to continue to care for his 78-year-old wife with Alzheimer's disease. An occupational therapist came to the home to instruct the caregiver in the proper and safe way of using the equipment to bathe his wife.

#### MEASURING SUCCESS

President Bush believes the truest kind of compassion does not only come from more government spending, but from helping citizens build lives of their own. It is compassionate to actively help our citizens in need, yet it is responsible to insist on accountability and results. AoA has made greater use of performance outcome measures and indicators for ongoing program assessment and to support evaluation decisions. We are applying this approach to the caregiver program. These measures include identifying the number of individuals served, the extent to which State entities are providing various types of services supported by the Older Americans Act (OAA), and a broad measure of outreach through the ratio of caregivers to OAA service clients. In addition, AoA and its partners have developed an outcome measures survey instrument specifically for caregiver services. This instrument will allow us to assess program implementation, including: The extent of services available specifically to caregivers; Caregiver satisfaction with services to the elderly; and Caregiver assessment of the impact of services to them and to the elderly.

#### CHALLENGES WHERE DO WE GO FROM HERE?

First, I believe we need to heighten public awareness that caregiving is a public health issue and it needs to be realized as such. Caregiving takes its toll on caregivers, jeopardizing their health and emotional well-being.

More than 44 percent of the State health departments have begun to address caregiving issues. Many of the millions of caregivers are aged themselves. All too often they assist loved ones at a considerable cost to themselves. The physical demands, emotional distress, and their sheer age increase their risk for health problems. Frequently, caregivers do not seek medical care or engage in preventive health practices. AoA has heard from caregivers that while health and social service providers often treat the caregiver's family members, they rarely ask about the caregiver's needs. It is important that we work to educate all sectors of the health care community about the importance of treating the caregiver as well as the care recipient.

A second challenge and a primary concern of mine is that caregivers often are not aware they are caregivers or that services exist. All too often, a caregiver seeks help only when a crisis occurs. I want all caregivers to be aware that help is available through the National Family Caregiver Support Program. Any one of us—at any time may be a caregiver to a member of our family. I am one and I know that there are many others like me here today in this room.

I am taking several steps to address these challenges. First, we have invested in a public service campaign which will be aired more than 100 times on PBS. It will focus on the caregiver program and how caregivers can access services. Second, we are forming grassroots community caregiver coalitions to complement the upcoming PBS caregiver documentary, "And Thou Shalt Honor." This mini-series is designed to make more Americans aware of help available through the caregiver program. Third, we are working with a coalition of States, area agencies, tribal organizations and service providers to develop a national public awareness campaign. I want people to know that they are not alone and that help is available. I am excited about this outreach campaign and have challenged the national aging network to join us in getting the word out to every corner of the nation no matter how remote or disadvantaged.

Our objective is to reach out to caregivers with information about local resources and recruit volunteers to support programs like meals on wheels and caregiver respite programs. We need to be more responsive to caregivers and their families by providing services that meet their needs. I am committed to working with you to support America's families.

One of the greatest strengths of this country is that we are a compassionate nation with a strong spirit of generosity, with a commitment to help people of all walks of life now, and to pave the way for a better future for our children and grandchildren. The National Family Caregiver Support Program embodies this compassionate spirit.

I would be happy to address any questions you have.

Senator MIKULSKI. Thank you very much, Madam Assistant Secretary.

I know that you could give us examples from each one of the States, and we would love to hear those stories, but let us get right to the heart of the matter.

Could you share with me and the committee the issue of information and referral as you look at your first year. First of all, I want to just say kudos for the public information campaign through public broadcasting, and hopefully, the private sector will step forward. But once they come into the gateway, the most important issue is information and proper referral. Could you share with us how that is going? Is it stronger in certain areas, for example, urban? Do we need more language training for some of our multi-ethnic communities?

Could you share with us, because information and referral is so crucial.

Ms. CARBONELL. Yes. There are certain areas where obviously, information about a new program is critical, particularly in the initial phase of the development of the program. So has been the importance of creating a solid program in communities where you use the best in services that have been providing in the aging network; that means using the solid base of the Older American Act Title III services and build upon that a new kind of system to provide services to the caregiver community.

For instance, there are still many challenges in the rural communities. As we went across the country and held nine listening sessions in both rural and urban and suburban communities, we heard very clearly the need to expand the information and assistance so we can reach out to families, particularly in rural communities and particularly ethnic communities and language disadvantaged communities.

There is a whole effort, and we have funded innovative programs in these areas to address not only the messages to be appropriately and culturally targeted to those communities but to reach out to those disenfranchised communities.

Senator MIKULSKI. Where do they get information? Do they dial in to a center? Are you using the internet? How does a family get information?

Ms. CARBONELL. We are seeing some innovative things going on in the field. For instance, some States have funded an information line or have added information to their State elder help line or to their local help line through the Area Agencies on Aging. We have seen how AAAs have also pooled resources through their State association and funded public awareness campaigns, billboard campaigns, PSA spots.

Senator MIKULSKI. But that is to get them to call. In other words, if you are a family person Arkansas, Utah, Maryland, on the Eastern Shore, you could be five blocks from Johns Hopkins or University of Maryland and still—is it that you are calling into an office on aging?

Ms. CARBONELL. Right. There is an eldercare locator number that people can call, which is a nationwide 800 toll-free number, and they are then connected to their local office. Or it might be, just as you said, two blocks away, and they are connected to that AAA provider in the locality, and that local AAA provider then directs the individual to the array of services available, from assistance to caregiver support training to respite, both center-based and home-based care, and other services that are implemented by the State.

The beauty of the program has been the way that the law was crafted to give the greatest flexibility to States and local communities to implement.

Senator MIKULSKI. Well, Senator Hutchinson and I worked very hard on that, because again, even in my own State, there are five different States—we have our mountain counties in Western Maryland, we have our Eastern Shore, the Baltimore–Washington corridor, which is very suburban and so on. So we wanted to have that flexibility.

In terms of the funding for the agency, as we work with our appropriators, Senators Specter and Harkin, do you think this is an area that needs to really be amplified, that is, the information and referral, or do you prefer just to increase it and look at where you need to deploy?

Ms. CARBONELL. The request for 2003 is for the same amount of dollars that we requested in 2002, and we thank the Senators for their support and the increase in 2002. It allows us to have the program in full implementation phase. It has allowed us this year and a half to have States and local communities respond to local needs—that means to develop a flexible system that has the capacity to respond to a new type of clientele. It has given time for States to implement a program that builds upon the existing aging network and expands from there. It has allowed them, for instance, to provide services to rural communities, to develop expanded services in not only respite but home care, the voucher systems and other choices. It has allowed to be developed, for instance, a whole information and assistance program.

Senator MIKULSKI. Are you saying you do not need more money?

Ms. CARBONELL. The President's budget calls for the same amount of dollars for next year, and we are confident that this is

a solid budget. It builds upon the development phase. We should have some more solid information at the end of this year, and I would be glad to come back and report to you those final numbers.

Senator MIKULSKI. Thank you.

I have some other questions related to innovation, but my time is up.

Senator Hutchinson.

Senator HUTCHINSON. Thank you.

Assistant Secretary Carbonell, you mentioned that you hope that by next year, we will have more data. In your written testimony, you talked about the importance of measuring the success of the program and that you have several performance outcome measures and indicators. Have you collected any data thus far, and when do you expect a broad range of data to be available for the committee?

Ms. CARBONELL. For the first time ever, a national survey will be conducted, and the caregiver program is included in that survey. That survey is slated to be completed hopefully by early fall, so we should have some numbers early on, in late fall of this year. And by next year, all of the States will be implementing and reporting on outcome measures, including the caregiver support program.

This is really the first year to a certain extent of the program, because it took approximately a year for many of the States to develop the capacity to fund these programs, to get the funds in place and to get the matching situations in place in their local and State communities, and to get the program up and running.

Some programs have been in place for about 6 months; some programs have been in place for about 10 months. But we are hearing some good outcome measures, particularly in the areas of information—we are dealing the capacity to expand that. We are expanding in areas of respite. We are using as a bar of measurement—out of the 7 million older Americans that we are serving in our Older Americans Act, approximately 3 million folks are homebound; that means they lack the activities of daily living, and they have trouble coming into congregate settings, so they are being served in a home-based setting—we are using that as a measuring tool to be able to get to the point where we will be able to reach. So we are assuming that for each of those 3 million seniors that we are serving homebound, they are being taken care of by caregivers.

Senator HUTCHINSON. When you describe the program as an unqualified success, that is based upon preliminary measurements, anecdotal evidence, and success stories that you have heard, as apart from an objective survey, and you would anticipate that in the next 6 months, we would have more concrete data—

Ms. CARBONELL. We anticipate that in the next 6 months, we will have the completed survey done, which includes the family caregiver programs, which give us specifically outcome measures, not only in rates of participation, but how people have improved, how caregivers have been able to go back to work, and other measurement models that we are using on the family caregivers program—not only attendance, but what kinds of services and expansion of services have allowed people to remain at home.

Senator HUTCHINSON. In describing the program as a success—and I do not think anyone on this subcommittee is going to argue

with that description, and certainly the evidence and the anecdotal success stories we have heard in Arkansas reflected that description as a success—but in the year that you have had, are there any changes—if you were able to right now rewrite the authorization for this program and make changes, not in the funding levels but the program itself and the way the program operates, can you describe anything that you might want to be different?

Ms. CARBONELL. I think that what we heard across the country in the listening sessions was please keep the flexibility, the flexibility, the flexibility.

I think caregivers are wanting to ensure that there is flexibility in the implementation of the programs. I think that has been the biggest beauty of the law. And we are passing that flexibility on to the States and local communities so they can implement it the way they want it, with the array of services that they want implemented.

We have heard about some difficulties with meeting match, yet none of the States—in the final reports that came in for the first year of implementation, everybody met their 25 percent match requirement. I think that due to the economic downturn, some States and local communities were having trouble raising that match, but they did meet it.

We heard the need for more information. We heard very creative recommendations on rural implementation and grandparents taking care of grandchildren. We met a grandmother in rural Idaho, a widow, the owner of a working farm, who takes care of three grandchildren. She said, “It has been a Godsend for me to have the family caregiver support program. It allows me to get a little bit of respite.”

Senator HUTCHINSON. So the message has been keep the flexibility.

Ms. CARBONELL. Keep the flexibility.

Senator HUTCHINSON. It is not that there are problems that you would like corrected; rather, we should not tinker with this program and mess up what has the promise of working very well.

Ms. CARBONELL. And we are taking that to heart in the sense that we are developing the new regulations, or clarifying the regulations that are unclear, including the family caregivers program. That is utmost in our minds to make sure we keep the flexibility and allow local communities and States to implement their own priorities and to implement the services that best meet the caregiver needs.

Senator HUTCHINSON. Thank you.

Senator MIKULSKI. I have a few other questions. First, all that you are undertaking and discussing really requires competent staff. We have talked about the need for competency in not only content but language, for example, for many of our communities. Also, there is a significant issue that has arisen on health care staffing, including a shortage of respite care providers, where housekeeping is involved, help with ADL when you do not need home health.

Could you share with us your observations on how serious this shortage is, and second, is this an appropriate function for the family caregiver program to undertake to see how we can recruit, screen, and train—what we would call the support for caregiving.



Could you comment on that?

Ms. CARBONELL. We have funded several of the national significance projects. For example, the American Society on Aging grant will collaborate with the American Nurses' Association, the National Association of Social Workers, and the American Occupational Therapy Association to increase the skill and knowledge of their members and to link these groups and these training modules with many of the caregivers and some of the formal, paid caregivers in communities.

When I talk about caregivers, obviously, the majority of the caregivers are informal or family members. I know we will hear from one of the caregivers later. I am a caregiver, and as we heard at the caregivers conference, they do not want to be called "informal"—they are formal, 7 days, 24 hours a day. So there is nothing informal about them. But many of the folks need a little bit of training to assist them in caring for their relatives in a better fashion so they do not get injured and so on.

We definitely have to do better in improving the training. The President's budget in the HRSA category has increased training for nurses, and we are working closely with our partners in HRSA to extend that training to the CNAs and to the certified nursing assistants, who are the bulk of the folks providing some of this non-medical in-home care in our communities.

We are looking, for instance, at the Family Caregiver Alliance in San Francisco, and we are developing caregiver programs nationwide, including 10 case studies, and providing training throughout.

Senator MIKULSKI. While we are looking at all of those wonderful case examples nationally, are you going to establish national standards for CNAs, or is this going to be left to the States? Are you going to encourage the States on retention?

Let us put the family training aside for a moment. We know that the first line of caregiving is the family and whatever help them can give; but then, we are also looking at other people to support the family.

Ms. CARBONELL. That is most important. Secretary Thompson and all of my colleagues in HHS are working very hard—for instance, as we did with the quality indicators—we are working with our Ombudsman Program which is under the Administration Aging, and the quality indicators or information offices out of Center for Medicaid Services to improve the capacity of the information that is given to relatives or persons in the nursing home.

Senator MIKULSKI. Coming back to the CNAs, ma'am, is this a function of your program to recruit, train, and have national standards for certification of CNAs? I am not saying that you should; I am just asking.

Ms. CARBONELL. This is not a function of the National Family Caregiver Support Program. The National Family Caregiver Support Program is to assist family and relative caregivers in ensuring that they have support services so they can continue to work with and take care of their relatives.

Senator MIKULSKI. Regardless of that, I would like to offer a challenge if I could, because I believe your incredible grassroots experience would be so helpful, and that is to establish an inter-agency group to really look at this shortage issue.

I have great respect for our Secretary of Labor, Ms. Chao, and I know this is an area of great interest to her. We also have many people who are now unemployed, have lost their jobs in the hospitality industry, people who already have people skills, but they do not have these kinds of skills. I know that Ms. Chao is very concerned about unemployment, work force shortages, skills shortages.

At the same time, we have CMS under Mr. Scully. I worked with Mr. Scully when he worked for President Bush's father over at OMB.

These are issues that we really have to address. It might require new legislation, but we have got to get the work force ready for the aging population. Presuming the program continues to be a success and that we have the right program and the right resources in place, we have got to have the right people, and—exactly as I said—they have to be recruited, and they have to be screened. We cannot have everyone going into homes or adult day care. And they also have to be trained.

The question is what is the best way to do that. And I am not talking about big, new bureaucracies, but I do believe there has to be national attention not only on the fact that we have a nursing shortage. Senator Hutchinson and I have been real leaders on the nursing shortage issue, and we have talked about long-term care and nursing homes and so on. But this is to keep people independent and what is the best way to do that.

So I would like you to really ponder that, and we look forward to working with you, but we would really like an interagency group to look at it and give us recommendations, and then let us see where we can go—not for bureaucracy but for people.

Senator do you have further questions?

Senator HUTCHINSON. Yes, just one question.

You mentioned a couple of times the six projects of national significance under the program. I am curious first of all how much of the total budget is allotted to these six projects of national significance, and how did you determine what those projects would be and what kind of resources would go toward them.

Ms. CARBONELL. Out of the original \$125 million for the program, \$6 million was separated for programs of national significance, and it was again based on the limited numbers; the bulk of the dollars go formula-based to States for implementation at the State level.

Senator HUTCHINSON. But what kinds of criteria were used to establish those projects of national significance?

Ms. CARBONELL. There were five areas that we determined. One of the areas was projects of national significance; projects of innovation that looked at, for instance, caregivers of relatives with mental retardation and developmental disabilities. We also looked at ethnic minorities and rural communities, and we looked at models of replication. We also looked at research in the sense of looking at the innovation and testing these models in particular communities.

So there are four or five different criteria for the development of the \$6 million innovation grants.

Senator HUTCHINSON. And will those six projects also be evaluated?

Ms. CARBONELL. Yes.

Senator HUTCHINSON. Will we have data on their success just as you are going to survey the States?

Ms. CARBONELL. As a matter of fact, all the innovation grants have outcome measures and research outcomes in them.

Senator HUTCHINSON. And the subcommittee can expect that information as well?

Ms. CARBONELL. Hopefully by the end of this year, yes.

Senator HUTCHINSON. Thank you.

Senator MIKULSKI. Thank you.

Thank you very much for your testimony. As you can see, both of us could spend all afternoon with you listening to the innovation.

Obviously, when we hear about the flexibility, things like respite care on wheels, also think about focusing on an area that does not get a lot of attention, which is the male caregiver, and the fact that it has been done in Virginia with military retirees. It really takes enormous cultural sensitivity and really very refreshing new thinking. This is exactly what we wanted, as well as the core program and how it would be value-added by innovation.

So we look forward to the data at the end of the year and our ongoing collaboration with you. You bring a great deal of experience, and again, I am an admirer of our Secretary of Labor. She was head of the United Way, so she knows the grassroots groups. She is our Secretary of Labor, and I think we could really focus on some of these—I am not going to call them “work force shortages”; we are going to call them skill shortages—and I believe that there are a lot of people out here, particularly many newcomers to our country, who are really looking for a ladder of opportunity, and in health care, I think this could be a marvelous ladder.

So we look forward to working with you, and we thank you. If you could stay, I think you might find it interesting; but if you cannot, we also understand.

Ms. CARBONELL. Senator Mikulski, may I add to my formal testimony? Maybe I did not respond directly to your question. Secretary Thompson is particularly active, particularly with HRSA and CMS and the entire Department, in ensuring that the nursing shortage and the training of the work force be improved. So we are working very actively with our partners in HHS to first of all get our house in order in making sure that those programs are available. And in CMS for respite programs and respite model programs in the year 2003, and in the HRSA budget for 2003, both budgets have increased dollars to ensure that the work force issue and specialized training are tested on a pilot basis so that we can go national.

Thank you very much.

Senator MIKULSKI. Thank you very much for that clarification.

We now call up witnesses with a great deal of professional expertise and experience.

Sue Ward is Secretary of the Maryland Department of Education.

John Skirven is Executive Director of the Senior Services of Southeastern Virginia in Norfolk.

And Barbara McSweeney is a family caregiver from Washington, D.C.

I know that Senator Warner wanted to introduce Mr. Skirven, Senator Hutchinson. Did you want to do that?

Senator HUTCHINSON. You go ahead.

Senator MIKULSKI. Okay. If Senator Warner pops in, we will accommodate him.

We want to welcome our panel. First, Sue Ward, who is Secretary of the Maryland Department of Aging. She oversees 19 area Agencies on Aging throughout our State. She earned a Master's Degree in social work from the University of Utah, so we are sister social workers. She is a member of the board of directors of the National Association of State Units on Aging. She has been a tremendous advocate for seniors in Maryland. She has held public office as well as now, this appointed office, and she comes with a great deal of hands-on experience and compassion.

We also want to welcome Mr. John Skirven. Senator Warner wanted to be here to introduce you. He is in an Armed Services Committee meeting right now, so just know that he wanted to be here to welcome you himself. It was through him and working with Senator Tim Hutchinson that we were able to bring someone like you, with your experience.

Senior Services is the largest area agency in Virginia. John Warner told me it helps over 20,000 seniors and family caregivers each year. Mr. Skirven is on the board of directors of the National Association of Area Agencies on Aging. He has 29 years of experience in community-based long-term care. He, too, has a Master's in social service from Bryn Mawr, as well as personal experience as a caregiver, caring for his mother at home for several years before her passing, and our respects to you.

And we welcome Ms. Barbara McSweeney, who has been a resident of the District of Columbia since 1958. She is married, with three children, and is currently caring for her mom who has Alzheimer's disease. She also had cared for her mother-in-law, who passed away from cancer. So Ms. McSweeney has tremendous experience in what it is like to be a hands-on caregiver—and this is after recently retiring after 31 years of teaching in the D.C. public schools. She holds a Bachelor of Science degree from Shaw University, a Master's Degree in teaching, and is an active member of the Takoma Park Baptist Church, a volunteer for AARP in the District Superior Court, a very active member of the United Negro College Fund and its Washington alumni.

So Ms. McSweeney has been an advocate, a community activist, and has really provided compassionate care.

We welcome all of you. Let us start with Sue Ward and go right down the table, and then we will go to questions.

Ms. Ward.

**STATEMENT OF SUE F. WARD, SECRETARY, MARYLAND  
DEPARTMENT OF AGING, BALTIMORE, MD**

Ms. WARD. Thank you very much, Senator Mikulski and Senator Hutchinson.

I am very pleased to be with you here today to talk about a very innovative program, the Family Caregiver Support Program. We are excited about this program. It allows the aging network so

much creativity and flexibility in providing information and services to family caregivers.

Just to digress for a moment, it is a response to increasing need. Senator Mikulski, as you talked about the “club sandwich,” I have been talking about the “submarine sandwich” generation, where the person is caring for the younger children and sometimes grandchildren, and aging parents and grandparents; so that stretch is sometimes very difficult.

The National Family Caregiver Program in Maryland is overseen by a program coordinator who works with the 19 local Area Agencies on Aging and is well aware that caregivers are often very isolated and feeling the burden of caring all by themselves. We feel that most of all, they need information and that they can do a lot if they can find out where the resources are and how to get help.

Our program coordinator conveys information via email, telephone calls, meetings and visits, the internet, national conferences, any other source that she can find to work with each of the local coordinators and their staff. Quarterly meetings are held to provide information, and ample time in those is used for the most helpful aspect of these meetings, which is sharing of information among the local staff.

At each meeting, there are opportunities to “show and tell” some of the services and items in the workshops that have been put into place at the local level. In addition, there are personal visits by the coordinator and others to the local area agency to help in any way possible.

Each area agency in Maryland has incorporated the new functions into the existing, but enhanced specifically for caregivers. Many local agencies are providing workshops and training sessions for caregivers; may have support groups. Each county provides respite services and supplemental services and integrates these with other existing State and Federal programs. The Department of Aging has an enhanced website to include information for caregivers, and we are updating our Grandparent Resource Directory to help grandparents who are caring for young children.

We use a consumer-directed model which allows each family to have the maximum possibility for choice and control, and as we move into the next phase of the program, the next years, we will have more local staff trained in that particular approach.

As an aside, we have a wonderful and exciting demonstration grant from the Administration on Aging which we talked about at your field hearing, Senator Mikulski, to provide respite services to families using that consumer-directed service model, and we plan to use that to expand the education throughout the State.

Let me give you a couple of examples. The Baltimore County Department of Aging is providing stipends to families after individual counseling so that respite care can be purchased by the family for their own needs from their own area. Most of this is for in-home care.

The Prince George’s County department has developed a caregiving gift pack which they give out to people when they first have information that the families need help.

There are other grandparent support organizations, and the MAC on the lower Eastern Shore has asked pharmacies to place information in every, single prescription envelope that is given out.

So many people have already received assistance and relief through this program, and Assistant Secretary Carbonell gave you a great deal of that information, so what I would like to do is move to the challenges, which are numerous.

There are so many caregivers who need assistance. We are doing our best to provide the services they need, but the amount of funds available still falls short. As you know, those of us in the State and local Area Agencies on Aging strongly support your efforts, Senator Mikulski, to double the program funds. We also plan to start gathering information about those people who are on waiting lists or who cannot be served.

Another challenge that many older caregivers face is caring for adult children with developmental disabilities, physical or mental disabilities. Many parents use the "prayer plan" to solve the concern—that is, to pray that the good Lord takes the child before he takes them, so there will always be a caregiver for that adult child.

I thank you for your interest and will be pleased to answer any questions.

[The prepared statement of Ms. Ward follows:]

PREPARED STATEMENT OF SUE F. WARD

Mr. Chairman and Members of the Committee: I am pleased to be here with you today to talk about the National Family Caregiver Support Program. We are so excited about this innovative program that allows the aging network so much creativity and flexibility in providing information and services to family caregivers.

National Family Caregiver Program services are overseen in Maryland through our program coordinator who works with our 19 local Area Agencies on Aging (AAA). Each local AAA provides a plan for how they will implement the National Family Caregiver Support Program. The Maryland Department of Aging provides funding through the Older Americans Act Title III-E, which allows AAAs to implement their plan. The State program coordinator is also a member of Maryland's Caregiver Coordinator Council, a working group of individuals charged with developing a model caregiver plan for all types of caregivers.

Our program coordinator works closely with the AAA coordinators via telephone calls, e-mails, meetings and visits. Any information that would be of assistance to them, whether from the internet, national caregiver groups, information from conferences, or other sources is shared with each of the local coordinators and their staff. Quarterly meetings are held to provide general information and updates about the program and about caregiver issues. Ample time is provided for the most helpful aspect of these meetings, which is information sharing among the local staff. At each meeting, there are opportunities to "show and tell" some of the services, items, and workshops that have been put in place. In addition, the coordinator visits each AAA to provide individual assistance, on issues from how to report their own program activity to how to implement certain aspects of the program.

Each AAA has integrated the Information and Assistance (I&A) pieces into the existing I&A functions, but enhanced information specifically for caregivers has been provided. Many local agencies are providing workshops and training sessions for caregivers, and many have support groups for caregivers. Each county provides respite services and supplemental services, and integrates these services with other existing State and Federal programs.

Our overall plan for the provision of respite and supplemental services is to use a consumer directed service model, for example: maximizing the amount of choice and control that a family has in choosing and receiving services. As we move into the third and fourth years of the program, more local staff will be trained in how to use this model. As an aside, we have a wonderful and exciting demonstration grant from the Administration on Aging (AoA) to provide respite services to families using the consumer directed service model. Our plan is to use the success of this grant program as a model and learning tool for all jurisdictions.

The Maryland Department of Aging has enhanced its website ([www.mdoa.state.md.us](http://www.mdoa.state.md.us)) to include information and resources for caregivers. This site is updated on a continual basis.

Here are some of the things that are happening at the local level:

- Baltimore County Department of Aging is providing stipends to families, after individual counseling sessions, so respite care can be purchased from the providers of their choice. Most families use the funds for in-home care. The maximum stipend is \$500. In the four months that this service has been offered, 133 families have used the stipends. This is an example of the consumer directed care model.

- Prince George's County Department of Family Services, Division of Aging and Disability Services is providing "caregiver gift packs," which include a caregiver planning calendar, a resource guide, and writing pads with relevant phone numbers. Gift packs are given to people who are caring for and have applied for the Medicaid waiver for loved ones.

- Several area agencies are publishing caregiver resource guides. One of the guides in Prince George's County will be geared specifically for grandparent caregivers.

- Several AAAs are entering into partnerships with existing grandparent support organizations to assist in providing information and services, including respite care.

- Evening, weekend, and/or daytime seminars and workshops are being held, with topics that include dementia care, home modification, depression, and legal issues. AAAs are offering respite care funds so that families can attend these sessions.

- Caregiver training sessions are being held in many jurisdictions. Several counties have purchased training curricula for their caregiver training sessions.

- Several jurisdictions have updated, or plan to update, their websites to include caregiver information.

- Dorchester County, part of the Maintenance of Aged in the Community (MAC) area agency, has asked pharmacies to place information flyers in prescription bags with medication.

- Every jurisdiction has developed, or is in the process of developing, written materials about the caregiver program and services. These include brochures, fact sheets, resource guides, newspaper, and other print ads.

Caregivers learn about the National Family Caregiver Support Program in a variety of ways. Many learn from the written information noted earlier in this testimony. Information is also available from our website or by calling our office or any of the local area agencies on aging. Access to services always begins with the local AAA, specifically through the Information and Assistance program.

So many people have already received assistance and relief through this program. In the first quarter of this fiscal year, more than 10,000 caregivers have inquired about and received information, and 1,700 have received one-to-one assistance. Close to 1,300 caregivers took part in counseling or training sessions that were geared specifically to caregivers. More than 300 caregivers have been able to get respite from their caregiving responsibilities as a result of this program.

As for how people are helped by these services, let me read you three letters that caregivers have sent.

The first letter is from Baltimore County, from a caregiver who attended a caregivers' conference that was held in November.

"Again this morning I had the delightful opportunity to pull your glass "Caregiver Connection"; mug from my cozy cabinet that I might indulge in some much-needed tea. Of course, simultaneously, I thought once more about your very successful and happily daylong conference (plus "fun," "tears," and "stories;") for those of us otherwise forgotten by others and distraught within ourselves or just merely "lost." Thank You! Your success is proven repeatedly day-by-day as we attendees recall salient advice, anecdotes, faces, facts and—well—precious, indefinable moments. I was excitedly able to convince both my brother and my husband to attend as well. Thank you again."

The next two letters are from Washington County, one about the respite she received, and the other about a wheelchair that was purchased using supplemental services funds.

"Respite for me has been a wonderful thing, as I am the caregiver of my husband who has ALS. It helps relieve some of the stress of the everyday things that must be done. All I can say is thank goodness for respite. Thank you so very much."

"Wayne and I can not thank you enough for allowing us to get the wheelchair. It has made such a difference for both of us. I don't feel as much pressure to "run around" and hopefully Wayne senses my patience. Again, thank you so much."

The challenges this program faces are numerous. There are so many caregivers who need assistance. While we are doing our best to provide the services they need,

the amount of funds available, through this program and other State, Federal and locally-funded programs, simply falls short. As you know, those of us at the State and local levels very much want funding for this program doubled. We have not yet begun to collect information about people who have been turned away or who are waiting their turn to receive services, but we are planning to collect this information next year.

Another challenge that many older caregivers face is caring for their adult children who have physical, mental, or developmental disabilities. My staff have told me about more than one older parent who uses the "prayer plan," that is, they pray that the good Lord takes their son or daughter before he takes them. We would like to see some support in the National Family Caregiver Support Program for older parents who are in this situation.

Thank you for your interest. Again, we are very excited about this innovative program that allows so much creativity and flexibility in providing information and services to family caregivers. I will be happy to entertain any questions.

Senator MIKULSKI. Thank you very much, Ms. Ward.

Mr. Skirven.

**STATEMENT OF JOHN N. SKIRVEN, EXECUTIVE DIRECTOR,  
SENIOR SERVICES OF SOUTHEASTERN VIRGINIA, NORFOLK,  
VA**

Mr. SKIRVEN. Thank you, Senator.

My name is John Skirven. I am the executive director of Senior Services of Southeastern Virginia, the Area Agency on Aging that serves Hampton Roads, which includes Virginia Beach, and Portsmouth. We actually serve from the ocean out to a rural county of Isle of Wight, from the North Carolina border up to the Chesapeake Bay.

I am really pleased to be here today with my son Timothy. He did not have the pleasure of spending much time with his grandfather as I helped my dad take care of my mom, and I am really pleased that Tim is here with me today.

Senator MIKULSKI. Where is Tim? Welcome.

Mr. SKIRVEN. He finished his SOLs yesterday.

I am here to report on how we have implemented the National Family Caregiver Support Program in our Area Agency on Aging, but before I begin, I really want to thank Assistant Secretary Carbonell for her swift actions in response to September 11. She was able to get funds to the Arlington Area Agency on Aging in Virginia, and they used those funds to coordinate with FEMA-funded programs and to continue to provide meds to older members following the aftermath of the attacks.

I do serve on the Board of the National Association of Area Agencies on Aging, and I have to tell you that my colleagues in New York and New Jersey are now caring for people whose caregivers did not come home, and the flexibility of their family caregiver support funds has allowed them to do things that otherwise could not have been done in the past. So it is really heartfelt from all of us around the United States for your work in behalf of older Americans. I mean that sincerely.

I can tell you that the local reaction to the Family Caregiver Support Act was jubilant in our region. When it was passed, we spent a day or two cheering and yelling, because we had sent thousands of letters up here to Congress, and we figured that finally, Washington gets it—and then we realized that we had gotten what we wanted. So we had to quickly focus our efforts on planning for how we would use this gift to serve the families and the older folks.



Our leadership structure has about 75 community leaders in it. We brought those folks together. We have about 142,000 elderly in our region, and we are actually the largest area in the State of Virginia for older adults. We are an in-migration or a retirement destination for military, so we have a lot of families with military history. In fact, one out of every five of our retirees is a veteran.

We looked at not only what our region needed but also at what the Act would allow us to do with these new resources, and we found a lot of overlap. So we focused on those areas where we knew there to be needs among family caregivers, and we also took the challenge of having a 25 percent match. Nothing comes free from the Government, and that means that you have got to leverage your resources and build relationships so that you can grow what you are given through the Government. And I am pleased to report that we are meeting our match requirements in a very wide variety of ways.

The gaps in service or the areas of importance that we really felt it important to address were access to service for caregivers, which includes care coordination, information and referral, transportation, public education and our ombudsman, respite care—our advisory councils and board of directors said we can find the printed materials elsewhere; we need to focus on some hard services—and finally, prescription medicines, because many of our older adults do not have the money to buy meds.

Let me go to exactly what we have done. We are establishing a new adult day care center that opens next month. We were able to get a \$100,000 grant from the State and match that with two grants from United Way. I can tell you that when the Centera Foundation heard about the family caregiver act, they kicked in, too. It was a leveraging effect.

We have increased our homemaker services and our personal care services. We have started a new overnight respite program. We have taken our award-winning senior companion program, for which we won a Governor's award, and we have been able to use the caregiver funds to add 15 senior companions, and each of those folks cares for two or three other older folks in their home to provide respite care for the families. We bundled that also with a grant from the Alzheimer's Association.

We have added a care coordinator, an information specialist. And in the area of pharmacies and medications, our Virginia Health Care Foundation has a software program that has all of the applications from all of the drug houses in one place, so we are using caregiver funds bundled with other Older Americans Act funds to do the outreach, and in the first 12 months, about 300 people have received over \$90,000 worth of free medicine as a result. That is a direct return on investment—

Senator MIKULSKI. I'm sorry. Could you repeat that number?

Mr. SKIRVEN. Yes, ma'am. It enabled 292 persons to save \$96,906.95 on over 1,500 prescriptions. It is remarkable. This is the kind of creativity and flexibility that Secretary Ward was talking about, to be able to leverage that sort of thing, and with the outcomes that come from prescription meds, you can see that we are preventing people from having to use emergency care or needing to use more expensive care in long-term care stay institutions.

We have also developed a new website and new print materials. I believe you may have received this today. I mentioned that we have a lot of military retirees. One of the photos in here is on the U.S.S. Wisconsin, which is now a naval museum, and the four guys in that picture are former enlisted people on the Wisconsin and are now docents and volunteers for our organization.

We have been really blessed that our State unit on aging included us in this grant to reach out to retired male military caregivers. As we speak, the first of the outreach staff hired by the Peninsula Agency on Aging yesterday started yesterday. We hope to have somebody on board in a couple of weeks. The issue there is to reach out to men who do not want to talk about what they are doing and who do not ask for help. I know that personally from my own dad; it was only when we got to that point when my sister and brother and I were asked that we pitched in. I can talk more about my family, but I think what is important here is that what we really intend to do is reach out to those folks, bring them in, and embrace them with the other services that are available through the Title III-E funds. All of that comes with an honor of their desire to contribute and to participate. Folks do not want anything free; they want to give what they can give.

We have our new print materials. Our website will be launched on the 16th; it is an upgrade of our existing website. I have included in my testimony the story of one person, but in the interest of time, I would really like to hear Ms. McSweeney's testimony, because I think that is what is really important.

Thank you.

[The prepared statement of Mr. Skirven follows:]

PREPARED STATEMENT OF JOHN M. SKIRVEN

Good Afternoon. My name is John N. Skirven. I am the Executive Director of Senior Services of Southeastern Virginia, the area agency on aging serving Hampton Roads. We are one of the original 10 area agencies on aging established as part of the national pilot in 1972.

I am here to report on how we have implemented the National Family Caregivers Support Program since it was enacted in 2000.

Before I begin, I would like to thank Assistant Secretary Carbonell for her swift actions in response to September 11. She was exceptionally effective in expediting the Title IV Older American Act funds to the Arlington AAA to coordinate transportation, counseling and mental health training with FEMA funded programs; and to provide medications for older people affected by the attack on the Pentagon.

I serve on the Board of the National of Area Agencies on Aging. My colleagues in New York and New Jersey tell the stories of parents whose caregivers did not come home from work that night. Those AAA's and others here in Virginia have joined with the families and other organizations to care for the elders left behind.

We would also like to publicly thank Virginia's Department for Aging for expediting the release of the Family Caregiver funds last spring. Every AAA in Virginia was able to begin delivering Family Caregiver Support Services by June 1, 2001 because the Department sought our input on funding formula issues, cleared the usual debris from the area plan amendment pathways and allowed the greatest flexibility possible to enable us to get services to people.

The local reaction to the reauthorization of the Older Americans Act and the Family Caregiver Support Program was jubilant. For the first time in over five years we had evidence that Washington got it. The seniors in our region had sent 1,000's of letters to Congress.

Together we had asked over and over that our Senators and Representatives reauthorize the Older Americans Act. First Senator Robb committed and then Senator Warner completed Virginia's commitment to a super majority. We cheered for a day or two and got to work.

We knew we had a challenge because Hampton Roads has more older people than any other part of Virginia; over 142,000 and growing fast. We are a major retirement destination, especially for military families. And our State's older population is expected to double by 2020.

The first thing we did at Senior Services was to engage our staff, Governing Board and Advisory Councils in an expedited planning process following the news that the new program was a reality. Senior Services is a non-profit 501(c)(3) organization. We have over 75 volunteers in our leadership structure.

They come from every walk of life and every locality in our service area. We are the largest AAA in the Commonwealth and are devoted to supporting and enriching the lives of older adults and their families through advocacy, education, information and comprehensive services.

Because we are in constant touch with the over 20,000 people we serve each year and have a very cohesive aging network in our region, we knew and could document that families needed the kinds of services that can be provided through the FCGSP.

Congress is to genuinely be thanked for building flexibility into the Older Americans Act. As a local AAA, being able to respond to our community's individual needs is the key to the success. An analysis of allowable activities, compared to our existing services showed us that we could adapt our existing models of care to expand services to caregiving families.

We also know, from long experience, that Federal funds come with a price. The FCGSP has a 25 percent match requirement, so we knew that what we had to do was leverage the new funds by strengthening the relationships we had and developing new partners who would expand services, either on an in-kind basis or with actual cash.

Prior to the FGSP, Senior Services had established the Hampton Roads Caregivers Coalition. Its signature event is a "Fall Festival for Caregivers." The event has grown to the extent that now attracts 250 people and is held at Little Creek Amphibious Base. This past September, unfortunately, Little Creek was off limits for obvious reasons. The caregivers were given a choice to cancel or move. The caregivers voted to hold the event off-base.

Senior Services is constantly monitoring for existing gaps in services and emerging trends in needs. The three service areas that our region identified as most important for family caregivers were:

Access to Services which includes Care Coordination, Information and Referral, Transportation, Public Education and Long Term Care Ombudsman; and

Respite Care, which includes adult daycare, homemaker services, personal care, and senior companions.

Prescription Medications, especially the cost.

So, armed with a solid foundation of needs information, regulatory guidance, the wisdom of our leaders and a lot of excitement in our network, we expanded the following services to families that were giving care to older members:

- Adult Day Care: Support for New Center in Portsmouth, VA June 2002
- Homemaker Services: Increased hours of service
- In-Home Respite: Expanded a Volunteer Based Program
- Overnight Respite: Established a new program: First in Virginia
- Personal Care: Increased hours of service
- Senior Companion Program: Increased number of Companions by 15
- Information/Intake Specialist: Added full time staff person: Senior Navigator.Com expert
- Care Coordination: Added full time staff person
- Emergency Services: Established Last Resort Purchase of Service Fund
- The Pharmacy Connection: Expanded outreach to low income seniors and families for obtaining free medicine
- Developed New Website and Print Materials

The Family Caregiver Support Act has also spawned new initiatives. Senior Services is proud to be a participant in one of them.

One in five retirees in Hampton Roads are veterans. Most are men, and the truth is that men are pretty stoic when it comes to asking for help. I know. My father was in Normandy. He didn't say much about D-Day or later, about what it took to care for my mother who was bedridden. My brother and sister and I lived far away. When it got too much, fortunately we did talk and we did help care for my mother.

In April of this year Senior Services was notified by the Virginia Department for the Aging that we had been included, along with the Peninsula Agency on Aging and the Crater District Agency on Aging, in a grant funded by the Administration on Aging to reach out to retired military male caregivers.

We have just begun to search out and engage the men who often are the most isolated of all caregivers. We will link them to the available services within the

Family Caregiver Support Program and make sure they too are receiving all of the benefits they should by virtue of their service to America. In fact, the first of the staff persons began yesterday.

You have before you the new Guide for Seniors and Their Caregivers. The new website, <http://www.ssseva.org>, will be launched on May 16, 2002. The attached chart shows the types and levels of service that we have provided with Family Caregiver Support funds; and we are considering new ideas for services in the near future.

We have helped hundreds of families in just under a year and we anticipate helping thousands more before the Act is next reauthorized.

Senior Services is not alone. N4A surveyed its members in December 2001 and collected several hundred stories of how caregivers have been helped by this program.

What I want to leave you with today is a one story of how the FGSP enabled one woman to care for her family.

Ms. J. is the primary caregiver for her 78-year-old father. He has Alzheimer's disease and requires 24 hour care. They live in Virginia Beach. The J's have a son, an alcoholic with end stage renal disease, who is in a V.A. hospital near Philadelphia. He is dying. In February of this year, Mrs. J. needed to travel to the Philadelphia area to attend to her son's business and arrange for his funeral. There are no other family members. Senior Services had been providing personal care for the husband, which allowed Ms. J. to get out of the house at least two hours, two days per week. None of their insurances pay for chronic care.

The new FGSP caregiver funding allowed Mr. J. to be placed in a nursing home for five days while Ms. J. made the trip north. She completed her son's business and returned home, getting up early and driving the six hours it takes to get back to Virginia Beach.

Ms. J. arrived Friday, around 1:30 p.m. as planned. She called the Care Coordinator. She sounded tired. She was supposed to go to the nursing home and pick up her husband. She asked if it was possible to have just one more night of service for Mr. J. We approved the extra night at a cost of \$75.00 to be paid with Family Caregivers Support Funds.

Mrs. J. got a good night's sleep. Mr. J. went home on Saturday afternoon. Her son is still in the V.A. hospital. Mr. J. is still at home.

Thank you for inviting me to this hearing.

Senator MIKULSKI. Thank you, and perhaps you could share that story with us during the questions.

Ms. McSweeney, thank you so much for coming. We really do want to hear from you.

Please go ahead.

**STATEMENT OF BARBARA McSWEENEY, FAMILY CAREGIVER,  
WASHINGTON, DC**

Ms. MCSWEENEY. Thank you, Senator Mikulski and Senator Hutchinson, for the opportunity to share how the National Family Caregiver Support Program has contributed to my overall caring of my 91-year-old mother and to my personal health and welfare. I have been caring for my mother in our home for 3 years and prior to that, for my mother-in-law, who also lived with us for 2 years. There was a period of a year and a half in which I had both of them.

I was a long-distance caregiver for my father, who lived in North Carolina, for several years and to my aunts, who lived in Washington, DC. All in all, I have been a family caregiver for approximately 10 years.

My early years of caregiving were done with very limited information and resources. I truly value the National Family Caregiver Support Program; I wish it had been available to me 10 years ago.

I would also like to note at the beginning that I have taken what I have learned through the services supported by this program and have shared the information with friends and family, including the

preparation of a monthly caregiver information sheet that I insert into our church bulletin.

I receive respite services through the National Family Caregiver Support Program, and I really feel that Home Care Partners, which is a community-based organization under contract with the local AAA to provide services under the National Family Caregiver Support Program, rescued me from a collision with poor mental and physical health.

The situation had reached the point where I really felt depressed and terminally helpless. I was unable to continue participation in most of the social groups to which I belonged or to make any long-range plans, including doctor's appointments.

This was traumatic for me, being a very involved person in community educational and religious activities and recently a retiree after 31 years in the DC public school system, with great expectations of doing the things I had put on hold for a long, long time.

I was fortunate enough to attend a meeting at which I was given information about the services provided by Home Care Partners under the National Family Caregiver Support Program. I cannot say enough about the importance of that information—it was really power for me—and subsequently, the 3 hours, 2 days a week, respite that my home aide provides for me at the present time.

Because of the declining health of my mother and my being the sole caregiver because I have no siblings, I still felt stressed many times, but I would be more stressed without this service.

My desperate search for help and information began when I recognized that my mother showed repeated signs of dementia and later, Alzheimer's disease was confirmed by her doctor. I began looking for information on the internet, libraries, everything I could think of, and made hundreds of telephone calls to find information. I felt so relieved to finally find out that there are places that offer the many resources, and that there are real people, with names, at the end of the telephone line that I can call when I just do not know what to do.

Many of the resources available via the National Family Caregiver Support Program are just what I need to continue quality at-home care for my mom, whose Alzheimer's disease has begun to invade more rapidly.

I can sum up my feelings and say that I feel more empowered to take charge of the challenges that caring for Alzheimer's patients brings. I hope that not one more caregiver has to feel terminally helpless or hopeless for lack of information about resources or how to access those services.

The respite care I have been given allows me to go to the gym, which is something that my doctor has asked me to do to lower my cholesterol which I have developed; I could not do this without my home care aide. I could not run errands to do things that I need to do or talk on the telephone and share the information I have with other people, especially my church and university families.

This respite service is really helping to prevent my own burnout and my own physical and mental exhaustion. This caregiver program is long overdue and without a doubt needs to be expanded so that every caregiver will have readily available access to these services. We need the National Family Caregiver Support Program

to continue the mission they have begun and to expand upon that mission by ensuring that persons caring for our older Americans have the resources to first take care of themselves so that they can pass along that energy to the persons for whom they are caring.

I am one of the lucky ones. I happened to attend a meeting and met some very good caregiving providers, because at times, I can be very persistent. But what about the other caregivers who are still making many, many phone calls and are told to call back, or it is the wrong number, and they have to keep calling?

I am sure that I speak for many caregivers who are receiving services and many who need to receive this service if they know about it. It is empowering to know that there is a program that cares about, appreciates, provides for, and focus on the caregiver.

There are many rewards of caregiving, but in most cases, these rewards do not include financial income. In my own case, I could not have continued even for a short time my substitute teaching, my AARP volunteering with the Medicare Patrol, or mediation with the Superior Court of DC without the help of my home aide.

Since my mother's condition has deteriorated to the point that she needs full-time supervision, I can once again no longer do these things—but since talking with my advisors at Home Care Partners, Peggy Nelson and Suzanne Athanos, and finding out about other community resources, I do feel that my request will be forthcoming in the near future, and I will be able to resume some of those things that I enjoy doing very much.

Before closing, I want to thank the National Family Caregiver Association of which I am a member for giving me this opportunity to speak for all of my fellow family caregivers. NFCA does not provide me with the actual respite the way the Family Caregiver Support Program does, but it does provide me with the information, the resources, and the validation of my feelings and concerns and experiences that give me the confidence to speak to you today.

Thank you for listening to at least a part of my story.

[The prepared statement of Barbara McSweeney follows:]

PREPARED STATEMENT OF BARBARA MCSWEENEY

Chairman Mikulski, and other Subcommittee Members, thank you for the opportunity to share how the National Family Caregiver Support Program (NFCSP) has contributed to my overall caregiving of my 91-year-old mother, and to my personal health and welfare. I have been caring for my mother in our home for three years, and prior to that, for my mother-in-law who also lived with me for two years. There was period of a year-and-a-half in which I cared for both simultaneously. I was a long distance caregiver for my father who lived in North Carolina and to several of my aunts who lived in the D.C. area. All in all, I have been a family caregiver for approximately ten years. My early years of caregiving were done with very limited information and resources. I truly value the National Family Caregiver Support Program, and wish it had been available 10 years ago. I would like to note at the beginning that I have taken what I have learned through the services supported by NFCSP and have shared this information with friends and family, including the preparation of a monthly caregiver information insert for my church bulletin.

I have received respite services through the National Family Caregiver Support Program, and I really feel that Home Care Partners, which is a community-based organization under contract with the local AAA to provide services under the NFCSP, rescued me from a collision with poor mental and physical health. The situation had reached the point where I felt depressed, and terminally helpless. I was unable to continue my participation in most of the social groups to which I belonged, or to make any long range plans, including doctor appointments. This was traumatic for me, being a very involved person in community, educational and religious activi-

ties, and recently retired with great expectations for doing things that I had put on hold in earlier years.

I was fortunate enough to attend a meeting at which I was given some information about the services provided by Home Care Partners under the NFCSP. I can't say enough about the importance of that information, and subsequently the three hours two days a week respite that their home aide provides me. Because of the declining health of my mother, and my being the sole caregiver (I have no siblings), I still feel stressed many times; but, I would be more stressed without this service.

My search for help and information began when I recognized that my mother showed signs of dementia and later Alzheimer's Disease was confirmed by her doctor. I began looking for information on the internet, libraries, friends, and everywhere I could think of, including making hundreds of telephone calls only to end up getting yet another number to call. I felt so relieved to finally find out that there are places that offer many resources and real people with names at the other end of a phone line to call when I just don't know what to do. I don't have to call all those other numbers and get referred to another number, or call back on a certain day to have my concerns addressed.

Many of the resources available via the NFCSP are just what I need to continue quality at-home care for my 91-year-old mother (whose Alzheimer's disease has begun to invade more rapidly). I guess I could sum up my feelings now, and say that I feel more empowered to take charge of the challenges that caring for Alzheimer's patients brings. I hope that not one more caregiver has to feel terminally hopeless for lack of information about resources, and/or how to access them.

The respite care I have been given allows me to go to the gym—Dr's. orders to get more aerobic exercise to lower my cholesterol—which I could not do without these few hours a week. I could not run errands or spend some time providing telephone help to other caregivers in my church. The respite services are helping to prevent my own burnout and physical exhaustion.

This caregiver program is long overdue, and without a doubt needs to be expanded so that every caregiver will have readily available access to these services. We need the NFCSP to continue the mission they have begun and to expand upon that mission by ensuring that persons caring for our older Americans, have the resources to first take care of themselves, so that they can pass that energy along to the persons for whom they are caring.

I am one of the lucky ones—I happened to attend a meeting and met some good and caring providers. But, what about the other caregivers that are still making many many phone calls, only to be told they have to call yet another anonymous number? I am sure that I speak for many caregivers who are receiving services from NFCSP, and many who need to receive these services. It is empowering to know that there is a program that cares about, provides for, and focuses on caregivers.

There are many rewards that caregiving brings, but in most cases, these rewards do not include financial income. In my own case, I could not have even continued for a short time my substitute teaching, or mediation with the Superior Court of DC without the help of my home aide. Since my mother's condition has deteriorated to the point that she needs full-time supervision, I once again can no longer do these things. But, since talking with my advisors at Home Care Partners, Peggy Nelson, and Suzanne Athanos and finding out about other community resources I do feel that my request for more help will be forthcoming in the near future. This is so important, we can't allow it to chance that people will automatically do these things, therefore, I urge you to do all you can to see that this program continues and that legislation is enacted that will mandate that family caregivers be given the training and support they need to do a successful job of taking care of their loved one, and at the same time feel good about themselves to the point that they can maintain high self-esteem and confidence in the job they are doing.

Before closing I want to thank the National Family Caregivers Association, of which I am a member, for giving me this opportunity to speak for all my fellow family caregivers. NFCA doesn't provide me with actual respite the way the Family Caregiver Support Program does, but it does provide me with information, resources, and validation of my feelings and experiences that help give me the confidence to speak to you today.

Thank you for listening to my story.

Senator MIKULSKI. Thank you very much, Ms. McSweeney, and to all of the panelists.

Ms. McSweeney, I have a question for you, as one who is out there as both a beneficiary of the service but also in touch with so many other people through church and your other extensive com-

munity network. If we wanted to strengthen, improve, or expand the program in any way, what areas would you suggest to us?

Ms. MCSWEENEY. Awareness; to make the information more accessible, to have the PSAs and those kinds of things that the Secretary talked about—to make it so available that people would not have to just wonder where to call, and to spread this one-stop shop number everywhere. So I would say awareness, make people aware of it, maybe by putting it in doctors' offices, particularly doctors' who see lots of senior patients. I have shared it with my mother's doctor. So I would say make the information readily available and accessible.

Senator MIKULSKI. Thank you. I think that is an excellent point.

Mr. Skirven, first of all, you have, as you said, many States within the State of Virginia, and caregiving is not one-size-fits-all. What can we do to enable there to be ongoing local flexibility but yet standards of quality, without regulatory shackling. You heard me raise issues around the need to ensure competency and safety for anyone who comes into your home. They have to be competent, but you also have to be sure that that person is the right person, for instance, when Ms. McSweeney steps out of the home, and you are left alone.

Could you share with us—because you sound like a man who is committed to mission and purpose but not bureaucracy—how we can have the standards, yet not overlegislate, regulate, or mandate?

Mr. SKIRVEN. That is a high compliment. Thank you.

In terms of having standards, the standards that are promulgated by Government, whether they be our service standards for our Area Agency on Aging services that come from our State unit on aging, or whether they be standards for certified nursing assistants who go into people's homes, or whether they be the standards for the volunteers, the screenings, the criminal record checks, the background checks, and that sort of thing, I think there is a certain required measure of standard-setting and investigation that you have to have in order to be confident that the people that you are sending to somebody's home are right.

Senator MIKULSKI. And does the national program require that?

Mr. SKIRVEN. I do not know the answer to that. I know that our State programs do or will. In Virginia, we are right in the middle of redoing our service standards. I think that in terms of how we can retain flexibility, because yes, there are many different States within every State—within our region, we have 7 percent of the State's rural aging in South Hampton Roads—so you have rural areas, urban areas, suburban areas, and I think the flexibility that has been built into this Act allows the local communities to look at how to best organize the resources that they have and then take the available dollars and build on those to increase them.

As we sit here, we have waiting lists of people like Ms. McSweeney, because we have the dollars, and Ms. McSweeney's cohorts in South Hampton Roads have the need, but there are not CNAs to fill the cases.

Senator MIKULSKI. You mean there is a work force shortage.

Mr. SKIRVEN. Yes, ma'am. Now, what we are doing about that at the Area Agency on Aging level, and one of the things I would sug-



gest for future reauthorization of the family caregiver support, is to allow it to be integrated with Title V of The Older Americans Act. Right now, you cannot use III-E money for senior employment programs. I know there is a great pool of talent and ability in terms of people age 55 and older to provide home care and shadowing younger folks. There are many ways that this can be done.

We sit on the Work Force Investment Board, which is under the Work Force Investment Act the local governing board. I actually represent the aging workers on that board, and our health care cluster—which includes the major health care providers in the region, and then, I am sort of the lone nonprofit—we are working on different models to recruit and retain CNAs, even reaching out into high schools. Where my son Tim attends high school—

Senator MIKULSKI. But tell me what the challenges are to be able to do that and what, if anything, we can do to help you.

Mr. SKIRVEN. You can create more flexibility within the Act with respect to Title V and Title III-E. That is one thing specifically. That is really my only specific for you.

Senator MIKULSKI. Thank you.

Sue, do you want to comment on that as well?

Ms. WARD. Yes. I think every State in the Nation is facing this particular area of crisis. One thing that we are trying to do with the Alzheimer's demonstration project through the Administration on Aging is to develop an entrepreneurial cadre of home health—the people that you were mentioning who have all of the interest and the warmth and skills, and they have gone a lot of caregiving—to help them develop a business kind of approach and also, of course, to do the careful checking of background and so forth. That is just one example.

There is so much to do. I think there are people out there, and we are hoping that we can train the new Americans to provide this kind of service as a way of integrating into the community. We are all facing that and struggling with it.

The other thing I wanted to comment on was your question about what can you do in the way of regulation. I agree totally that the philosophy should be regulate not so much, and monitor a lot. If the Administration on Aging is watching and working with us on developing these systems, which they are, that is better than having a whole new set of regulations to have to accommodate.

I agree also that anything you can do to loosen the structure more—but the flexibility of this Act is what has made it so valuable to us, the flexibility and the opportunity to be as creative as we want to be, within guidelines which the AoA will monitor.

Senator MIKULSKI. Thank you.

Senator SENATOR HUTCHINSON. Thank you.

Ms. McSweeney, thank you very much for sharing your story with us.

Mr. Skirven, I am especially interested in your efforts of outreach to military retirees and to males. Could you expand a bit on what you are doing particularly in regard to the military retirees?

Mr. SKIRVEN. Yes. We just signed paper on this with the State on April 1, so this is still very new. The game plan is for—there are three area agencies involved in that Southeastern corner of the State. Each of us will be hiring one person in our area agency—

we are calling it the MAC man, MMAC, or the MAC man. That person will specifically go out to the military retiree groups, the ship retiree groups, the retired officers association, and that sort of thing.

It is really a matter of reaching out to where people are in non-traditional ways that we have not done before. Because one in five of our retirees is a veteran, pretty much whenever you do a public speaking engagement, you are going to be speaking to a retired veteran. But in terms of having specialized support groups and trying to engage particularly men in those, men of that generation do not share real well, so what we are doing is taking the support group models that have been developed by the Alzheimer's Association and some nurses in our region and adapting those as we can bring men into them. We are starting small. Our goal over time is to at least get our foot in the door with groups and have retired men become our own advocates.

We are fortunate through our instance counseling assistance program to have a lot of really great retired military insurance counselors who are guys, and they are volunteering to help us do the outreach into their circles of friends.

We are really struggling now. We originally thought that men want to talk to a man, so we had better hire a man for this job. In our focus groups, the retired military men say, "We do not want to talk to a man; we want to talk to a woman about these things." So—okay, go figure—we are in the process now. The Peninsula has hired a man, and if we can hire a woman, we will be able to really compare those kinds of activities.

Senator HUTCHINSON. Thank you.

Secretary Ward, I think you answered the question that I was going to ask, which was what kinds of impediments and obstacles or problems have you run into in the implementation of the Caregiver Program. I think you said and Mr. Skirven said as well that, if anything, you like the flexibility and the ability to innovate, and that if there is anything we should do, it is give you more. Am I on track, and do you want to expand on that?

Ms. WARD. Yes, Senator—and double the funds would be very nice. [Laughter.]

Senator HUTCHINSON. Thank you.

Mr. SKIRVEN. May I add to that? There is something else that we are experiencing, and that is in regard to grandparents. You can use 10 percent of these funds to support grandparents and parents. The fastest-growing age group of grandparents is 35 to 45 in this country. That is the truth. But this is a 60-plus threshold. I think that somehow we have to address the issue that we have a new generation of young grandparents who are serving as parents.

I can tell you that my employment director—she will admit it; we had a party for her—is 50 years old, and she is a grandparent. She is caring for her grand-daughter, and she is a working mom.

So one of the things we have to really look at is how we make that work and still preserve the integrity of The Older Americans Act. That is an issue.

Senator HUTCHINSON. Okay. Thank you.

Thank you all. This has been a good hearing.

I am going to have to leave, but I want to thank the panel for the excellent testimony.

Senator MIKULSKI. Thank you very much, Senator, and thank you for your bipartisan support on this.

Mr. Skirven, I want to come back to the male caregiver for a moment and also address it to a larger audience. When my father was so ill with Alzheimer's—and we, of course, had wonderful support in a day care program that literally helped provide respite care for my mother—but there were also the support services, and we were struck by men who were caring for their spouses and, from their perspective, the very awkwardness of this in terms of the kinds of things that needed to be done with the activities of daily living. They were troopers.

First of all, I think we really want to follow your retired military thing. And when I say that we want to follow, I think this is lessons learned; I think this is a whole silent and invisible population of men who are trying to do it on their own and not wanting to show any sense of weakness or failure if they cannot do it—in other words, “I can take care of my wife”—well, maybe they cannot, or maybe they can in some ways but not in other ways, which then goes to the variety of support services. It could be housekeeping or particularly the personal things related to helping with spouses—and I am now focusing only on spouses.

The other thing—and I would really like to say to the men but also to the women who are caregivers—is not only respite care, but I would encourage the thinking—and maybe you are doing it already; please give me feedback—is social activities. People need a break. And my observation with some support groups is that they do not only want to talk about their problems; they would like to go out and go fishing or bowling or go to a motive, catch a baseball game at Camden Yards—but essentially, some socializing, even with people who are in the same group. So if you have to say, “I have to leave early because my home health aide has to leave at 2 o'clock,” everybody will say, “Right. Goodbye Charlie,” or “Goodbye, Charlotte”—and they understand. And there is nothing like fun and being with pals and peers.

So I would encourage that, and I have a feeling that particularly with them men in social groups, sporting activities or others, they would get a chance to talk it over with other guys, and that is where you can also have other people in terms of teaching. We see this in breast cancer, the whole thing of women doing fly-fishing. I do not know if you have heard about it, but one group of breast cancer survivors started it—Orvis, the great fly-fishing teaching group encouraged them to try this—not only to meet with each other on survivor issues, but to go out and do the same exercises that women need to do who are survivors—just as I am doing here—of course, they would die if they saw what I just did; I am swinging my arm like a badminton racquet rather than a fly fishing rod—but the point of the story was that they became outdoor women. They took up fly fishing. We have a group of survivors called “The Happy Hookers” in Maryland.

So my point is that in support groups and socializing, they really had a chance for true refreshment and at the same time, camaraderie with peers who have gone through the same thing. So that

if somebody says, "I just need to sit on this rock for 15 minutes," everybody else says "Fine." They know why she has got to catch her breath.

So I would encourage that as a way of drawing this in. Anyway, I did not mean to go on.

Ms. McSweeney, you have several degrees in education, and we three have degrees in social work, so we are just going to grandmother you into this social work groups. I am going to give you an honorary M.S.W. right this minute, but do not tell the University of Maryland or Howard.

Ms. MCSWEENEY. That is fine. I have done a little bit of that, too.

Senator MIKULSKI. So those are some of the things, but essentially, it has got to be the core program of information and referral, of real, genuine services, and then a certain hospitality around inviting caregivers in to do this.

It seems to me that one of the characteristics has to be one of hospitality because the family caregiver or someone else in the family acting in behest of the family caregiver is usually so enormously stressed that they need welcoming with every call; with every call, that has to be one of the signatures.

Is this hard to do? Is it hard for you to get staff to do this? If staff are overburdened and receiving all kinds of calls, how does this all work, Ms. McSweeney?

Ms. MCSWEENEY. How is it working?

Senator MIKULSKI. Well, how do you experience it? I mean, do you get a different person each time? Do you feel like a number? Do you feel like a statistic?

Ms. MCSWEENEY. Sometimes, yes, but the home aide that we have has been with us for a while, and she is wonderful. We know her, and my mother has developed as much of a relationship as she can develop with her.

But sometimes when I call for additional services, until I talked with Ms. Nelson, from Home Care Partners, to find out all the information that I can have access to, and she can sort of help me run interference to get the information and the services that are available, it is much better—much, much, much better.

Senator MIKULSKI. That sounds good.

Would others like to comment?

Mr. SKIRVEN. We hired an information and referral person, and with III-E, we had to hire a third. I have to keep saying that the fact that these dollars are here and this program is in place made everybody so happy and so excited that there is a real enthusiasm about helping, because we feel supported.

One of our intake specialists is over 65, and he has a voice like honey. The other lady is legally blind, so she really has an empathy for the people to whom she speaks on the phone. That lady has a master's in social work, too, so these are talented people.

The third person we hired is a young woman who was a customer service rep for a health insurance company, and she is tickled pink not to have to be talking to disgruntled customers, so she always has a smile on her face when she comes to work.

I think we really do believe in the individual integrity of everybody who calls us, and it is our job to—if Ms. McSweeney calls, we

are there to serve her. That is kind of the culture that we have done with our staff.

So is it hard for our staff to do that? No. Do we sometimes have cranky days? Yes. But I think we are really in it for the people whom we serve, and that is what drives it, and the notion that we are all in this together, so we know that our State unit is behind us. Your having this hearing today tells us that this is behind us.

Senator MIKULSKI. Well, we are going to hold it every year.

Ms. WARD. Senator, could I just brag for one minute?

Senator MIKULSKI. Yes, go ahead, Sue.

Ms. WARD. I think we have the prime receptionist in the whole country. She is 90 years old, comes to work every day and works a full day. Her job as she sees it is to work with each individual senior who calls and make sure they get to where the need to be, with gentleness, graciousness, and Irish wit—she is Irish.

I was getting some complaints once in a while—and this is probably a story I should not tell—from some people in the Governor's office because they were flipped over to the voice-mail and waited 7 minutes sometimes before getting a call back. But that is because she will never put a senior on hold. She says that one of these days, she may be that way herself and may need that kind of help, so she is going to be there for them.

Senator MIKULSKI. That is a great story.

Ms. WARD. Yes. She is wonderful.

Mr. SKIRVEN. There is a practical matter, if I might add.

Senator MIKULSKI. Yes.

Mr. SKIRVEN. You have the information haves and the information have-nots, and that means computers and interne.

Senator MIKULSKI. Yes; the digital divide.

Mr. SKIRVEN. Yes. It is a very real issue when you talk about different States within a State. We have a new board member from Branchville, VA who happens to be on the volunteer fire department, and he talked about the circle that had been broken because so many of the older ladies in his community had died. Every day, one would call one, and the next one would call the next one, and the next one would call the next one. He told me that he was so glad to have been appointed to the Board by the county board of supervisors because now what he would do is take this brochure and give it to his women's auxiliary for the fire department and ask them to take on rebuilding that circle.

The internet absolutely, positively has to be there, but I think part of what we need to be thinking about is how we can use existing community structures.

Senator MIKULSKI. Thank you, and I think you are right. There are different ways for different people. It could very well be that it is the grandchild who goes on the internet to find the resources for the grandmother and so on.

But I think that what we are impressed with at today's hearing and at the Federal level from our assistant secretary and those of you at the grassroots level is the dedication—whether it is the dedication of being at the bedside of your own family member—and, Ms. McSweeney, I know the experience of the long goodbye—and in fact, later on this month, the United States Congress will give the Reagans the Congressional Medal of Honor—really, I

think the first caregiver is a former First Lady, and I have referred to her as “America’s First Caregiver,” as Mrs. Reagan continues, every day, to say goodby to President Reagan—and we all do in one way or another, and there are all of these wonderful guys out there named “Ron” or “Linda” that we are saying goodbye to.

So caregiving is with the family, and we say thank you to each and every person who every day is caring for somebody whom they love, and they do it because it is the right thing to do. And for all of you who are giving help to those who are practicing self-help, we say thank you.

We want to ensure that there are adequate resources and the right legislative and regulatory framework. It is my intention for as long as I chair this subcommittee to hold an annual hearing on caregiving. I want to make sure that we do not lose sight of this program. To me, this is not just one more program; I believe this is one of the anchor programs in services to the elderly. Medicare, in terms of its health care—that we need a prescription drug benefit has been very clearly indicated; we need to help our families be able to help other members of their families and really ensure that there is income security—if we are in the country that invented the drugs, you ought to be able to afford the drugs—and last but not at all least, if we really do say that we want to put families first, we need to say it and put it in the Federal checkbook.

So we want to thank you for the very important roles that you play. Ms. McSweeney, thank you. And to my brother and sister social workers, I am really proud of the great job that you are doing, and I know that you really represent all those who are working in the field of aging.

So God bless you, and may the force be with us.

This hearing is adjourned.

[Whereupon, at 4:08 p.m., the hearing was adjourned.]