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THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM ITS IMPACT ON IDAHO

FORUMS

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

FIRST SESSION

TWIN FALLS, ID, MAY 29, 2001

LEWISTON, ID, MAY 30, 2001

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THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM ITS IMPACT ON IDAHO

TUESDAY, MAY 29, 2001

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Twin Falls, ID

The committee met, pursuant to notice, at 10:02 a.m., at the Department of Health and Welfare, 601 Poleline Road, Twin Falls, ID, Lupe Wissel presiding.

Ms. WISSEL. Good morning. I would first of all like to thank all of you for being here today to the forum that is put on by the Senate Aging Committee. My name is Lupe Wissel and I am the staff director. I work for Senator Craig. Senator Craig is still the chairman until June 5. And so today we had planned to come to Idaho and hold hearings on the new Family Caregiver Program. Senator Craig feels that this is very important. This is a new addition to the Older American Act. And he wants to make sure that the program is being implemented and that the program does what Congress intended for the program to do.

There were various roundtables that took place prior to the reauthorization, and because of what Congress heard from caregivers, he felt it was very important that we now get out to the States and take a look at how the program is being implemented.

I want to first of all introduce staff members that are here today. And let me see, Jeff Schrade, our communications director. He has been traveling the State this week. Janine Scott to my right. Lisa Kidder, also right here. Many of you already know Lisa from Boise. And Janine, well, we adopted her. We decided she is from Shoup, ID. Then, of course, you are going to hear from the folks that are here to testify today. Dick Juengling, to my left, he is with the Idaho Commission on Aging, Acting Director. Dick Boyd, the director at the AAA here in Twin Falls. AAA is the Area Agency on Aging. Mr. Dan Norton, who will be speaking as the caregiver.

Let me tell you a little bit about what will happen here. We will have each one of the witnesses speak, and then after they finish with their testimony, we will have them all go through their testimony. Once they all finish the testimony, we will allow for questions for the panel. You have some cards on the table, you can go ahead and write your question. We will read the question and have whoever you want the question directed to, answer the question.

Once we complete the forum, then we will do a short break, come back to the room, and then we want to talk to you about the Senate Special Committee on Aging, the agenda, what we have been doing and where we are going. We have Lisa and Janine who will

be speaking about the issues that they are responsible for on health care, Social Security, prescription drugs, and Medicare. We will also take questions that you may have in regards to those issues.

Before we get started, I want to thank Mike Matthews and Leanne Farland for all their work. And I want to also thank Linda Norris that is here from Senator Crapo's office. We have Charlie Barnes and Linda Copen, I believe, from Congressman Simpson's Office, I want to thank them for being here today. We have also a great, great commissioner here with the Idaho Commission on Aging. Helen Arnold is here this morning. Thank you, Helen.

We will now get started. We would like to start with Dick Juengling with the Idaho Commission on Aging.

Dick.

STATEMENT OF RICHARD JUENGLING, ACTING DIRECTOR, IDAHO COMMISSION ON AGING, TWIN FALLS, ID

Mr. JUENGLING. Thank you, Lupe. It is a pleasure to be able to speak this morning about the Family Caregiver Program. We feel this is an important program for the State of Idaho, and we look forward to implementing it successfully over the next year.

I would like to talk briefly about the process that we went through to get the program established and get it up and running in a fairly quick period of time, and I would also like to comment a little bit about the assistance and conversations that we have had with the Administration on Aging in the course of this process of getting set up.

You may or may not know that the State of Idaho will receive about $564,000 for this program. We first got notice of the written guidance from the Administration on Aging on January 17. And about a month later, on February 20, was when we actually got the notice of what that amount of money was going to be. At that point in time, we began internally discussions on how we would implement this program, and brought to our commissioners in the middle of February, on February 15, before we actually had the notice of how much money we were going to get, a plan for how we would put this together and carry it out around the State.

One significant piece of that plan was to develop a small work group that could help guide us through the process of developing that plan. That work group was made up of three family caregivers, one of our commissioners, an area agency director, a representative of the Alzheimer's Association, a Native American and Hispanic representative. That group met twice in late February and again in the middle of March.

And in the first meeting, we just brought people up-to-date on the amendments to the Older Americans Acts and the Family Caregiver Program that was included. We also in the course of that meeting had a telephone conference call with the regional administrator for Administration on Aging to discuss the questions that people had about how this program could be put together. And actually we received some follow-up correspondence addressing some of those questions later on. During that meeting we also had a presentation on grandparents raising grandchildren, and we heard some of the personal experiences that caregivers could share with

us about what it was like to attempt to help family members as they were aging.

The second meeting of that group is, I am sorry, is in March. I do not have the date here. Again, we went over various questions that came up as the area agency directors were discussing how they would implement this at the local level. We talked about some of the cultural caregiver issues that were presented by Native American and Hispanic representatives on the work group. Discussed some of the most critical services that were needed in the local communities, and began reviewing a draft application packet that we had prepared for the area agencies to submit to us for their portions of the funding. That packet was finalized and sent to the area agency directors and discussed with them in a conference call on April 4.

Those applications will require that the area agency directors tell us what programs they intend to fund at what levels and how they will carry out the purposes of the caregiver program, and those applications are due from them to us on June 1. So we at this point know a little bit about what people are proposing, but we do not have their final applications in yet.

At the time we were doing this, it was our understanding from the Administration on Aging that we could put together the mix of programs that would best serve the folks at the area level in the State of Idaho. And at that point in time, people saw the following as being their primary needs in their areas: Information and assistance to caregivers; case management to assist them in caring for their loved ones; and respite care, which for any who do not know is a service that provides a brief rest for the individual who is giving caregiving so they can get their breath, take care of business that they may need to take care of that would require them being away from the individual that they would normally be caring for. Our intent was to have those applications into us by June 1, and be able to award funds by July 1, so that those programs could begin very shortly after July 1.

We moved quickly to design the program and implement what we thought was a model approach. We have received phone calls from a number of other States inquiring what we were doing, and we got the impression from those phone calls that we are ahead of many in that implementation curve. We felt that we had a lot of helpful input from the Administration on Aging staff, particularly from the regional office in Seattle. I attended a all-day conference there on April 25, and a portion of that conference involved a live television link with folks in the Washington office of AOA. I went away from that understanding, most significantly, that they were interested in providing us with maximum flexibility to carry out the programs in ways that best benefit caregivers in Idaho. I was very, very pleased with that approach, and thought that that was in concurrence with where we were heading.

What I found out late last week is that we may need to change course somewhat. There are two things that raise problems for us. One probably would not mean anything to any of you, but it has to do with how we match these Federal funds. There is a requirement that we put our own resources into this program, not just the $500,000 in Federal funds. And we used to have the flexibility of

being able to match all of the various programs that we provide under Title Three of the Older Americans Act with just sort of a pool of matched money. We did not have to have a specific amount set aside for our case management or a specific amount set aside for information and assistance or any other specific programs under Title Three. But now we learned late last week that we have to have a specific matched amount for this family caregiver amount, and it cannot just be pooled along with the rest of our Title Three matched money. I do not yet know whether that creates a significant problem for us. It does reduce our flexibility dramatically, and that troubles me some.

The other thing that we learned very late in the week last week is that under the program there are five categories of programs, and we understood and we were actually told by Administration on Aging that we would be able to implement a mix of programs that would best suit the caregivers in the State of Idaho. And we passed that along to the area agencies. We said you cannot just fund one program out of that, you have got to have at least two of those things, but you do not have to fund all five. And the word that we got on Thursday of last week was that we must carry out programs in all five of those categories. That would be with Federal funds or with State or local funds, but nevertheless, it does create a bit of a problem for us as contrary to what we have understood and been told by the Administration on Aging until now, and it is contrary to what we told the area agencies about the way it would be carried out.

I will be interested to see how the Administration on Aging pursues this issue. I have written to them and requested that they return to the more flexible approach that they started out with. Whether there is any chance they will do that, I do not know.

Again, thank you, Lupe, for allowing me to speak today. This is a great opportunity. We are excited about this program. It is badly needed in the State of Idaho, as I am sure it is throughout the country. Caregivers in Idaho have tremendous needs and have been overlooked and neglected for a long time because there simply were no programs or funding available to serve the needs of caregivers.

[The prepared statement of Mr. Juengling follows:]

Testimony

of

RICHARD JUENGLING

Acting Director
Idaho Commission on Aging

before the

Senate Special Committee on Aging

on

"National Family Caregiver Support Program"

Tuesday, May 29
Twin Falls, Idaho

Good morning. My name is Richard Juengling, Acting Director, Idaho Commission on Aging. Thank you for the opportunity to testify this morning on the National Family Caregiver Support Program.

My remarks will focus on implementation of the program here in Idaho, including the service package and timelines for beginning the delivery of these much-needed services. I will also comment briefly on the assistance and guidance we have received from the Administration on Aging.

We received notification of Idaho's allotment of $564,300 and our first written guidance from the Administration on Aging on January 17 of this year and our "Notification of Grant Award" a little over one month later on February 20. Soon after receiving the information from AOA the Commission staff began discussions about how we would implement the program and prepared a "Power Point" presentation for our upcoming Commission and Area Agency Directors meeting which was held February 14 and 15. At the Commission's business meeting, February 15, we presented a plan for the design and implementation of the program and requested their support of the plan. Our plan called for the formation of a small "Work Group" that included three family caregivers, one of our Commissioners, an Area Agency Director, a representative of the Alzheimer's Association, a Native American and Hispanic representative.

Our Work Group met twice, once on February 28 and again on March 14. Our first meeting covered the following:
Review of the 2000 Older Americans Act Amendments pertaining to the Family Caregiver Program and AOA's written guidance
Telephone call with the Region X Administration on Aging Administrator and staff to discuss questions regarding the program (the questions were made official in a letter dated March 7)
A presentation on grandparents raising grandchildren
Personal experiences from the family caregivers on our work group.

Our second Work Group meeting focused on:
Review of concerns and issues raised by our six area agency on aging directors
Cultural caregiver issues presented by our Native American and Hispanic representatives
Discussion of the most needed support services caregivers identified by our caregivers
Review of a draft application prepared by ICOA staff to be submitted by our area agencies.

The draft area agency application form was sent to the area agency directors and discussed with them on a telephone conference call April 4 before it was finalized and mailed in mid-April. These applications are due June 1 for ICOA review and approval. Until then we will not know what service packages the area agencies are proposing. Preliminary information indicates that area agencies will be proposing to use the funds primarily for Information and Assistance, Case Management, and Respite. The three caregivers in our Work Group identified Respite (including Adult Day Care), caregiver education and training, and support groups as services that would most directly benefit them. We plan to award funds to the area agencies by July 1 and shortly thereafter services will begin.

As you can see Idaho has moved quickly to design and implement a program we feel will be a model for other states. We have received telephone calls from a few other states asking how Idaho was planning to implement the program and it appears we are well ahead of the implementation curve.

I would like to close by saying that our regional Administration on Aging staff has been very responsive to questions we have raised both in writing and by telephone. I attended a meeting in Seattle on April 25 that included a video conference with AOA central office in Washington D.C and two "Power Point" presentations- one that addresses reporting requirements and the other provides information on caregiver programs already in existence prior to the Older Americans Act Family Caregiver Support Program. At that meeting AOA staff said they wanted to allow states maximum flexibility in implementing the program to meet their own needs. In addition, they have provided a list of "Frequently Asked Questions" and answers to those questions. The AOA web site and implementation of a national "list serve" on caregiving has also been helpful. An AOA sponsored conference on the program is scheduled for September 6-7 in Washington D.C.

On behalf of the Idaho Commission on Aging, I would like to thank Senator Craig for bringing the Senate Special Committee on Aging to Idaho and for the opportunity to testify here today. As my testimony indicates, we are well on our way to providing solid support for Idaho's growing number of family caregivers. The goal of the Idaho Commission on Aging and it's six area agencies on aging is to provide the most needed supportive services to family caregivers that will enable them to continue to care for their elderly family members in their homes and prevent or delay more costly institutional care. We are committed to meeting the congressional intent of this program and working with your committee to be responsible stewards of Idaho taxpayer's dollars that support this program. I would also like to thank Senator Craig for his support for the 2000 reauthorization of the Older Americans Act (including the Family Caregiver Support Program) that allows states more flexibility in using these federal funds to serve the needs of their elders and family caregivers.

I would be happy to respond to questions.

Ms. WISSEL. Dick, thank you. You are right, and again, that is why Senator Craig wanted to make sure that we came to the State to hear how the program is working out, if it is already implemented, or what stage it is at, and any barriers to the implementation of the program.

But on Thursday, as you know, we have the hearing that Senator Craig will be chairing, and that will be in Caldwell. At that time, I understand that we will have someone from the Administration on Aging present to provide testimony. Those questions, those issues, you brought up may be some questions that he may need to ask at that time.

So thank you again for agreeing to be here today and for the information.

We will move on with the testimony. As I mentioned earlier, we will come back for questions once we finish with all testimony.

Now we have Richard Boyd, and he is the director at the Area Agency on Aging here in Twin Falls. We will now hear from him. He is going to give us his perspective and where his area is on the family caregivers implementation.

So, Dick, thank you.

STATEMENT OF RICHARD BOYD, DIRECTOR OF THE OFFICE ON AGING AND ADULT SERVICES, ON THE COLLEGE OF SOUTHERN IDAHO CAMPUS

Mr. BOYD. Thank you, Lupe. Good morning. I appreciate the opportunity to testify this morning on the National Family Caregivers Support Program. I am a little bit surprised to what Dick had to say because we are changing horses in the middle of the stream, it looks like.

The Office on Aging at the college serves the eight counties of South Central Idaho. There are approximately 165,000 persons residing in an 11,000-square-mile area. Of this number, 24,000 are over the age of 60. Twelve percent of the over–60 population is estimated to be at or below the poverty level. The eight-county area is qualified by definition as rural.

I am going to focus the remainder of my remarks on the process we used to develop the National Family Caregivers Support Program. We certainly found value in all the service options available in the program. Interestingly enough, the same services were included in this area's identification of service need. Service need was identified by caregiver contact with this office and agency and through staff experience with the target population. Considering limited funding available, we present the following service priorities: Information services; case management; and intensive respite. We expect to improve caregiver recognition of the serviceable moment, defined as that point at which the caregiver is providing extensive care and have identified themselves as the caregiver. This is necessary before institutional placement is the only option they believe is available to care for a loved one. Information services will be allocated $17,486. This will involve reaching out to potential consumers through increased public presentations, television and other electronic media to educate the community regarding the challenges of intensive caregiving and the services available to provide critical relief to the caregiver.

Intensive respite services have been identified as critical, and as such will receive the majority of our funding, $52,000. This service will provide short periods of relief or rest for 24-hour live-in caregivers that are caring for family members who have more intense needs than the current volunteer respite programs are able to provide. The priority to receive the intensive respite services will be spousal caregiver or an adult child caregiver. The services will focus on supervision, personal care, and hands-on type of care. Flexibility of service will provide service during nontraditional hours, such as evenings and on weekends, in addition to normal day service. The service may be provided either in home, adult day care, or institutional respite for an overnight stay on an intermittent, occasional, or emergency basis.

We propose that intensive respite services be secured through a voucher system with the units of service managed by the case manager, develop vendors of service brought delivery in lieu of sole source contractors. Multiple vendors will increase the likelihood that at least one of the vendors will be able to provide service instead of one contractor that may or may not have staff available. The caregiver will determine how much respite is needed at any given time, when to use the service, and if in-home adult day care or institutional respite is the most appropriate. Consumers will be allowed to bank the respite hours. A sliding fee scale will be used to determine what, if anything, the caregiver will pay. Caregivers able to contribute must be encouraged to do so.

Case management service will receive $13,500. This will be used to educate older persons or their caregivers who may be experiencing diminishing functioning capacities to serve as options available and link the caregiver to efficient care providing communication of service among the approved providers. The case manager will authorize services and manage respite hours allocated to their client or their consumer.

Thank you for the opportunity to testify before you today. This is a wonderful program and much needed. However, the current funding just scratches the surface. The National Association of Area Agencies on Aging estimate that the current allocation will provide $5 for every caregiver in the United States.

One final thought. I really appreciate the flexibility that has been associated with implementing this program to this point. The issues are universal, yet each area has been afforded the opportunity to develop a caregiver program that will best meet the need of the family caregiver, and in this case, rural Idaho.

Thank you.

[The prepared statement of Mr. Boyd follows:]

Good morning. My name is Dick Boyd and I am the Director of the Office on Aging and Adult Services located on the College of Southern Idaho campus. I appreciate the opportunity to testify this morning on the National Family Caregiver Support Program.

The Office on Aging serves the eight counties of Southern Central Idaho. There are approximately 165,600 persons residing in an 11,000 square mile area. Of this number, 24,420 persons are over the age of 60. 12% of the over 60 population is estimated to be at or below the poverty level. The eight county areas qualify, by definition, to be classified as rural.

I am going to focus the remainder of my remarks on the process we used to develop the National Family Caregiver Support Program. We certainly found value in all the service options available in the Caregiver Program. Interesting enough these same services were also included in this areas identification of service need. Service need was identified by caregiver contact with the agency and through staff experience with the target population. Considering the limited funding available we present the following service priorities:

- Information Services
- Case Management
- Intensive Respite

We expect to improve caregiver recognition of the SERVICEABLE MOMENT, defined as "that point at which the caregiver is providing extensive care and have identified themselves as caregivers." This is necessary before institutional placement is the only option they believe is available to care for a loved one.

Information Services will be allocated $17,486. This will involve reaching out to the potential consumer through increased public presentations, television and other electronic media to educate the community regarding the challenges faced by intense care-giving and the services available to provide critical relief to caregivers.

Intensive Respite Services have been identified as critical and as such will receive $52,000. This service will provide short periods of relief or rest for 24-hour live-in caregivers that are caring for family members who have more intense needs than the current volunteer respite programs are able to provide. The priority to receive the Intensive Respite Services:

- Spousal caregiver
- Adult child caregiver

The services will focus on supervision, personal care and hands on type of care. Flexibility of the service will provide service during non-traditional hours such as evenings and/or weekends in addition to normal day service. The service may be provided either in-home, Adult Day Care or Institutional Respite for an overnight stay or an intermittent, occasional or emergency basis.

We propose that the Intensive Respite Services be secured through a voucher system, with units of service managed by the Case Manager. Develop vendors of service delivery in lieu of sole source contracts. Multiple vendors will increase the likelihood that at least one of the vendors will be able to provide service instead of one contractor that may or may not have staff available.

The caregiver will determine how much respite is needed at any given time, when to use the service, and if in-home, Adult Day Care or Institutional respite is the most appropriate. Consumers will be allowed to bank their respite hours. A sliding fee scale will be used to determine what, if anything, the caregiver will pay. Caregivers able to contribute must be encouraged to do so.

Case Management Services will receive $13,500. This will be used to educate older persons or their caregivers, who may be experiencing diminishing functioning capacities to service options available and link the caregiver to effective care providing coordination of services, among the approved providers. The Case Manager will authorize services and manage respite hours allocated to the client/consumer.

Thank you for the opportunity to testify before you today. This is a wonderful program. However, the current funding just scratches the surface. The National Associates of Area Agencies estimate that the current allocation will provide $5.00 for every caregiver in the United States.

One final thought. I really appreciate the flexibility that has been associated with implementing this program. The issues are universal, yet each area has been afforded the opportunity to develop a Caregiver Program that will best meet the need of the Family Caregiver in the rural area.

Thank You

Ms. WISSEL. Richard, thank you very much for providing us with your testimony today.

Next we are going to hear from a caregiver who provides the caregiving services. Dan Norton, we are looking forward to hearing from you.

STATEMENT OF DAN NORTON, CAREGIVER

Mr. NORTON. My wife and I moved down here in 1994 to take care of three of our parents, and it has been quite an experience. My dad died a year ago next month. But we only began to get assistance from Linc just a little over a year ago. Otherwise we have done this on our own. We bought a large house out on the far side of Filer so that we would have room for them and ourselves. And it has been interesting, to say the least.

My mother has Alzheimer's, high blood pressure, and diabetes, but otherwise she is pretty good, you know, get around good. My wife's mother fell and broke her hip 2 years ago, so that has slowed us down tremendously as far as doing anything. We have no free time, except we get 4 hours possibly three times a week where somebody comes in and grandma sits, as we call it. And so that gives us time to go out and shop and possibly run some errands and have lunch, which we usually do. And today is one of those days. And then I have to go to a funeral in Hailey. But it is something that we felt was necessary. And we know it is working out. It has prolonged their health, or their lives, I should say. My mother is 93 and my mother-in-law is 95, and my dad would have been 100 in November. He died in June just prior to that, so they had pretty good lives.

We have been in public service. I was in law enforcement forever it seemed, and my wife ran a day care center in Hailey, so we have had a lot of experience, but it has just been hands on, no professional help. Nobody has complained yet, so I guess we have done all right.

It is something I would not recommend unless you have got a lot of patience. And my wife has most of the patience in our family. So that is about it.

Thank you.

Ms. WISSEL. Mr. Norton, thank you for sharing, the information with us. And that is why we are here and that is why Senator Craig felt it was very important that we heard from the caregivers because that is what the program is intended to do. Provide the relief to the caregivers, because without the caregivers, well, I do not know what any of us would do.

Mr. NORTON. Well, the county or the State would be capable, yes, but the main thing that we need is some time, you know. An overnight, even a day. Because the way it is now, we can just, just go do our shopping. And one of us has to be home all the time, except when we do have a caregiver, so it is something that if you get into this type of thing, you have to be prepared for, losing your life basically. But we do not resent it. We think we have done the right thing. So thank you.

Ms. WISSEL. Thank you.

We have heard from the three witnesses that shared their information with us. And now we will open the mike. And you have

cards. If you have any questions for any of the three panelists up here, please do so. Jeff will go around and pick up the questions, and he can go ahead and use the microphone and ask the question.

Mr. SCHRADE. I think I see a few more people scribbling, so I am going to read this first question.

This is for Dick Juengling. What are the five categories that must be funded, referred to in the packet as required by the Federal office?

Mr. JUENGLING. Let me make sure that I have them right. Mr. Boyd has handed me a document, but I do not want to swear that they are actually set out correctly there.

The five categories are: (1) information to caregivers about available services; (2) is assistance to caregivers and gaining access to the services; (3) is individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving role; (4) is respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and (5) is supplemental services on a limited basis to complement the care provided by caregivers.

Mr. SCHRADE. Mr. Boyd, please clarify. Did you say the average benefit per caregiver is $5?

Mr. BOYD. What they were saying was that this—was it 125 million that was allocated across the country? That equates to $5 for every caregiver in the United States. Does not mean they are going to get it.

Mr. SCHRADE. And a follow-up question for you. Explain vendors and explain bank respite hours.

Mr. BOYD. OK. What they were doing with vendors as opposed to a sole source contractor, there are vendors currently that have been identified by Health and Welfare that do provide these kinds of services, and they are throughout the valley. If you get contractors, what we find is most of them are located either in Twin Falls close by or in the Burley-Rupert area. And when we get out into the rural areas, that is where we have the problem.

Banking of the hours is meant that once it is determined that these people can use respite hours and they qualify, they are the most critical, they will have X number of hours they can use when they deem it necessary.

Mr. SCHRADE. Another question for you. What defines income eligibility?

Mr. BOYD. The State and the Federal have income guidelines that we use, and it has to do with poverty, the level of poverty.

Mr. SCHRADE. Is it at poverty or do you know?

Mr. BOYD. Well, we will be at poverty.

Mr. SCHRADE. At poverty level?

Mr. BOYD. I think we will be looking at 125 percent of poverty.

Ms. WISSEL. Mr. Norton.

Mr. NORTON. Well, she had one. Excuse me.

Ms. WISSEL. Oh, no, I thought you had a question.

Mr. Juengling, you mentioned that you were in the process of or you thought that maybe by the 1, the money would go out by June 1, by July 1, the program would be implemented. Where are you at this point?

Mr. JUENGLING. What we had required was that the area agencies provide us with their plans by June 1. We would then go through those plans, make sure that they were meeting all of the various requirements, and actually begin to make the money available by July 1. Given what we see as a significant change in guidance from the Administration on Aging, I honestly cannot tell you right now whether we will still be able to meet that July 1 deadline, because at least some of the proposals that we have received or that we have already heard about that the area for area, for example, does not address all five programs in their proposal. So we may need to go back to the issue and make sure that we have that adequately covered, unless AOA goes back to what their prior position was on the issue.

Ms. WISSEL. Mr. Juengling, another question for you. You heard Mr. Norton talk about the need for that relief and just, being able to get away even 4 hours. Now, how are you going to prioritize, to make sure that those with the most need are provided with the services? If they really need to get away for a day or even the weekend, are you making some provisions for that?

Mr. JUENGLING. We have not yet addressed that specific question. One of the things that we have been working on for some time is a means to prioritize a variety of services that are provided through our agency, not just the National Family Caregiver Program. And the purpose of that prioritization is to see that those with the greatest need get moved to the top of the list of clients to be served. We are doing that because it is clear that there is not enough money, and there certainly in the future will not be enough money to provide all the services that all of the elderly in the State of Idaho need. We have not yet worked at taking that prioritization system that we have developed and converting that to cover caregiver needs. It will not be difficult to do that, but we have not got to that step yet.

It will be necessary to do that, I believe, because if you look at the money that comes to the State of Idaho, there will not be enough money to serve everyone. As I said before, we have $564,000 coming to the State of Idaho, but when you start splitting that up between the six area agencies that serve the State, it becomes a little bit tricky. Mr. Boyd told you how they are going to spend their money, or how they were planning to. Mr. Boyd's agency is in a somewhat better position than some of the other areas.

The various area agencies do not receive equal funding. They receive funding based on a formula that takes into account, among other things, age of residents and numbers of residents. The result of that is that we have one area that is only going to receive $57,000 total for this program, a couple of others that will receive $77,000. The largest area, the area three which serves the Boise and Treasure Valley area, which obviously has about a quarter of the State's population, they will receive almost $197,000. Even for them, the $197,000 would not go far. So it becomes necessary to find a way to prioritize service to those who are most in need. We will be pursuing further development of that prioritization system that we are working on in order to apply it to this program as well.

Ms. WISSEL. Thank you.

Mr. Norton, as you know the National Caregivers Support Program will provide relief and information to caregivers this year for the first time. How will this program be most beneficial to you as a caregiver?

Mr. NORTON. Just giving us time to go somewhere, you know, maybe, well, Jackpot or, just for instance, someplace where we can go and we do not have to worry about what is happening at home. Since they are our parents, it is a little different. And also so we can relax and know that things will be good when we get home. It is extremely important, because, like I say, we have done this for 7 years without, pretty much respite help, except for the 4 hours two times a week was, and now we are getting sometimes three times a week. So that is 12 hours that we get to go shopping, you know, and have lunch.

Ms. WISSEL. You heard about the five categories, information assistant, case management, respite, supplemental services. Out of all of those five categories, which would you see as the most important to you as a caregiver?

Mr. NORTON. Time off, as far as I am concerned. As far as I am concerned, that is it.

Mr. JUENGLING. Let me see if I could respond. When we had the meetings in Boise, where we brought the folks in from all over the State, respite by and large was the number one issue, by and large.

Ms. WISSEL. And Dick, I appreciate you sharing that, because I heard that in Idaho as well as the round tables that took place around the country when this program was being discussed. That was the number one need, which is the relief that the caregivers so much need.

Any other questions from the audience that you may have for the panelists up here?

UNIDENTIFIED SPEAKER. Do you have an idea of the number of family caregivers that are in Idaho now?

Mr. JUENGLING. It seems to me that someone came up with an estimate, and I honestly do not remember what it was, but it was purely an estimate. It was based on some national figure that was extrapolated down to Idaho's population. And I do not remember what that was. Not a hard number by any means.

Ms. WISSEL. Ma'am?

UNIDENTIFIED SPEAKER. OK. For those of us who do not fall below poverty but are below having sufficient funds to give care, where do we go for it?

Ms. WISSEL. Mr. Juengling, could you answer that question?

Mr. JUENGLING. Well, to a certain extent, those decisions will be made by the local area agency when they set their priorities. If they have a income requirement, it may be that you will have to cost share; in other words, you may have to pay for a portion of that service in order to be eligible. Again, it may also depend upon the level of need that is out there. If there is an overwhelming demand for the service, those who are dealing with the most difficult situations and those living in poverty may be a higher priority. I do not think anybody has actually figured out where the cutoff is likely to be because nobody has really been able to identify just how many people might qualify or seek this service.

Mr. BOYD. I could just expand on that. Here in our area, I think we are looking at need as primary, then look at finance, if you are able to pay part of it, but I would not see you being thrown out because you had above poverty level. It would be strictly on need. We have so many people that are primary caregivers that if we do not give them some assistance, they are going to need help also, and then we have lost everything we had in their home. And one of the things that we find on an isolated basis is that we start having problems, and adult protection has to get involved because the caregiver is so tired and so totally stressed that then they start abusing the person that they are caring for.

Ms. WISSEL. Very true. Any other questions?

Here is one.

UNIDENTIFIED SPEAKER. I have a question for Mr. Boyd. You mentioned vendors were available against contract people. What would be your criteria for judging and, you know, making sure that the vendors are able to take care of such circumstances?

Mr. BOYD. Let me just answer this way. What we looked at when we saw this—and understand this is a new program, it is a new concept. There are current vendors that are with the Health and Welfare on the waiver program. They have already been looked at. We do not know whether those same vendors would be ones that we could utilize. But the idea is that we are certainly going to make sure, if we get a vendor on our own, that there is a background done and that they, in fact, can do the job before we are going to hook up with them. So it is a new concept, it is a new rule, and I cannot really have the answers. Ideally we would use vendors that are already in place that have the background and have a proven track record.

Ms. WISSEL. Any other questions?

Well, I would like to, on behalf of Senator Craig and the Senate Special Committee on Aging, thank the three of you for agreeing to be here today for providing the information that you did. It is very helpful to hear from you because this information will be recorded, we take a look at it again, the Senator will review all this information again. And as we move forward, it is very important that we hear from the people themselves. So we are doing this as part of the Older Americans Month. May is Older Americans Month. We had the family caregiver hearing in Washington, DC., on May 17, we plan to do this same forum throughout the State. We have our hearing that will be chaired by Senator Craig in Caldwell on Thursday, so all of you are invited to attend that hearing. It should be a very interesting one because this is such an important program. I thank all of you for being here, and thank you for providing the information.

We will now conclude the forum. We will now take a few minutes, maybe a 5-, 10-minute break, we will come back, and then we will talk about Senate Special Committee on Aging and any questions you may have. We have Janine and Lisa that will provide you information on different issues they have been working on, and so thank you.

[Whereupon, at 10:46 a.m., the committee was adjourned.]

THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM: ITS IMPACT ON IDAHO

WEDNESDAY, MAY 30, 2001

UNITED STATES SENATE,
SPECIAL COMMITTEE ON AGING,
Lewiston, ID

The committee met, pursuant to notice, at 1 p.m., in the Clearwater Snake River Room, Williams Conference Center, Lewiston, ID.

MS. WISSEL. We want to go ahead and we will begin this forum. We have the panel, it's all ready and staff is here. So, please let me introduce the panel first.

We have Ken Wilkes. And Ken Wilkes is with the Idaho Commission on Aging, and he is the support service manager. I call him the godfather of older Americans. You know, he's been there for a long time. He's gone through a few re-authorizations.

Then we have Bobbie Sailor, and Bobby is interim director of the area Agency on Aging in Coeur d'Alene. And then I understand you hired a director that starts on Friday, and that's Pearl Prichard. And, so, you are going to be speaking on behalf of the area agencies. And then we have Kay Wilson, and Kay is a caregiver.

So, and right here to my right, we have Janine Scott. She's with the Senate Special Committee on Aging staff in DC, and she handles pension and health care issues. She's an attorney, and she's been doing quite a few hearings this year as well. To my far right, we have Lisa Kidder, and Lisa has worked for Senator Craig for a number of years doing health issues. Now she is with the Senate Special Committee on Aging. Both of them have been very busy developing a number of hearings on programs under the Older Americans Act, and other health issues, such as prescription drugs, et cetera. My name is Lupe Wissel, I'm the staff director with the Senate Special Committee on Aging. And I work directly for Senator Craig. We held the family caregiver hearing on May 14. Senator Craig called the hearing, to celebrate the Older Americans Month and also to make sure that the money was being used to meet the intent of Congress. And that's why we are here today, and we're holding these forums throughout the State to hear from the State representative from the area agency, the caregivers, and see where they are in this process. And hopefully, that we get insight as to, whether it is working; if it is going the direction that it was intended to go; and is it doing what it was intended to do.

With that, we will go ahead and have the panelists present their testimony. Once they finish with the testimony, we will then allow for questions. You can ask questions to any of the three, and then

we've got a few questions ourselves. But we want to allow you to ask those questions. You have, I believe, some cards so that if you have a question, write it down and then you can come forward to the mic and read it, or we can pick it up. We can have Lisa or Janine pick them up and get the question from you and then have it asked to the panelists. So, with that, why don't we start with Kay Wilson, the caregiver. We'd like to hear from you and maybe share your experience with us. Could we get the microphone to Kay, please? Thank you.

STATEMENT OF KAY WILSON, PROGRAM SECRETARY, AREA AGENCY ON AGING

Ms. WILSON. As she said, I'm Kay Wilson. I also work for Area Agency on Aging in area one. I'm the program secretary. I'm doing a talk on grandparents raising grandchildren. I'm one of the 3.2 million grandparents in the United States who have custody or have assumed a temporary role in responsibility for raising grandchildren. The ages of my grandchildren that live with me are eight, seven and two, and I have eight altogether and three great-grandchildren. I say temporary responsibility, because I keep hoping that my twenty-seven-year-old daughter will turn around and become the full time responsible mother.

The frustration and emotional roller coaster that I have been on with the grandchildren also includes 9 years of being a caregiver for my mother, who passed away last May at 99 years of age. I was that sandwich generation they talk about that added grandparenting on top of caring for my mother. The frustrations have been many, wondering who was going to take care of the now 8 year old when he was a few months old on Monday when I had to go to work and hadn't seen his mother since Friday evening, when she was just going to the store. Seeing all three children as babies in dirty clothes and soiled diapers all day when there were washing facilities right there. The frustration of calling child protection and personally taking pictures into their office because of the filthy conditions they lived in and have the child protection tell me they aren't in imminent danger, can't do anything. Several times kicking daughter and grandchildren out of the house to have her come back in 3 to 6 months later with dirty, crying grandchildren begging me to let them stay because that is only stable place they have in their lives. The anger that goes along with feelings of helplessness when two little boys tell me they hurt on their back and legs to find open sores from their waist to the back of their legs, so sore that they can't sit in the tub so I can get them clean. That time I took them to the doctor and found that they had scabies. The doctor took pictures and reported to child protection. I also called the police, because I wasn't going to give them back to their mother but was told they could do nothing, I had to give them back. That trip, even though the boys were on Medicaid, cost me $45.00 for the doctor visit and $40.00 for medicine. I couldn't use their Medicaid, because I wasn't the one that was on the insurance. Emotionally, it is very draining.

I thought the school system would be able to help me, but as much as principal, teachers, and counselors have tried, their hands are tied. The 8-year old second grader is reading above his grade

level as well as the 7-year old is reading above his grade level. They are very bright children. The older boy has a serious anger problem with regards to his mother and father. That may take a doctor's intervention. The younger boy is taking after mother with an attitude problem that he doesn't have to do what his elders ask him to do. The 2-year-old granddaughter I fear for every time mother gets involved with another man. She is a beautiful, bright and happy little girl. What things could happen to her in the settings her mother takes her into gives me nightmares.

I would take these children if health and welfare stepped in, but I am also planning on retiring in 3 years. And, for once in almost 47 years, I can go and do as I want to and care for only myself. I was a part-time caregiver of my grandmother who lived with my family before I was out of high school.

To get custody of the children is almost impossible, because their parents are still involved, partially. Though the oldest boy is the only one who sees his father part of the time, there is no child support from any fathers. Legally it would be costly with no guarantee that I would succeed in getting custody. Temporary custody would be the best I could hope for, knowing that at any time if mother or fathers proved they could raise the children, they would be able to take them back.

The big questions facing me are financial, child care, medical while I'm still working, and emotional. Can I begin to raise grandchildren at age 62 by myself and hope that my good health I now have continues? How much will it cost if the oldest boy needs more counseling to deal with his anger problems? How do I connect with daycare and costs while I'm still working? Where and how do all the government systems work? These are all questions that grandparents in these situations will face. Getting grandparents through the system when they have never asked for help like this before can become the most stressful—almost more stressful than raising the children.

We have a chance to help not only the grandparents but also the new generation that will be taking care of us in later years. If there are going to be more grandparents raising grandchildren in the future, as predicted, we, as an agency, need to be the best informed and willing to walk these grandparents through all the hoops in order to make this a less stressful thing. Thank you.

Ms. WISSEL. Thank you, Kay. We will now hear from Bobbie Sailor. Bobbie.

STATEMENT OF BOBBIE J. SAILOR, ACTING DIRECTOR, IDAHO AREA ONE AGENCY ON AGING

Ms. SAILOR. Hi. I'm Bobbie Sailor, acting director, Area Agency One in North Idaho, and I've been with the agency since 1993. Thank you for the opportunity to discuss Area One's efforts to implement the National Family Caregivers Support Program. Area One on Aging is comprised of five northern counties in Idaho; Bonner, Boundary, Shoshone, Benewah, and Kootenai.

In order to assess the needs of family caregivers, the agency conducted a written survey which was completed by our advisory council members, a local hospital caregiver support group attendees, and attendees at our agency annual conference. The following serv-

ices, identified as a need, Area One will focus on implementing. Category two, which is assistance service, this includes information and assistance providing current information on opportunities and other available services and linking individuals to opportunities and available services. And case management, assessing the needs, developing care plans, authorizing services, coordinating the provision of services among the providers and follow up and reassessment, as required.

Our plan is to develop a resource data base. Case managers will assist in completing the required in-home assessment and assist the caregiver in assessing services offered by formal service providers.

Another category that we're putting funding into, proposing, is the respite service. This will be used to provide respite care to enable caregivers temporary relief from their caregiving responsibilities. It may be in the form of in-home respite, adult daycare respite, or institutional respite for the overnight stay on an intermittent, occasional or emergency basis.

Our plan is to develop a competitive bid process to identify licensed facility providers available in each of our five northern counties and a daily rate to be paid in order to provide up to 7 days of respite in a twelve-month period. Paid respite would be considered a cost-sharing program utilizing the current Idaho Commission on Aging sliding fee scale. Agency case managers would complete the in-home assessment, identify respite as a need, and assist the family in making arrangements for the paid respite with the closest provider. The family would pay their cost-sharing portion, if appropriate, directly to the facility, as determined by the case manager and the agency's current agreement with that provider.

Supplemental services, legal assistance, is another area we're proposing. Providing assistance for family caregivers with specific legal issues, such as emergency guardianships or other legal matters. This would be an expansion of legal services with our current service provider, and it would not duplicate services currently available.

Information and assistance for grandparents is the last area that we're proposing to develop a data base of information regarding eligible services for grandchildren and how to access those services. We would provide assistance for grandparents in accessing the services, walking them through the maze.

Our primary objective is to reach and assist as many caregivers as possible. In order to notify the public of available resources, we would see that we would have to do local newspaper articles as well as presentations to organizations and community organizations.

I appreciate this opportunity to share our progress in Northern Idaho on the implementation of the National Family Caregiver Support Program, and I would be happy to address any questions. Thank you.

[The prepared statement of Mr. Sailor follows:]

Statement of

Bobbie J. Sailor

Acting Director

Idaho Area 1 Agency on Aging

Before the

Special Committee on Aging

United States Senate

May 30, 2001

Mr. Chairman and Members of the Committee:

Thank you for the opportunity to discuss Area 1's efforts to implement the National Family Caregiver Support Program.

Area 1 Agency on Aging is comprised of the five northern counties in Idaho: Bonner, Boundary, Benewah, Kootenai and Shoshone.
In order to assess the needs of family caregivers, the agency conducted a written survey, which was completed by AAA Advisory Council members, local hospital caregiver support group attendees and agency annual conference attendees.

The following services, identified as a need, Area 1 will focus on implementing:
Category 2: Assistance Services.
This includes **Information and Assistance**: providing current information on opportunities and other available services, and linking individuals to opportunities and available services; and **Case Management**: assessing the needs, developing care plans, authorizing services, coordinating the provision of services among the providers, follow-up and reassessment, as required.
Plan: Develop a resource database. Case Manager will assist in completing the required in-home assessment and assist the caregiver in accessing services offered by formal service providers.

Category 4: Respite.

This will be used to provide respite care to enable caregivers temporary relief from their caregiving responsibilities. It may be in the form of in-home respite, adult day care respite, or institutional respite for an overnight stay on an intermittent, occasional, or emergency basis.

Plan: Develop a competitive bid process to identify licensed facility provider(s) available in each county and daily rate to be paid in order to provide up to seven (7) days of paid respite in a twelve-month period. Paid respite would be considered a cost-sharing program utilizing the current Idaho Commission on Aging sliding fee scale. AAS case managers would complete the in-home assessment, identify respite as a need and assist the family in making arrangements for the paid respite with the closest provider. The family would pay their cost-sharing portion, if appropriate, directly to the facility as determined by the case manager and AAS's current agreement with provider.

Category 5: Supplemental Services – Legal Assistance.

Providing assistance for family caregivers with specific legal issues, such as emergency guardianships or other legal matters. This expansion of legal services with current service provider will not be a duplication of services currently available.

Category 5: Supplemental Services – Information and Assistance for Grandparents.

Develop a database of information regarding eligible services for grandchildren and how to access. Provide individual assistance for grandparents in accessing the needed services.

Our primary objective is to reach and assist as many caregivers as possible. In order to notify the public of available resources, local newspaper articles will be necessary, as well as, organization and community presentations.

Mr. Chairman, I appreciate this opportunity to share our progress in northern Idaho on the implementation of the National Family Caregiver Support Program. I would be happy to address any questions you have.

Ms. WISSEL. Bobbie, thank you. And, as I said earlier, we'll hold the questions till right after Ken's testimony. Ken Wilkes is with the Idaho Commission on Aging, he is the Support Service Manager.

STATEMENT OF KENNETH C. WILKES, PROGRAM OPERATIONS MANAGER, IDAHO COMMISSION ON AGING

Mr. WILKES. Thank you, Ms. Wissel. Good afternoon, my name is Ken Wilkes, program operations manager for the Idaho Commission on Aging. I am appreciative of the opportunity to testify this afternoon on the National Family Caregiver Support Program.

My remarks will focus on implementation of the program here in Idaho, including the service package and timelines for beginning the delivery of these much-need services. I will also comment briefly on the assistance and guidance we've received from the Administration on Aging.

We received notification of Idaho's allotment of $564,300, and our first written guidance from the Administration on Aging on January 17, of this year, and we received our notification of grant award a little over a month later, on February 20. Soon after receiving the information from AOA, the Commission staff began discussions about how we would implement the program, and we prepared a power point presentation for our upcoming Commission and area agency directors meeting, which was held February 14 and 15. At the Commission's business meeting on February 15, we presented a plan for the design and implementation of the program and requested their support for the plan. Our plan called for the formation of a small work group that included three family caregivers, one of our commissioners, one of our area agency directors, a representative of the Alzheimer's association, and a Native American and Hispanic representative.

Our work group met twice, once on February 28 and again on March 14. At our first meeting, we covered the following: We reviewed the 2000 Older Americans Act Amendments pertaining to the new National Family Caregiver Support Program, and we also reviewed the written guidance we had received from the Administration on Aging. We also included a telephone call with the Region Ten Administration on Aging administrator and staff in Seattle to discuss questions regarding the program. These questions were made official in a letter dated March 7.

We heard a presentation on grandparents raising grandchildren, and the three family caregivers on our work group shared personal experiences in their situation as a caregiver.

In our second work group meeting, we focussed on a review of concerns and issues raised by our six area agency on aging directors. We also listened to a presentation from our Native American and our Hispanic representatives to talk about some of the cultural differences in caregiving. We had a discussion of the most needed support services, and they were identified by the three caregivers on our work group. And, finally, we reviewed a draft application that our staff had prepared for the area agencies to submit to us in order to receive these funds.

The draft area agency application form was sent to the area agency directors and discussed with them on a telephone con-

ference call April 4, before it was finalized and mailed in mid April. These applications are due Friday for the review and approval of the Idaho Commission on Aging.

Until we receive these applications, we will not know exactly what service packages the area agencies are proposing, however preliminary information indicates that area agencies will be proposing to use the funds primarily for information and assistance, case management, and respite.

I need to note here that the three caregivers in our work group identified the following services as most needed; respite, including adult daycare; caregiver education and training; and support groups. They felt these were the services that would most immediately and directly benefit them.

We plan to award funds to the area agencies by July 1, and shortly thereafter services will begin. So, as you can see, Idaho has moved quickly to design and implement a program that we feel be a model for other States. We have received telephone calls from a few other States asking how Idaho is planning to implement the program, and it appears we are well ahead of the implementation curve.

I would like to close by saying that our regional Administration on Aging staff has been very responsive to questions we have raised both in writing and by telephone. Our active director attended a meeting in Seattle on April 25 that included a video conference with Administration on Aging central office staff in Washington DC. And, during that video conference two presentations were made, one that addresses reporting requirements under this new program and the other provides information on caregiver programs already in existence prior to the Older Americans Act Family Caregiver Support Program. At the Seattle meeting, Administration on Aging staff said they wanted to allow States maximum flexibility in implementing the program to meet their own needs. In addition, they have provided a list of frequently asked questions and answers to those questions. The AOA website has also been somewhat helpful, and a conference on the program is scheduled for September 6 and 7 in Washington DC.

I would like to raise what I feel is a major concern with the program, Ms. Wissel. The Administration on Aging has made an interpretation of the law that it requires each area agency to fund all five categories of services. This is a concern to me and I would think to at least some of our area agencies. And, particularly here in Lewiston, because area two receives the smallest allotment under this program based on population. Their total funding is a little over $57,000, and if they spread that through the five categories of services, my concern is that none of the categories will have been adequately funded. And I'm not sure that that was the intent of Congress as I read the law. So, I'd like to ask that you take a look at this, because it is a concern, I think, that needs to be addressed.

Another issue of some concern is a more restrictive interpretation by AOA of a match than is applied to the rest of title three. The interpretation they have made is that the funding we used to match this program has to be money that is currently being used to directly provide caregiver support services, whereas with all the

other programs under title three, any State or local money that is received can be applied to match the title three funding. So, I think that's another issue that, I think we'll be able to work it out in Idaho, because we do receive good support from our legislature with State funding. As you know, we have the respite program, and some of the current case management services are being provided to caregivers.

On behalf of the Idaho Commission on Aging, I would like to thank Senator Craig for bringing the Senate Special Committee on Aging to Idaho and for the opportunity to testify here today. As my testimony indicates, we are well on our way to providing solid support for Idaho's growing number of family caregivers. The goal of the Idaho Commission on Aging and its six area agencies on aging is to provide the most needed supportive services to family caregivers that will enable them to continue to care for their family members in their homes and prevent or delay more costly institutional care. We are committed to meeting the congressional intent of this program and working with the committee to be responsible stewards of Idaho's taxpayer dollars that support this program. Thank you.

[The prepared statement of Mr. Wilkes follows:]

Testimony

of

Kenneth C. Wilkes

Program Operations Manager
Idaho Commission on Aging

before the

Senate Special Committee on Aging

on

"National Family Caregiver Support Program"

Wednesday, May 30, 2001
Lewiston, Idaho

Good afternoon. My name is Ken Wilkes, Program Operations Manager for the Idaho Commission on Aging. Thank you, Mr. Chairman, for the opportunity to testify this afternoon on the National Family Caregiver Support Program.

My remarks will focus on implementation of the program here in Idaho, including the service package and timelines for beginning the delivery of these much-needed services. I will also comment briefly on the assistance and guidance we have received from the Administration on Aging.

We received notification of Idaho's allotment of $564,300 and our first written guidance from the Administration on Aging on January 17 of this year and our "Notification of Grant Award" a little over one month later on February 20. Soon after receiving the information from AOA the Commission staff began discussions about how we would implement the program and prepared a "Power Point" presentation for our upcoming Commission and Area Agency Directors meeting which was held February 14 and 15. At the Commission's business meeting, February 15, we presented a plan for the design and implementation of the program and requested their support of the plan. Our plan called for the formation of a small "Work Group" that included three family caregivers, one of our Commissioners, an Area Agency Director, a representative of the Alzheimer's Association, a Native American and Hispanic representative.

Our Work Group met twice, once on February 28 and again on March 14. Our first meeting covered the following:

- Review of the 2000 Older Americans Act Amendments pertaining to the Family Caregiver Program and AOA's written guidance
- Telephone call with the Region X Administration on Aging Administrator and staff to discuss questions regarding the program (the questions were made official in a letter dated March 7)
- A presentation on grandparents raising grandchildren
- Personal experiences from the family caregivers on our work group.

Our second Work Group meeting focused on:

- Review of concerns and issues raised by our six area agency on aging directors
- Cultural caregiver issues presented by our Native American and Hispanic representatives
- Discussion of the most needed support services caregivers identified by our caregivers
- Review of a draft application prepared by ICOA staff to be submitted by our area agencies.

The draft area agency application form was sent to the area agency directors and discussed with them on a telephone conference call April 4 before it was finalized and mailed in mid-April. These applications are due June 1 for ICOA review and approval. Until then we will not know what service packages the area agencies are proposing. Preliminary information indicates that area agencies will be proposing to use the funds for Information and Assistance, Case Management, and Respite. The three caregivers in our Work Group identified Respite (including Adult Day Care), caregiver education and

training, and support groups as services that would most directly benefit them. We plan to award funds to the area agencies by July 1 and shortly thereafter services will begin.

As you can see, Senator, Idaho has moved quickly to design and implement a program we feel will be a model for other states. I have received telephone calls from a few other states asking how Idaho was planning to implement the program and it appears we are well ahead of the implementation curve.

I would like to close by saying that our regional Administration on Aging staff has been very responsive to questions we have raised both in writing and by telephone. Our Acting Director attended a meeting in Seattle on April 25 that included a video conference with AOA central office in Washington D.C and two "Power Point" presentations- one that addresses reporting requirements and the other provides information on caregiver programs already in existence prior to the Older Americans Act Family Caregiver Support Program. At that meeting AOA staff said they wanted to allow states maximum flexibility in implementing the program to meet their own needs. In addition, they have provided a list of "Frequently Asked Questions" and answers to those questions. The AOA web site has also been helpful and an AOA sponsored conference on the program is scheduled for September 6-7 in Washington D.C.

On behalf of the Idaho Commission on Aging, I would like to thank Senator Craig for bringing the Senate Special Committee on Aging to Idaho and for the opportunity to testify here today. As my testimony indicates, we are well on our way to providing solid support for Idaho's growing number of family caregivers. The goal of the Idaho Commission on Aging and it's six area agencies on aging is to provide the most needed supportive services to family caregivers that will enable them to continue to care for their elderly family members in their homes and prevent or delay more costly institutional care. We are committed to meeting the congressional intent of this program and working with your committee to be responsible stewards of Idaho taxpayer's dollars that support this program. I would also like to thank Senator Craig for his support for the 2000 reauthorization of the Older Americans Act (including the Family Caregiver Support Program) that allows states more flexibility in using these federal funds to serve the needs of their elders and family caregivers.

I would be happy to respond to questions.

Ms. WISSEL. Thank you, Ken. You make two points, and the first one was on the interpretation of the law regarding the five services. And I know Lisa is planning to look into that as soon as we get back and find out what that's about and really look at the law. The second one, you talk about a more restrictive interpretation of the match, and that's an issue that came up during the hearing that we held in Washington on May 14. The problem with this is that there are States that are using other services funding to meet the match, and that was not Congress's intent. That the twenty-five percent, isn't it? Match that's suppose to be new resources, not money taken from in-home services, nutrition, or any other program to meet the match. So, that was the concern that came out during the hearing that was held in Washington, and that's probably why it was brought to the State's attention to make sure that you don't take money from one program to fund another.

Mr. WILKES. Right, and we don't.

Ms. WISSEL. And I did not think that would be an issue in Idaho, but that was the concern, that you would take money from other very-needed programs to fund another one.

I'd like to open it for questions that the audience here may have for any of the panelists up here. If you have them written, then, please raise your hand. We'll have someone pick them up. Or you are more than welcome to come up to the microphone and ask the question yourself. Any questions that we have out there?

While you pick them up, I will ask one of Ken. Do you feel that you have been getting adequate guidance from the Administration on Aging? I'm talking about not the regional office, but from the administration itself.

Mr. WILKES. No. I think that I would like to have seen guidance more early on, and it's trickling down now. We're starting to get a little more information. I mentioned in my testimony, the frequently asked questions, that has been quite helpful. This guidance about the having to put money in all five categories, if that is going to hold, we should have been notified of that well before now, because we have not given that guidance to our area agencies. And, on Friday, their applications are due to us, and now we have new guidelines we have to issue. So, that's troublesome to me.

Ms. WISSEL. Now, a follow up question to that, you talked about applications or program plans being due by June, then the program is to begin July 1. Are you going to be able to keep that time line?

Mr. WILKES. Yes. I'm certain we can keep that time line. We should be able to complete our review of these applications that gives us thirty days to review them. The only thing that could create a problem again, however, to alter that schedule is now if we do have to tell the area agencies they've got to budget money in all five categories, they'll have to re-submit their applications to us.

Ms. WISSEL. I have a question here, but I'm wondering if it was a question that we needed to address here? Was that a question you wanted—any particular panelist to answer?

SHARON. I have no preference.

Ms. WISSEL. It says, Medicaid now reimburses participation in a——

SHARON. Adult day health.

Ms. WISSEL. Adult day health, when did you anticipate that Medicare will reimburse for adult day health?

Mr. WILKES. I can answer that, no. Medicare?

Sharon. Uh-huh.

Mr. WILKES. I don't see it.

Ms. WISSEL. And probably not right now. Do you know, whether it's something that is being looked at as part of the Medicare reform, I don't know. Ma'am?

SHARON. My concern is that we are about to open an adult day health facility in Moscow, ID, that will cover a good portion of region two. We already have fourteen people signed up, and we will open July 1. But the biggest problem we are seeing is that there are a number of people on Medicare who could use this service that can't afford it. And we know this is a cost-effective alternative to hospitalization, so I would petition that you would question in terms of Medicare covering adult day health services in the future.

Ms. WISSEL. I have another question here. This is for Bobbie Sailor. It says, concerning respite care, will there be additional staff to make a determination, and how long will that determination be effective?

Ms. SAILOR. For the caregiver to access the respite, we would see that we would probably need an additional case manager, part-time case manager to go out and do the assessments. And hopefully the turnover from the time we get the referral to the case manager going out will be shortly, because that's something that needs to get taken care of right away. Usually when they need respite, it's not 6 months down the line, it's right now that they need it. So, our hope is that we would address it with a timely fashion.

Ms. WISSEL. I have another question for the caregiver. If you were to design this program yourself, which one of the five categories would you see as the most important when it comes to the family caregiver program?

Ms. WILSON. I think probably the information assistance, so that we, as I'm talking as a person that would be possibly a caregiver, would know where to go find the information, be able to pick up the phone and call a number and have them tell you, OK, either this is where you go or this is what you do. So, I think the information, I think that's probably been one of my biggest frustrations with the grandchildren is trying to find out what's there, how I go about accessing it. With my mother, it was a frustration; however, working for an area agency was a real benefit in that way, because I had them to come to. But other people who have never accessed any type of help, never done anything with Medicaid, never had any reason to, the frustration is really high, and just not knowing what to do.

Ms. WISSEL. Thank you. Bobbie?

Ms. SAILOR. Yes.

Ms. WISSEL. I don't recall how much your area is getting for the family caregiver program, but of the allotment to your area, what percentage of the funding will go for respite services?

Ms. SAILOR. We're getting 68,000, and I believe—I don't have it right in front of me, I believe around 20,000 is going. So, almost a little over a quarter, about a third, almost a third is going to respite.

Ms. WISSEL. The reason I ask is because during discussions regarding the round tables and in discussing the National Family Caregiver Program, as you'll recall, there were three areas that caregivers brought up every time, that was the education, the support, and the respite, and that's why we're interested of, to know, how much is going for those categories that we heard the family caregivers talk about.

Any other questions out there. I have a gentleman right back there.

Mr. ADAMS. Thank you, Lupe. I've been handed a letter from our local case manager in the Agency on Aging. I'm Bob Adams. I'm the chairman of the local advisory board, and this is a letter that I think kind of fits in to the things that we've been hearing today and especially from the Senator. This is a letter from a lady in Grangeville dated yesterday. She says, my husband and I, ages 69 and 60, have moved in with my parents age, 87 and 80, because they require 24-hour-a-day care. My father suffers from advanced dementia as well as heart disease. He is very weak and forgets how to walk, talk, eat, and use the bathroom. He wears diapers and has to be bathed. He has difficulty swallowing and becomes dehydrated. Also, he requires a strict regimen of medications to keep him calm. My mother is a bedridden diabetic with both legs amputated and is partially paralyzed on her left side. She also requires a great deal of care. She uses a bedpan six to twelve times in a 24-hour period. She suffers from diabetic paresthesias, which is a partial paralysis of the bowels. She requires the assistance of a home health aide three times a week to assist her with bowel movements with occasional visits by the registered nurse. This costs us over $200 a month, since Medicare does not pay for this. The pharmacy bill runs from $250 to $600 a month. We were also paying for diapers for both of them until a kind pharmacist informed us that Medicare would pay if we obtained a prescription for these items. They have a total monthly income of $1435.30 from Social Security and a small IRA. Expenses greatly exceed income each month. Fortunately, they still have some savings, so we are able to hire some outside help, mostly for the night shift so that we can get a little rest and 2 days a week for a few hours so we can get away for a little while.

This letter is not meant to be a complaint. Rather, it is to give a picture of what many seniors are going through. In fact, one of the nicest things happening to us is the respite care provided by the Area Agency on Aging. The agency has arranged for a health worker to be available from 9 to 12 each Sunday morning so that I can attend Bible study with my husband. This enables us to keep up our spiritual strength, without which the distress from this situation would mentally overwhelm us and cause these two fine people to have to be placed in a nursing home. This would be an unhappy situation for us all.

This is not necessarily an unusual case anywhere for old people. Our case manager worker wanted me to read this in case some of you don't realize how well off you really are. Thank you.

Ms. WISSEL. And that is very appropriate for this forum. Larry?

LARRY. I have another short, one-page letter that I was asked to read, if that's OK. I guess I'll get up to the microphone. I spent 2

years as chairman of the Idaho Commission, and just want to tell the people here at home how much I appreciated you there and how comforting it is to know that you're in DC looking after our needs and also to thank Ken Wilkes. I spent a number of years working with him. You've both been a pleasure, and now I'll go on with my letter. It is dated to the Senate Special Committee on Aging. Just a year ago a horrible disease took my husband's life. It was devastating to me and to his children. During the last few months of his life, the help we received through home health and then through family hospice was of the greatest value. The financial drain of the care and of the medicine could have been a great burden. But because of the aid through the program of hospice, I could be reassured that my husband would not worry about being able to pay for the drugs that kept him nearly pain-free. It was extremely important to our family that he received the financial medical assistance during those last days of his precious life. I will be forever grateful, sincerely Pat Ebel.

Thank you.

Ms. WISSEL. Thank you, Larry. Any other questions?

Ms. PEW. My name is Becky Pew, and I work as a coordinator of domestic violence services in Latah County, in Idaho. And while many of the areas that you guys are addressing, and this is for anybody on the panel, such a respite care, information and support to caregivers are good ways to combat domestic elder abuse. Knowing that the statistics show that one in 25 older Americans is abused or neglected, 90 percent of that coming from family members, I'm wondering if domestic elder abuse is being addressed and how it's being addressed?

Ms. WISSEL. Ken, I think you can answer that, can't you?

Mr. WILKES. Yes. We have an adult protection program here in the State of Idaho that is administered through our Commission, and it is available to address those kinds of issues. It's available through your Area Agency on Aging. Jenny Sorens is the director, and I don't recall who your adult protection coordinator is here.

Ms. SORENS. Elizabeth Allen.

Mr. WILKES. Elizabeth Allen is the coordinator. So, if you needed more information about the program, you could talk to Jenny.

Ms. WISSEL. Sir?

Mr. JOHANSON. My name's Carl Johanson, and I'm the director of Counsel on Aging Human Services, which is located across the river and over in Washington State, but our agency is the rural transportation provider in all of Central Idaho. And I have a couple of comments to make both—not really questions, but comments to make in relating to this bill and also to relay on to the Senator, I didn't get a chance to both thank him and also ask a question. So, I'll start my remarks with, the bill has an assumption of access. Funding from the Family Caregiver Support funding, I think, can be used, as I understand it, for adult day health, which has been mentioned and out-of-home respite. But in the planning that's been done and so on, both nationally, I have not heard any dialog about how people get to those services. There has not been a corresponding increase in funding to those that would be expected, other than the family caregivers themselves, to provide transportation to get them to those services, which almost always is going to require lift

vans, specialized vehicles, specialized training for drivers and so on, and no increase. Now, Senator Craig has helped us with another hat on, the State of Idaho, ten of us receive a 5309 earmark, which we've been able to get vehicles. And we're trying for another one as we speak, so I can mention that. But there is no funding through the Federal Transportation Administration, 5309, Special Funding, related to health care access and the growing demands from the senior population. And, so, more directly, I was going to ask the Senator that there is growing interest in a non-emergency transportation benefit under Medicare, similar to Medicaid. It could save bundles of bucks. Because, oftentimes, the reason that people are prematurely institutionalized is because they can't get to the needed community-based services that they need. I don't know of the couple that was mentioned in the previous letter from Grangeville, but until 2 years ago, there was not an accessible vehicle in that county that would have transported the woman with the double amputation to needed services. She would have needed to go by ambulance, and that's not appropriate for routine things like any socialization or just routinely to any other activities other than a doctor. And I would just mention that if we were to grow in that area, and I see a need, one of the agencies that's really working on trying to have that be a legislative proposal is the Community Transportation Association of America, has recently, last week, made it its No. 1 legislative proposal for the next year, Del Marsico there as the director. I think it be really helpful, particularly in rural areas.

Ms. WISSEL. Thank you, Carl. Any other questions for the panel?

UNIDENTIFIED AUDIENCE MEMBER. I think it was, Bobbie, you mentioned a guardianship?

Ms. SAILOR. Emergency guardianships.

UNIDENTIFIED AUDIENCE MEMBER. Emergency guardianship, is that only for family caregivers at home, or do you come into long-term care settings as well? And, is there something in Lewiston area?

Ms. SAILOR. I really don't know at this point. I would—for the caregiving, I really don't know. I couldn't answer that.

Ms. SORENS. We have not utilized our legal contract funding, which is very limited, to bring forth guardianships in long-term care facilities for many reasons, Nancy. We haven't done that. If a facility has felt the need to proceed in that direction, usually the facility's attorney or their corporation has footed the cost of that.

NANCY. Really? Because that's a conflict, I think. That's a real conflict. But there isn't in Lewiston, because it involves caregivers and family members as well, I guess.

Ms. SORENS. You know, I'm not saying that we probably wouldn't look at it, but it's not something that we do, in general. Our contract this year had $9,000 in it to cover five counties, and we've had to prioritize. And in prioritization, you know, it doesn't mean that issues that fall to the bottom aren't important. They are, but we've just had a limited amount of funding to work with in five counties.

NANCY. Does that apply to assisted living and people living in retirement settings as well?

Ms. SORENS. It does. It applies to anybody who might be in need of legal services in our five counties, facility or not.

NANCY. OK. And this question is to Ken Wilkes, and that is, I heard it referred to that, at least the illustration was, there is long-term care or nursing home that is the tip of the iceberg and 90 percent home caregivers, at home, and their identified top issues would be education as well as counseling and support services; and, that is, how do you care for someone at home. Do you anticipate a joining or working together in support of older Americans between facilities and nursing homes who do have all the abilities to train and to do that kind of thing to the general public?

Mr. WILKES. Well, I would hope that our area agencies in submitting these applications would include some funding to provide education and training, and certainly facilities such as yours would be a resource, as well as the Alzheimer's Association, who does a lot of training on development of support groups and provides education on training of caring for a family member with Alzheimer's. So, the money under this program, we are required to pass it all on to the area agencies. We cannot keep any of that money at the State level. So, it will be the area agencies to determine how much and if they plan to put any into that category of service. And it is one of the categories under this program, and then they, in turn, would identify local resources that can provide that kind of education and training. So, you need to deal with your area agency. However, I will say that when we review these applications, we'll be looking to see if any money is being proposed by any of the area agencies for that purpose, because that certainly was one of the services that the three caregivers on our work group identified as important.

NANCY. Thank you.

Ms. WISSEL. Thank you. Any other questions?

Ms. KRAMER. Hi. I'm Krista Kramer from the Disability Action Center in Moscow, and one of the questions I have is about the parameters for who qualifies for caregiver support under this program. Working for a cross-disability organization, I see the caregiver issues as being very similar, whether that caregiver is a 21-year-old parent of a newly disabled child or a 65-year-old caregiver for their elderly parents or a spouse who's 35 whose husband just received a spinal cord injury. Will this caregiver program support people across the board even though the funding is coming through the Committee on Aging?

Ms. WISSEL. Ken.

Mr. WILKES. You have to keep in mind that this is under the Older Americans Act, and it is for caregivers age 60 or older or——

Ms. KRAMER. So the caregiver has to be age 60 or older?

Mr. WILKES. Yes. The caregiver has to be age 60 or over, which is the basic age requirement for all services under the Older Americans Act. However, there is a provision that up to 10 percent of this money can be used for grandparents raising grandchildren. In that case, the grandparent could be, say, a forty-year-old grandparent, as long as the grandchild they're raising is under the age of eighteen. Those are the guidelines for the program.

Ms. KRAMER. OK.

Ms. WISSEL. Did that answer your question?

Ms. KRAMER. Yes, it does. It brings up again one of the concerns that I have about the financial pathways through which money travels to provide similar sets of services, because I often see the same needed service being provided through different funding streams and very inequitably, depending upon the specifics of when the disability or the need was acquired. One system provides those services if the disability was acquired before age 22. A completely different service system provides the same services for age 60 and over, and a different one yet provides it in an intermediary. And, I'm wondering if there is a way to communicate and collaborate and to keep the equity across those systems when the needed services are the same but the time period of acquisition is different.

Mr. WILKES. Lupe, I need to correct myself. The caregiver has to be over 60 or a caregiver caring for a family member over age 60.

Ms. WISSEL. OK, great.

UNIDENTIFIED AUDIENCE MEMBER. I guess my question is kind of in a round about way. As a previous business office manager for a long-term care facility here in Lewiston, I used to admit patients or residents for respite care. And, as a taxpayer, I guess my feeling is, if we can get the caregivers to come in the home to let the spouse at 60 years old or older to give them a little break, I think in the long run, I think that's so much better, because it saves money. And like this is starting to affect my family now because of Alzheimer's and dementia, and I know if we took my father-in-law out of his home on a bad day to give my poor mother-in-law a little bit of a break, it would probably be fifty times worse had he not be been taken out of his home. And it's got to be cheaper than going into a long-term care facility. So, as a daughter-in-law who loves her father-in-law very much as well as the business side of me thinking how we can save taxpayers a lot of money, I really hope that the respite care is really—I know you said as one of five categories. I hope that's one area that really has a lot of attention, because I think as a family member, this really does need to be addressed.

Ms. WISSEL. And, again, you're echoing what we have heard during many round tables when this program was coming about.

UNIDENTIFIED AUDIENCE MEMBER. I got three of the five categories, respite care; education slash information, I guess those two are together; support and counseling. What were the other two, other services?

Ms. WISSEL. It's the other services, support services, and what's the fifth one?

Mr. WILKES. The categories are, information assistance, individual counseling, organization of support groups—this is all one, individual counseling, organization of support groups and caregiver training. The fourth one is respite care, and the fifth one is sort of an open-ended one called supplemental services.

UNIDENTIFIED AUDIENCE MEMBER. OK, thank you.

Ms. WISSEL. Another question back there?

UNIDENTIFIED AUDIENCE MEMBER. I only had half of my question answered on the first written ones. The second part of it was, how long would the determination for respite care be effective? Is it like a month, or can they come in like in 6 months and say, I need another respite?

Ms. WISSEL. I think you would answer that.

Ms. SAILOR. I'm sorry?

Ms. WISSEL. The question is, once someone applies and found eligible for the services, how long is that eligibility good for?

Ms. SAILOR. I don't know that. As far as the plan, we haven't come up with that. We're still doing the planning process, so we haven't gotten everything ironed out yet.

Ms. WISSEL. So, if someone applies today and 6 months later they need the service again, would they have to reapply?

Ms. SAILOR. For the respite, we're looking at a 7-day voucher within a 12-month period, so it would be for a 12-month period.

Ms. WISSEL. Does that answer your question?

Unidentified Audience Member. Uh-huh, but I have another one.

Ms. WISSEL. OK.

UNIDENTIFIED AUDIENCE MEMBER. Where is the respite care? Are you going to say it has to be done in the home?

Ms. SAILOR. We have currently respite services available in the home, but one of the things when we did our written survey was that we found they also needed longer respite than just a couple hours. So, a weekend or a few days, and so for those we would be looking at a long-term facility, probably contracting out with them to do that. The couple hours would be done in the home. Whatever best meets the need of the client.

Ms. WISSEL. And with that question, I am going to conclude the forum, first, because of time; second, we have a plane to catch. But we want to take just a few more minutes to answer any other questions you may have for any of us up here. But we will go ahead and conclude the forum.

[Whereupon, at 2:19 p.m., the forum adjourned.]

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

THURSDAY, MAY 31, 2001

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Caldwell, ID

The committee met, pursuant to notice, at 3:12 p.m., in Langroise Hall, Albertson College, 2112 Cleveland Boulevard, Caldwell, ID, Hon. Larry Craig, (chairman of the committee) presiding.

Also present: Representative Michael K. Simpson.

The CHAIRMAN. Ladies and gentlemen, if I could have your attention, first of all, let me thank you so much for coming out this afternoon, but before we start our hearing, I'd like to take a few moments to tell you a story that was brought to my attention about a year ago. This is a story that has culminated in success of the kind that both the Congressman Mike Simpson who has just joined me and I really appreciate being involved in.

OPENING STATEMENT OF SENATOR LARRY CRAIG, CHAIRMAN

The CHAIRMAN. The Senate Special Committee on Aging will be convened.

Good afternoon, and let me thank you all for attending this Senate Special Committee on Aging hearing on the issue of National Family Caregiver Support Program. Last year, Congress passed legislation reauthorizing the Older Americans Act. I was an original cosponsor of that legislation which updated and amended the Older Americans Act, and I was extremely gratified that finally Congress could come together in the reauthorization of this important national law.

As part of this reauthorization, Congress added an important and exciting new component to the Act. Specifically, this legislation authorized 120 million to establish a new National Family Caregiver Support Program to assist those many daughters, sons, husbands, and wives who struggle with the daily task of caring for an older member of their family.

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

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

Second, basic and practical education about the nuts and bolts of being a caregiver: How do you bathe someone who can't walk. Where do you go to get special beds and other needs equipment. Most family caregivers are not formally trained and many are desperate for some place to turn to for answers to the basic questions they need to have responded to.

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

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

Our first goal today will be to look at how the States are setting up their programs. I believe it is imperative we ensure that the new funding be focused as directly as possible on those things their caregivers themselves tell us they need most; namely, respite, education, and support.

Similarly, we must keep a watchful eye to make sure that as many of the new dollars as possible get to the actual caregivers on the front line, rather than simply being used for more agency staff or administrative duties.

Second, we also hope today to examine whether or not States are receiving the clear and effective guidance they need from the Federal Administration on Aging regarding the program's implementation.

Again, I would like to thank all of the witnesses for being here today, for attending the hearing, and for providing their testimony. Before I turn to those witnesses, let me say that I am pleased that Senator Mike Simpson of the Second Congressional District could join and be with me this afternoon. Mike's taken a very special interest in one of his Congressional responsibilities, and that is, of course, looking after the senior citizens and the laws that pertain to them as it deals with the folks in the Second District. So let me turn to Mike for any comments he would like to make.

Mike.

STATEMENT OF HON. MICHAEL K. SIMPSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF IDAHO

Mr. SIMPSON. Thank you, Senator Craig. I appreciate the opportunity to be with you here today on this issue and talk about what's happening with our senior citizens and senior caregivers, but first let me congratulate Phyllis on her new citizenship. Some people wonder why we do this job because of the travel and all the things that it involves, and I can tell you that's exactly why we do this job. That's one of the things that makes it exciting.

But, I took a special interest particularly in this area of senior caregiver, and it occurred probably 8 or 9 years ago when my mother-in-law who had dementia very bad couldn't stay in her own home any longer, and we had the opportunity to add a place onto our house and have her live with us for 8 years and then about a

year ago she passed away; but it presented, obviously, unique challenges and also opportunities. I got to know Margaret better than I ever would have had she not lived with us. But we were fortunate in that we were able to do that, and that's not the case with all senior citizens or all families that had the ability to do that. And so it was, as I say, it was a blessing that we were able to take care of her.

And I would like to, in this hearing, focus on what we need to make sure that these senior citizens are able to stay with their loved ones or in those types of situations where they will be taken care of by people they know. So I appreciate the opportunity to be here with you, Senator Craig, and talking about this issue. Thank you.

The CHAIRMAN. Well, Congressman, thank you very much for being here with us.

Before we turn to our panelists, recently on a hearing that we held in Washington on this issue, a very fascinating statistic was provided that amazed me. We recognize that our elderly who live in nursing homes and assisted living facilities and retirement centers, oftentimes when we see those facilities and the people in them, they are drawn to our attention because they are, without question, a higher profile group by their presence. The statistic that fascinated me is that 95 percent of the elderly who are being provided care are not in those facilities. They are in homes; private homes.

So when we see a nursing home or an assisted living facility or a retirement center that offers advanced care, it really is merely the tip of an iceberg, and underneath are all of the private caregivers out in private homes caring for their loved ones as I mentioned, their mother or their father or their husband or their wife, and that's where this program has begun to focus. And that's why we are here today, to begin to improve by information and assistance that broad 95 percent where care is being given.

So with that, let me turn to our panelists. We are fortunate today to have our first panelist, Linda Carpenter, being an actual caregiver, and I think that's special that we can have someone who is engaged right now in caring and providing for a loved one.

So, with that, Linda, welcome to the committee, and please proceed with your testimony.

Ms. CARPENTER. Thank you so much, Senator Craig. I just want to kind of make this clear: I am just a part-time caregiver right at the moment.

The CHAIRMAN. All right.

STATEMENT OF LINDA CARPENTER, CAREGIVER

Ms. CARPENTER. My mother has Alzheimer's. She was diagnosed about 5 years ago. At that time, she remained in her home with my stepfather taking care of her, and about 3 years ago, she got even more severe enough that we had to move her in with relatives. And she was from the Lewiston area and they moved to Hermiston, OR, where she was staying with my stepfather's family down there. I found out about caregiving in great detail from what they went through with my mother and my stepfather, having two

that they were taking care of and dealing with; it was quite intense.

And I had been in charge of the respite program in Washington County and still am, and so I had done a lot of volunteering myself. By the way, all the people who did the caring in the respite program are volunteers, and really one of the things that would really be helpful is if these people could get a little reimbursement for what they do. They do a wonderful job going in sometimes four to 6 hours a day, sometimes even overnight, just to give the caregiver a break. So, you know, this is such a wonderful program, and in the Oregon area where my mother and my stepfather was, they didn't have nearly as good as respite care down in Hermiston as we do in Washington County in Idaho, but thankful we have that. But that would really improve it, I think, if we could get a little funding for the people that go in and do health care.

And then also I have done home health, and a lot of the people that I have taken care of have Alzheimer's and I know now they have an Alzheimer's Association does have funding. They will pay a certain amount every month for people to go in and take care, so that does help, but that's a little different than what the respite care program does.

But about January, my relatives called and said, you know, It's getting really stressful with your mom and with your stepdad, and we cannot continue to keep both of them.

So I had to make a decision. I had to decide whether I wanted to keep my mother in our home or whether I thought she was needing a facility care. And so my husband and I sat down and we talked, and she had been getting a little bit more severe. Sometimes Alzheimer's patients get fixations on things so they have to have certain things. One man that I heard of, he liked keys, so they would have to give him a ring of keys to carry around; that's fairly innocent. But my mother had started getting a fixation on matches. This was very dangerous, and this really worried them down there as one of the reasons why they said, "we just can't continue to do this". We're very worried that she's going to harm us and herself.

So, we did have to make a decision on whether to keep her in our home at that time. After we discussed it—we're a busy family, I still have a child at home, and we just decided, you know, we think she's ready for a facility, but then it comes to the problem of where, you know, what is a good facility, and was she ready for the nursing home or was she ready to go, you know, in maybe something that was assisted living.

So we began looking around. And in talking to my mother, I realized that she was about level two, which is not severe but it's not the beginning stages either. She can still converse and talk, she did not wander like some of the Alzheimer's patients did, and so not knowing whether this was going to get more severe, so we looked around and we found a wonderful facility in Payette, it's Ashley Manor, and they have facilities everywhere. And I was very impressed with the staff. They have been trained for this and they know what they're doing over there, they can redirect them if they decide they don't want to get up in the morning and do things they should, like get certain clothes on and things. They're wonderful

that way. So this is a wonderful facility and it's an opportunity for us to learn a lot from them too. They are very well trained and I appreciate that.

But for those that want to keep their loved ones in the homes, respite care is such a wonderful program. We need more of it. We need more funding for more hours for the volunteers, as well as for the coordinators that do this in all the counties.

And I think it's a wonderful thing if the loved ones want to keep their mother or their father at home to do this, but for us, that was not the option, and we just had to make the choice. This is sometimes what you have to do. You can keep them for a while and then decide to put them in a facility if this is what you think is the best.

I found out in dealing with my mother and all the things that you have to do to make these decisions, you know, there's her medications, there's, you know, the doctor that she used that's best for her, there's all these decisions that you have to make, and sometimes it's very hard. You don't know who to turn to. I was fortunate: I had dealt with these people and I tried to help them through the respite program and through the home health, so I had an idea, but for people who don't, they don't know where to turn, and it would be really nice to have somebody who can counsel them on these things and people who would be in charge of something like that. So that would be very helpful also.

So I would like to share in the last newsletter from Ashley Manor ten things, and this would apply to anybody that's taking care of somebody at home. I thought these were very good things.

And just training for people, for caregivers, too is so important, and we do a little bit of that with respite but they need more training if they're going to keep somebody at home. It's a full-time job.

These are ten requests from an Alzheimer's victim, or could be dementia or anybody that's at home with a loved one:

Be patient with me. Remember, I am the helpless victim of a brain disease which is out of my control.

Talk to me. Even though I cannot always answer you, I can hear your voice and sometimes comprehend your words.

Be kind to me, for each day of my life is a long and desperate struggle. Your kindness may be the most important event in my day.

Consider my feelings, for they are still very much alive in me.

Treat me with human dignity and respect, as I would have gladly treated you if you had been in this bed.

Remember my past, for I was once a healthy, vibrant person, full of life, love, and laughter, with abilities and intelligence.

Remember my present. I am a fearful person; loving husband, wife, father, mother, grandmother, grandfather, aunt, uncle, or a dear friend who misses my family and home very much.

Remember my future. Though it may seem bleak to you, I am always filled with the hope for tomorrow.

Pray for me, for I am a person who lingers in the midst that drifts between time and eternity. Your presence may do more for me than any other outreach of compassion you can extend to me.

Love me. The gifts of love you give will be a blessing for which we will both live our lives with light and forever.

These are some things which would be very helpful for all caregivers and for the training that would help them.

My mother's doing very well, by the way. She's adjusting. They are enjoying her over there. She can still converse and carry on a conversation, but not all of them over there can, and sometimes that's very hard to deal with too.

That's all I have to say. If anybody has any comments or——

The CHAIRMAN. Thank you, Linda.

Let me now turn to Russ——

It's on? There we go. Thank you. That's much better.

Let me now turn to Russ Spain, director for Area Six, Agency on Aging in Idaho Falls. Russ, thank you for coming over and being a part of our hearing, today.

STATEMENT OF RUSS SPAIN, DIRECTOR OF AREA SIX, AGENCY ON AGING IN IDAHO FALLS, IDAHO

Mr. SPAIN. Thank you, Senator Craig and Congressman Simpson. I am here as the president of the Idaho Association of Area Agencies on Aging, taking the place of Brenton Sempreviva, who is the director here in Area Three, and the testimony that I will be giving is his. You will hear mine tomorrow in Idaho Falls.

The CHAIRMAN. Fine enough. Thank you.

Mr. SPAIN. Under the National Family Caregiver Program, we were only awarded $187,582 for direct service delivery. Due to the size of our service area, we felt it best to enhance other nonprofit programs currently providing caregiver support and not attempt to duplicate services.

In category one of the legislation, 11 percent was allocated to information and outreach to provide information to the public concerning this program and identifying caregivers in need of service provisions.

For category two, 11 percent was allocated to case management to assess needs of caregivers, develop care plans, authorize services, coordinate the provision of services and providers, and follow-up and reassessment as needed. The Idaho Association of Area Agencies on Aging has already developed a draft caregiver assessment instrument.

Category three. Eight percent was allocated to counseling, slash, support groups, slash, training, to support existing support groups and training for caregivers.

Category four. Sixty percent was allocated to actual respite care to establish nonprofit respite care programs in our service area.

Category five. Ten percent was allocated to supplemental services, including legal assistance to caregivers and grandparents raising their grandchildren.

This additional money for respite care has been needed for a long time, and we appreciate being able to better serve our seniors and their caregivers.

And that is the text of his testimony, Senator Craig. Thank you.

The CHAIRMAN. Russ, just in clarification: Of the little over 500,000 received, you're speaking in that amount the 187,582 specific to that area, Area Six?

Mr. SPAIN. To Area Three.

The CHAIRMAN. This area here.

Mr. SPAIN. That is correct, this area we are in now.

The CHAIRMAN. Thank you. That's right, you did make that clarification. I appreciate that.

OK, thank you very much, Russ.

Now, let me turn to Ken Wilkes, the program operations unit manager of the Idaho Division on Aging in Boise. Ken, thank you for being with us.

STATEMENT OF KEN WILKES, PROGRAM OPERATIONS UNIT MANAGER, IDAHO DIVISION ON AGING, BOISE, ID

Mr. WILKES. Thank you, Senator, for the opportunity to testify this afternoon on the National Family Caregiver Support Program. My remarks will focus on implementation of the program here in Idaho, including the service package and time lines for beginning the delivery of these much-needed services. I will also comment briefly on the assistance and guidance we have received from the Administration on Aging.

We received notification of Idaho's allotment of $564,300 and our first written guidance from the Administration on Aging on January 17 of this year, and our Notification of Grant Award a little over 1 month later, on February 20. Soon after receiving the information from AOA, the commission staff began discussions about how we would implement the program. We prepared a Powerpoint presentation for our upcoming commission and Area Agency on Aging directors meeting, which was held February 14 and 15. At the commission's business meeting on February 15, we presented a plan for the design and implementation of the program, and requested our commissioners' support with the plan.

Our plan called for the formation of a small work group that included three family caregivers, one of our Area Agency on Aging directors, a representative of the Alzheimer's Association, one of our commissioners, and a Native American and Hispanic representative.

Our work group met twice: Once on February 28, and again on March 14. Our first meeting covered the following:

We reviewed the 2000 Older Americans Act amendments pertaining to the Family Caregiver Program and AOA's first written guidance that we received.

We also included the telephone call with the Region Ten Administration on Aging administrator and staff in Seattle to discuss questions regarding the program. The questions were made official in a letter dated March 7.

We have listened to the presentation on grandparents raising grandchildren, and listened to the personal experiences from the three family caregivers on our work group.

Our second work group meeting focused on review of concerns and issues raised by our six Area Agency on Aging directors.

We also discussed some cultural caregiver issues that were presented by Native American and Hispanic representatives.

And, finally, we reviewed a draft application that our staff had prepared for the Area Agencies to submit to us in order to receive these funds. This draft application was sent to the Area Agency directors and discussed with them on a telephone conference call on April 4 before it was finalized and mailed in mid-April. These ap-

plications are due tomorrow for our review and approval, and until we receive the applications, we won't know exactly what service packages the Area Agencies are proposing, but preliminary information indicates that they will be proposing the use of funds primarily for information and assistance services, case management, and respite. You've just heard what Area Three is proposing.

The three caregivers in our work group identified respite—including adult daycare, caregiver education and training—and support groups as services that would most directly benefit them.

We plan to award funds through the Area Agencies by July 1, and shortly thereafter, services will begin.

So as you can see, Senator, Idaho must move quickly to design the program that we feel will be a model for other States. We received telephone calls from a few other States asking how Idaho was planning to implement the program, and it appears we're well ahead of the implementation curve.

I'd like to close by saying that our regional Administration on Aging staff has been very responsive to questions that were raised both in writing and on the telephone. Our acting director attended a meeting in Seattle on April 25, that included a video conference with the AOA's central office that addressed reporting requirements and provided information on other caregiver programs. At the Seattle meeting, AOA's staff said that they wanted to allow States maximum flexibility in implementing the program to meet their own needs. In addition, the Administration on Aging has provided a list of frequently asked questions and answers to those questions. The AOA's Web site has also been helpful and AOA's sponsored conference on programs scheduled for September 6 and 7, in Washington, DC.

I would like to raise one major concern that we've identified in the past week, and that is a requirement that each Area Agency fund all five categories of services under the Act; that we feel that some of our Area Agencies receive such small allotments—the one you just heard from Russ is the largest allotment of any of our area agencies, but we have one area agency in Lewiston who was only to receive about $57,000, and to spread that through all five programs would mean that none of them would be adequately funded. And so that's a concern we have and would like some clarification on it.

On behalf of the Idaho Commission on Aging, I'd like to thank you, Senator Craig, for bringing the Senate Special Committee on Aging to Idaho, and for the opportunity to testify here today. As my testimony indicates, we're well on our way to providing solid support for Idaho's growing number of family caregivers. The goal of the Idaho Commission on Aging and its six Area Agencies on Aging is to provide the most-needed supporting services to family caregivers that would enable them to continue to care for their elderly family members in their homes to prevent or delay more costly institutional care. We're committed to meeting the congressional intent of this program and working with your committee to be responsible stewards of Idaho taxpayer dollars and support this program.

And I'd also like to thank you, Senator, for your support of the reauthorization of the Older Americans Act, includes this program,

and also allows States the flexibility of using these funds to meet their own needs. Thank you, Senator.

The CHAIRMAN. Ken, thank you very much.

Let me turn to our last witness on the panel today Edwin Walker, who is the director of program operations and development group for the Administration on Aging in Washington. We appreciate you coming out to be with us here in Idaho. We hope that it's a treat getting out of the Washington, DC., area to be with us. I'm sure you'll find it that way. Please proceed.

Mr. Walker. Indeed, it's always a treat to leave Washington, but sometimes it's also nice to go back home.

STATEMENT OF EDWIN WALKER, DIRECTOR OF PROGRAM OPERATIONS AND DEVELOPMENT GROUP, ADMINISTRATION ON AGING, WASHINGTON, DC

Mr. WALKER. Mr. Chairman and Congressman Simpson, thank you for this opportunity to discuss the Administration on Aging's efforts to implement the National Family Caregiver Support Program. We appreciate your leadership and look forward to working with you, and on this issue as well as other issues concerning older Americans and their caregivers.

The past several months have been very exciting ones for the Administration on Aging. With your support and support of other members of the Committee, the Older Americans Act was reauthorized. That reauthorization included the new National Family Caregiver Support Program.

The National Family Caregiver Support Program is the first major new component of the Older Americans Act since the establishment of the nutrition program in 1972. For the first time in the history of the Act, there is now a national focus on caregivers as well as care receivers. The Administration on Aging was honored that one of Secretary Thompson's first official acts at the Department of Health and Human Services was to authorize the release of $113 million to States to begin implementation of this program.

Attention to the needs of caregivers could not come at a better time in our country. Research has confirmed that families provide upwards of 95 percent of the long-term care for frail, older Americans. Almost three-quarters of informal caregivers are women, many are older and vulnerable themselves, or are running households, are employed, or are parenting children.

Estimates from the 1994 National Long-term Care Survey indicate that over seven million Americans are informal caregivers providing assistance to spouses, parents, other relatives, and friends. Approximately five million older adults with disabilities receive significant levels of service from these caregivers. According to the survey, if the work of these caregivers had to be replaced by paid home care staff, the cost to our Nation would be between $45 and $94 billion each year.

The assistance provided to the elderly or disabled friends and relatives may range from bill payment, transportation for medical appointments, food shopping and preparation, and more complex personal care. As our older population continues to grow, especially with the increased numbers expected as a result of the aging of the

baby boomers, we can anticipate that the challenges of caregiving will increase as well.

Mr. Chairman, I am pleased to report that the Administration on Aging and the national aging network have made good progress in implementing the National Family Caregiver Support Program. This Committee knows the caregiver program is based upon three things:

First, our review of the recent research on caregiving; second, guidance from professional caregivers; And, third, discussions with family caregivers themselves.

We looked closely at the programs in various States across the country—among them, Wisconsin, Pennsylvania, Michigan, and Oregon—and engaged Federal, State, and local leaders in our discussions. The Administration on Aging convened a series of roundtables with caregivers in more than 30 cities across the country, involving hundreds of caregivers and service providers, policymakers, and community leaders. These individuals shared with us their joys in caring for their loved ones; their difficulty in accessing services; their unpreparedness for this new and often scary responsibility; their loneliness and isolation; and the compromises they had to make in order to juggle work, families, and finances.

As a result of this invaluable input, the National Family Caregiver Support Program is designed to be as flexible as possible to meet the diverse needs of family caregivers. We've encouraged States to develop multifaceted programs as required by the statute, based on their own service to the network, and to develop programs that are responsive to the needs of caregivers.

We offered and we continue to offer and will provide guidance and technical assistance to States and the national aging network to help them understand and utilize the National Family Caregiver Support Program's flexibility to design their own systems within the bounds of the statute to best meet the needs in their communities.

The statute requires the multifaceted system of support in the National Family Caregiver Support Program to consist of five broad categories of services:

The first category is information about health conditions, resources, and community-based long-term care services that might meet a family's needs.

The second is assistance in securing appropriate help.

The third is counseling and support groups to caregiver training to help families make decisions and solve problems.

The fourth is respite care so that families and other informal caregivers can be temporarily relieved from their caregiving responsibilities.

And the fifth category is supplemental services on a limited basis. This could include a wide range of services designed to support the efforts of caregivers. Some examples from State-funded caregiver programs include such supports as home modifications, providing incontinence supplies, nutrition supplements, and assisted devices. Again, all are designed to be responsive to the needs of caregivers.

The legislation targets family caregivers of older adults, and grandparents and relative caregivers of children not more than 18

years of age. It also directs that States give priority to services for older individuals who embrace social and economic need, with particular attention to low-income older individuals and older individuals providing care and support to persons with mental retardation, or who have developmental disabilities.

The $125 million we received in fiscal year 2001 will enable State, local, and tribal programs to provide services to approximately 250,000 of America's caregivers.

We distributed $113 million to States.

An additional $5 million is designated to assist caregivers of Native American elders and will be released shortly, in accordance with the guidance the Administration on Aging received from tribal listening sessions held recently.

In the next week or so, we will announce the availability of almost $6 million for competitive innovation grants and projects of national significance. These projects, once awarded, will demonstrate the test of new and diverse approaches to caregivers, providing us with knowledge that will be critical to the future success of the program.

The remaining $1 million is used for technical assistance to the aging network to provide State and local networks with the tools to be responsive to family caregivers. These includes, as Ken mentioned, a national technical assistance conference entitled From Enactment to Action to be convened in Washington, DC., on September 6 and 7 later this year. It also includes a moderated listserv on which expert researchers prepare monographs on specific issues related to caregiving, and enter into a dialog with the aging network on how to best implement that issue in our country. It includes an expanded Web page containing the most recent caregiver information and resources for our aging network, and other educational and public awareness conditions.

We have recently completed a series of regional video conferences with all the States to discuss and clarify issues related to implementation of the program. In addition, we presented promising approaches from various caregiver programs throughout the country that will be helpful as States design their own systems. Specifically related to this great State, in February, Secretary Thompson allotted $564,300 in caregiver funding to Idaho for the establishment of a multifaceted system of support in the State.

We applaud the efforts of the Idaho Commission on Aging for conducting informational meetings with the aging network within the State, and for establishing a very inclusive work group to plan the program's components. We understand, and as you have heard from Ken today, that proposals from the Area Agencies on Aging have been solicited, with the expectation that funds will be awarded throughout the State in July.

Ken has been a very active participant in the technical assistance sessions that AOA has provided, including the video conference convened by our Seattle regional office. By all accounts, the implementation of the program here in Idaho is well under way. We, at the Administration on Aging, stand ready to provide additional assistance and guidance as needed.

In fiscal year 2002, the President's budget request for the National Family Caregiver Support Program is $127 million, an in-

crease of $2 million over the fiscal year 2001 level. This is designed to help maintain the current level of services to caregivers as our program begins to take hold. Over the next year, the Administration on Aging is committed to develop partnerships with our sister Federal agencies and other national organizations to further the caregiving agenda; we are committed to implement a public awareness campaign to inform America of the importance of caregiving, and to encourage caregivers to seek assistance and training as they begin their caregiving careers; and we are committed to continuing to provide the aging network with assistance and support to better serve our caregivers.

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

I would be happy to address any questions you have, but first I want to clarify an issue that Ken raised with regard to AAAs having to fund all five of the service categories.

The CHAIRMAN. Edwin, I'd appreciate that, because I was going to start questioning with you and you've already been sensitive to what the first question might be.

Mr. WALKER. As I indicated in the prepared testimony, the statute requires the development of a multifaceted system of support. The statute also indicates at least five categories of services that should comprise a multifaceted system of support. In our guidance to States and in recognition of the fact that it is only $113 million that was allocated to States, we are not requiring States or area agencies to fund out of the caregiving money all five of the categories of services. What we are saying has to be in place is that those categories of services have to be provided.

An example: Information. We are well aware that information, and information and assistance, is provided already in the aging network by our area agencies. There may not be the need to put additional caregiver money into the provision of information, or information and assistance. That is the kind of flexibility that we believe the State should be free to deal with in this situation.

The CHAIRMAN. Thank you. In other words, I gather that you believe that within the total system, there's flexibility because of information that's available, and within the new program there's flexibility so that you can be more targeted as it relates to the use of the money?

Mr. WALKER. That is correct.

The CHAIRMAN. OK. Edwin, what specific steps is the AOA taking to assure that the maximum amount of new dollars are used for direct services to caregivers, rather than administration and staffing? And when you were breaking out the money outflow and the new programs that are to be implemented, and the Native American program in addition, and I was trying to add up the total in relation to 124, how does the rubber meet the road?

Mr. WALKER. Sure. The important thing for us all to remember is that the National Family Caregiver Support Program was included as a subpart of Title III in the Older Americans Act, which means that the regular rules related to the administration

of Title III apply unless there is a specific statutory provision in Title III–E., the National Family Caregiver Support Program, that would supersede the general provisions.

In saying that, the general provisions with regard to the amounts of Administration and the remaining amounts with regard to service dollars remains. States have an incredible amount of flexibility, but the bulk of the dollars and the requirement in the statute is for the development of a multifaceted system of support. That support is services. Certainly we understand, as I think Ken indicated, we are in this first year, we are just out of the starting blocks, we are learning as we go. We have encouraged States to do exactly what Idaho has done, the Idaho Commission has done: Sit down with the aging network, employ and thoughtfully plan, strategically plan, how the system of services for meeting the needs of caregivers in your State should look. Allocate your services in response to that plan.

The CHAIRMAN. Edwin, thank you.

Ken, 2 weeks ago, I'd mentioned in my opening statement to the Senate Special Committee on Aging hearings on this issue, and during those hearings we learned that some States are simply diverting funding from existing senior programs in order to meet the requirement of 25 percent State match of this program. How is Idaho coming up with their match now, and will this affect other senior programs?

Mr. WILKES. Senator, we have funding appropriated by our State legislature currently for some caregiver support services. You heard mention of the respite program we had. With that amount of funding and a small amount going into adult day care, as well as some of the case management services being provided currently to caregivers, we will have no problem meeting our match requirement and there will be no problem, no need whatsoever, to take money away from other programs to meet this requirement.

The CHAIRMAN. So existing programs that fall within these qualifying areas can be considered, especially if you blend the new program into it. That would be considered a match and that's acceptable to AOA.

Mr. WILKES. That's correct.

The CHAIRMAN. Yes. You mentioned constructive ways the Administration on Aging has been helpful as you set up your program, and I'm pleased to hear that Idaho is well advanced in the development of it, including video conferencing and their Web site. If you have specific questions on implementation of the Caregiver Support Program, do you have immediate access to find answers; and if not, how are you securing the additional information you need; and, third, I would say what more might AOA offer you that you currently are not being offered or that you found you might need?

Mr. WILKES. As I mentioned in my testimony, Senator, I've had regular contact with our regional office of AOA and they have been very responsive. They're probably getting very tired of hearing from me: I call about every other day it seems like, I've had a lot of questions, and for the most part, we've been provided answers in a pretty good, prompt, manner.

I raise this concern about the funding of all five categories, because that's something that we just heard in the past week and that concerned us that once we had already sent out our guidance to Area Agencies and we're expecting applications tomorrow, to have to turn around and give them some additional instructions was disconcerting. It would have been difficult to meet our July 1 time line. So it's very helpful that Edwin clarified this issue for us, and maybe we can proceed in meeting our guidelines.

I feel that sometimes when we contact our regional office, well, more often than not, with a question, that we are not able to get an official answer because we have to put it in writing so they can forward it on to the central office, and so sometimes the bureaucracy seems to slow things down; and if the central office can maybe do something to give the regional offices a little bit more flexibility or authority in responding to questions, that might be helpful for States. That would be probably one thing I would say about the response you get.

The CHAIRMAN. In other words, the turnaround time on information. I can appreciate that you not sign off on something what might be considered official, but at least maybe the ability to get advisory opinions while moving toward an official opinion that gives you some direction might be helpful?

Mr. WILKES. Correct.

The CHAIRMAN. Russ, let me now turn to you if I could, please.

Of the various eligible services identified in the Caregiver Program, which do you believe are the most important and why, based on your experiences?

Mr. SPAIN. Senator Craig and Congressman Simpson, I think, based on experience, I really do think that the respite, providing some sort of respite, and using a large majority of the allocated dollars per Area Agency on Aging to supplement what we already have in respite contracts or respite service in our particular areas is one of the best uses of the money. Excuse me.

One of the things that we heard we did, as you will hear tomorrow in our particular area, we have had a caregiver support group in Area Six for a number of years, and we went to that group first and asked them what would be the best use of the money in our area, and respite came out No. 1; but not only respite, but when to provide that respite care: Weekdays, after hours weekdays, or on weekends. And the variety of responses we got we used to craft the plan that we provided to the Idaho Commission on Aging. So respite is No. 1.

I think support for the caregiver support or for the caregiver support groups and being able to establish grandparents as parents support group is really important. We're finding more grandparents raising their grandkids in our area than we ever knew existed before, and establishing some sort of support group for them is going to be important. And I think, from what I know of the plans from the Area Agencies that went to the Idaho commission, one of the things that they're going to do as part of that grandparent as parent allotment is to use some to supplement our legal aid contracts, because legal advice is one of the things that these grandparents need more than anything else. They can't sign the kids up for

school, they can't do other things that these kids need, without some sort of legal control over the matters of these children.

The CHAIRMAN. Russ, help me out there. I guess I did not recognize that grandparents as parents fell within this category. I appreciate the definition of caregiving there broadly spread, but that's looking at it in different perspective than I had thought was the charge here.

We're clear with that, we're within the realm of this new program?

I see Edwin moving his head "yes".

Mr. SPAIN. Yes, we are, sir. We can use up to, within the State, and that's true of each State, up to 10 percent.

The CHAIRMAN. OK.

Mr. SPAIN. Of the State allotment for support of grandparents as caregivers of grandchildren.

The CHAIRMAN. Well, you're right: I think that's much larger than most realize, and I bump into them quite often. And I bump into very distressed grandparents sometimes, find that they've taken on a phenomenal burden, yet their love causes them to do that and they do need assistance in that area, and that's pleasing to hear.

Russ, do you think that the Administration on Aging is providing adequate guidance into the States as the programs are implemented, based on your experience?

Mr. SPAIN. Based on my experience, Senator, yes, I do. And I appreciate as an Area Agency director and speaking for the other directors the flexibility that has been allowed to us within this program.

One instance, as an example, a listserve that was mentioned. I'm a participant in that listserve, and the information provided to us about what other Area Agencies in other States are doing or have implemented, had in progress for years, has been very valuable to us.

The CHAIRMAN. Thank you very much, Russ.

Linda, let me turn to you, and, again, let me thank you for being here and bringing your perspective as a caregiver and an adviser in this program to the committee.

If you were designing a program to provide support for people yourself, what type of assistance would be most helpful in it? And by that kind of question—and I am suggesting to you—do you find out that what we're proposing and what's being implemented is adequate, or based on your experience would you wish to modify it?

Ms. CARPENTER. It sounds really good to me. It's just something that we've needed for so long.

And I think the training for caregivers would be invaluable; we've had nothing like that. And we have used things from the Alzheimer's Association; that has been a big help. We've not had training and we've not had the adequate funding at all for the respite care. And as I said, the volunteers, if they could get funding, would help so much for them. And transportation costs, they do allow for that, but it's very difficult to find a lot of people that want to just volunteer for this task because sometimes it is very difficult, and I think this is going to help so much in the respite care program

in the counties. And I think that it just sounds like it's going to be covered very well.

We do have a caregiver support group in Washington County also and it's been very helpful. One of the ladies down at the care center in Weiser, her husband had gone through a lot of that, and she started just a general care support group. We had already had Parkinson's and Alzheimer's, but we just continued them. And just any help with that.

Training. And people just come and just like to talk, but the training and the funding for that would help and improve it so much, and they have a group that come to that and it's helped them so much. They just don't have anywhere to turn.

And counseling and things like that just really be a big boost. I think it sounds wonderful.

The CHAIRMAN. You mentioned in your testimony "counseling," and you've talked about the support group. If you could, for a moment, expand on the counseling, what you feel needs to be there? I sense other testimony that I've heard before the Committee that that really is key in helping mental conditions, if you will, these caregivers for what they are experiencing or may experience.

Ms. CARPENTER. Exactly. Talking about within the support group, the counseling that's received?

The CHAIRMAN. Yes.

Ms. CARPENTER. It's so valuable, and, you know, just to get trained people in there to counsel them would really help. We have a lot of volunteers that come and talk to support groups and people who work with——

The CHAIRMAN. You're telling me that you really believe there's a need for additional trained counsel members, if you will.

Ms. CARPENTER. Definitely. Definitely. And the funding for that would be valuable. And just even the families could sit down one-on-one and talk with them and they could go visit with them at their homes or whatever would be very helpful, because you just don't know what to do. Every situation is different and that's why the support group is so valuable, because you feel like you're all alone sometimes, I know that the people do, just from helping them; and that no one else is going through what you're going through, but they find out that they are sharing common problems. And it's so helpful just to sit down and be able to talk to it.

The CHAIRMAN. Before I turn to Congressman Simpson, let me turn to all of you and put you on notice so you can be thinking: Once the Congressman has finished his questions, I would welcome any of you to come forward with questions you might have of the panel, or of myself, or the Congressman. There's a mike at the podium in front of the stage. So you might be thinking of any questions you might have, additional to those that we've asked of the panel, or questions you would like to ask of the two of us.

With that, let me turn to Congressman Simpson.

Mr. SIMPSON. Thank you, Senator, and I thank all of you for your testimony today. It was very enlightening to us, and helpful as we try to make this program work.

First, I'd like to—it seems like we've been in the same place before, taking care of our parents, and I can tell you how important respite care is, whether it is from another family member or from

someone who is trained to do that or whatever, because sometimes people don't realize how stressing it can be on an individual just to answer the same series of questions six times in an hour asked by your mother-in-law or your mother. And I know that when my wife and I both worked, it was very difficult with her mother at home, and it got to the point where we were concerned for her safety, because of something she might do to herself as the condition deteriorated, and ultimately, came to the conclusion that it would be best if we could put her in a nursing home, living center, you know. And so we did that, and within a week she had died, which was not because of the care that was given there or anything. But it was very stressful on her also.

And so being able to take care of her at home and having someone that could come and relieve them for a while so that you can go away for a weekend or for an evening or for an hour or something like that is vital.

And this type of service is incredibly important, and not only is it the right thing to do, it is, I think, cost effective. When you look at in the long run the amount of money that we will save as a society by being able to keep people that we are able to keep and want to keep and want to stay in their own home rather than put them in more expensive nursing homes, skilled nursing homes, and other facilities, then better we are off as a society.

And one of the tragedies I think of our age is that we have a tendency or have had a tendency to forget about our senior citizens. It used to be that parents took care of their children until they grow up, and then children took care of their parents until they passed away, and maybe it's just part of today's society that doesn't seem to be the tradition that exists anymore, or at least not enough of it.

But I do appreciate your testimony.

What kind of training would you envision that a respite care individual would need? As an example, we have relatives, we're fortunate enough, that lived around us so that if we needed to go somewhere where we couldn't stay at the house to take care of Margaret and those types of things. What type of training would be involved when you talk about training for respite care workers?

Ms. CARPENTER. Well, we trained—like I said, we used material, a lot of material, from the Alzheimer's support group and we had videos on just basic health care, and that's very important. I happen to have my CNA, which I got just so it would help me in the respite care program, but if they had little basic health care or they're CNAs, certified nursing, that would help so much, because you never know when an emergency is going to come up and you need to know how to handle it. Something like that would be very helpful. Even having a nurse come and talk to them about the basic care would be very helpful; that would be very, very helpful.

Mr. SIMPSON. Is there any type of training that you would envision as an individual, say, as a family looking at the options of being able to take care of one of their elders in their home or whether other types of services would be necessary or whether they needed to go into some type of assisted living center or some predecision type counseling?

Ms. CARPENTER. Yes, that would also be helpful. A lot of the nursing homes do, I think, provide helpful counseling and things like that for people. I really think it would be, because there are so many decisions to make, as you all know, on finances, on medications, on Medicare, and things like that. There's just so many decisions to make, and now with this new program, they will also need to know, what is available. So things like that would be, yes, invaluable and there needs to be something set up for that, I believe.

Mr. SIMPSON. Well, thank you for both your testimony and what you do.

Russ, you mentioned in your testimony categories one, two, three, four, and five, and then percentages: 11 percent for public information and outreach and so forth, and 11 percent for education management. Is that statutory, is that rule and regulation, and is that the maximum amount that can be spent in each of those categories?

Mr. SPAIN. Congressman Simpson, Senator Craig, no, there's no statutory provision of what, in each category, needs to be spent. This is purely based upon in this particular case what the director in Area Three—this area here—and his staff and those that he consulted, that is what they feel is the need in this area.

The only statutory requirement that I am aware of is that concerning grandparents as parents of grandchildren, that in the aggregate, up to 10 percent in the State can be spent for that portion. That's the only restriction we're under.

Mr. SIMPSON. So if you got an aggregate program of information, outreach, you've got an aggregate program through other means—say a case management and stuff—you don't have to spend as much there. You can spend more in respite care, actual respite care, and other types of things; that flexibility exists?

Mr. SPAIN. That is correct, sir.

Mr. SIMPSON. OK. I'm glad to hear that.

So these percentages that you gave us are what is in this Region Three projected. Is that typical from what other programs around the country are submitting in their programs or does it vary from area to area, do you know?

Mr. SPAIN. I honestly don't know, Congressman, but from what little I know from what the other area directors within the State is going to propose to the Idaho commission tomorrow, this would be very close to what we were all doing.

Mr. SIMPSON. OK. I appreciate that.

Edwin, one: You mentioned that this program you anticipate, I believe I heard you correctly, assisting 250,000 caregivers. Is that——

Mr. WALKER. That's correct.

Mr. SIMPSON. With this, that's obviously tip of the iceberg, I guess. I would think so. Is there any idea, any estimates, on how many home caregivers there are, family members, other types of things, other types of individuals that are giving home health care?

Mr. WALKER. The estimate that we have is that there are approximately seven million individuals trying to care for elderly or functionally disabled adults, and that is from the National Long-

Term Care Survey, which is updated periodically. That is the most recent data we have.

Mr. SIMPSON. So we're looking at maybe one twenty-eighth of the total, or 28 times as many. Is that right? Something like that?

Mr. WALKER. Something like that.

Mr. SIMPSON. Four times as many would be a million.

And what's the total cost of this initial program here that we're looking at?

Mr. SPAIN. The total program was appropriated at $125 million. That includes both the funding that went to the States, as well as the funding we're about to release that's going to establish a similar program for Native Americans throughout this country.

Mr. SIMPSON. OK. So we could anticipate if it's successful and if this program actually works—obviously not everyone would apply for it or receive assistance from it—but you could anticipate once this is implemented, some fairly substantial increases in budget over the next several years. I know that's a hard thing for a Congressman to ask someone, but we could anticipate some increases in budget. Is that——

Mr. WALKER. There certainly is a lot of need out there. We are looking at establishing a program right now, one that is going to be administered by the aging network. As I indicated, this is a new era for the aging network in focusing on the needs of caregivers versus the care recipient, and so we think it is important to establish a very firm foundation upon which we can build additional populations that are people who receive care that's not covered by the statute or other aspects in terms of growing the program. So we look forward to the future, but want to establish things well first to get a good start.

Mr. SIMPSON. Right, and I appreciate that.

You did mention that attention was to be focused on those most in need: Lower incomes, so forth. Are there any eligibility requirements or, as an example, I didn't need the assistance and I say that I was fortunate. I didn't need the assistance to be able to do this. Had the government given me assistance to do it, certainly, like most people, I probably would have taken it, but I didn't need it. So are there requirements, eligibility requirements?

Mr. WALKER. I stumble with the word "eligibility." There are priorities established in the statute for the caregiver program, just as there are priorities established for the rest of the Older Americans Act program. We generally refer to it as "targeting." States and area agencies ought to target their resources to those most in need. And that is how they make their decisions. It is a prioritization process to determine who should receive our funding, and we find that the aging network are very good stewards in that regard.

Mr. SIMPSON. As long as you have limited resources, the targeting will be down to where it's necessary.

I do appreciate all of your testimony. This is an important program, one that I hope we can work together to ensure it is successful, because I think with the grain of America, this is going to be even more important in future years as when we're seniors and retire. As I get closer to that age, I start to become more and more interested in it daily. So, thank you all.

The CHAIRMAN. I thought it was a service of Congress. [Laughter.]

Well, I have a marvelously efficient staff, and I understand that they handed out cards in which you were to write your questions, which would help facilitate it, and then we would respond to those questions. So if you want to pass those cards in for those of you who have written on those cards, we'd appreciate it, and we would be happy to respond to those questions.

Edwin, you appropriately talked about eligibility criteria as "targeting," and I appreciate that term. One of the things that became evident, and I think you mentioned that you had some capability of finding assisted care for your mother, and many do certainly, not all need the financial assistance and that's why we've targeted at the less fortunate. Are there any sliding scales that you've used for adjustment or for evaluation purposes as to targeting?

Mr. WALKER. Well, in terms of the overall Older Americans Act and the most recent reauthorization that you assisted us with last year, has always been based on individuals voluntarily providing a contribution in order to further expand the services. And that really is the beauty or one of the beauties of the Older Americans Act. Seniors embrace this program. There is a real sense of ownership, because they know that their participatory contributions go to further expand the program.

In the most recent reauthorization an additional component was added, which is to give States the option of implementing a cost-sharing methodology. That cost-sharing methodology must be based on a sliding fee scale, based on an individual's income, not their assets or any property, and that is based on a self-declaration of the older person.

The Congress also was very clear that there are only certain services where a contribution in terms of a cost-sharing contribution could be implemented, and therefore, they excluded services such as gatekeeper services, information, assistance, case management, services that assist people just getting to a maintenance type of service. But certainly we would anticipate, because we know that, for instance, adult day care as a form of respite care is a very expensive service, and so States would have the option of implementing with the consultation of their area agencies a cost-sharing methodology to share in the cost of providing adult day care.

The CHAIRMAN. Jeff, are you ready?

Jeff Schrade of my staff is going to read the questions. The reason is not your handwriting, folks. I know that it's all tremendously legible and easy to read. It's just that I'm blind. That's the excuse we're offering up.

While you're preparing there, Jeff, let me introduce the gentleman who rode over with Claudia Turner on my staff and that's Art Bell, who's a commissioner for the Idaho Commission on Aging.

Art, nice to see you, and thank you for being with us. [Applause.]

All right, sir, if you would, please.

Mr. SCHRADE. All right. Under current Medicare rules, J. R. Simplot pays the same as an elderly widow on minimum Social Security. This results in doctors opting out, HMOs dropping out, and those doctors who still accept senior patients being overworked and

underpaid. Why doesn't Medicare have graduated rates so that better care is available to all?

And they have a few more comments in the back: We have a friend, retired nurse, who has enjoyed helping as a respite volunteer, but I'm being told that rules prohibit any patient help such as bathing and other nursing activities. She quit. Being limited to housework or doing merely dishes by dumb rules when a person is fully qualified and experienced is an unexcusable waste. Can you help change this rule?

The CHAIRMAN. We want to respond to that question, but part of it really does not have anything to do with the caregiver provision. What I might do, because we do want to accept your questions and respond to them, or have the panel respond to them, but at the same token, the hearing record specific to this, let me do this: Let me close out the hearing so that the hearing record will be complete, and I'll do that by the adjourning of the Committee, and then we will proceed to respond to your questions.

So, with that, I will close the Senate Special Committee on Aging hearing on Caregiving, and I will call that closed.

[Whereupon, at 4:30 p.m., the committee was adjourned.]

FORUM ON NATIONAL FAMILY CAREGIVER PROGRAM

FRIDAY, JUNE 1, 2001

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Idaho Falls, ID

The committee met, pursuant to notice, at 10 a.m., in the Idaho Falls City Council Chambers, Idaho Falls, ID, Lupe Wissel, staff director, presiding.

Ms. WISSEL. Good morning. This forum was scheduled to start at 10 o'clock and I believe it is 10 o'clock. My name is Lupe Wissel and I'm here on behalf of Senator Craig. Senator Craig would have been here today, but he's had quite a busy, busy week and he sends his regards to you.

First of all, on his behalf, thank you for attending the Senate Special Committee on Aging hearing on the National Family Caregiver Program. Before I start, I would like to introduce the people here in front. To my right we have Lisa Kidder, and she's worked for Senator Craig for a number of years, doing health issues; and now she's working for the Senate Special Aging Committee on Aging and still dealing with health issues. To my close right is Janine Scott and Janine is an attorney handling pension issues Social Security, Medicare, and prescription drugs. To my left we have Robert Lundblade, and he is a caregiver that will be testifying this morning. Next to him is Russ Spain, director of the Area Agency on Aging here in Idaho Falls, Area Six. And to the far left is Ken Wilkes, and he is the Program Operations Manager for the Idaho Commission on Aging. And thank you, all of you, for being here this morning.

Last year Congress passed legislation reauthorizing the Older Americans Act. Senator Craig was an original co-sponsor of that legislation which updated and amended the Older Americans Act and he was extremely gratified when it became law.

As part of this reauthorization, Congress added a very important component, which was the Family Caregiver component, which authorized $125 million for family caregivers to assist those many daughters, sons, husbands and wives who are struggling with the daily task of caring for the older family caregiver—for the family member. When considering the reauthorization, Congress heard overwhelmingly from caregivers themselves about the need for this service and that's why they all concurred and they all supported. It was a very bipartisan issue and one that was supported across the board.

However, the things that Congress heard from the caregivers were three very important services, which are the need for respite care, which provide the caregivers with that relief to be able to take that very needed time off, time for themselves so that they can continue doing the work that they do on a daily basis.

Second, they talked about education, the need to get the information on how to provide for those needs, the care giving needs. Information such as what to do in case of emergencies, how to assist with the daily needs and even sometimes what kind of diapers to buy, when those are services that the senior needs. That was one area that was overwhelmingly voiced.

Third was the support and counseling, just a need to be able to talk to someone, to be able to get that counseling because of all the stress caregivers experience on a day to day basis.

The State's just received the funding and they're in the process of planning as to how the money is going to be spent. They are in the process of sending the money to the local communities and so that's why Senator Craig is very interested in making sure that the money does what Congress intended for the money to do. That's the purpose for holding this hearing or this forum and traveling throughout the State of Idaho to discuss what the States are doing. Are they getting the information that they need from the Administration on Aging and just making sure that the most money possible goes to the caregivers themselves.

With that I would like to go start the forum. We will start with the caregiver. Then we'll go to the area agency to talk to us about where they are in this process, then we will conclude with the State Program Operations Manager. We will then allow for any of you who have questions, to ask any of the panelists up here, to ask those questions.

We have a microphone right up front. All of the information will be recorded today and will go back to Washington and become part of the record with the Senate Aging Committee. So with that, we will start with Robert Lundblade a caregiver that will share his story. This is what the program is all about, Robert. So thank you Robert, for being here this morning.

STATEMENT OF ROBERT LUNDBLADE, CAREGIVER

Mr. LUNDBLADE. I was called upon to come and testify for caregivers. It's an important thing and I don't know if I'm really a qualified man to do that but caregiving is very, very—particularly in the home—is a very important part of our life. Now to be a caregiver, how did you get this name? I'm going to go back a few years; what happens.

You have a wonderful life and then all of a sudden, you find out that you're 75-years-old and you've been down to St. George, you've been playing golf and looking at the beautiful scenery. You have your wife with you. The world is fun all the way around you. And so you notice that your wife starts to have a little trouble with walking and things like that.

You go to see a doctor. Well, after surviving with her and myself, I got two artificial hips and she's got an artificial knee and osteoporosis, we decided to go see the doctor and take care of the—she had one knee put in, to have the other knee put in. And we

were sitting on the chair there and the doctor looked at her, the x-ray's right in front of her. And he said one half of her knee is gone. You could see it on the x-ray. So he says Marion, he says, I'm not going to operate on that knee. Just like that. I'm going to send you to another doctor.

Just like a glass plate slipped down in front of you. Then, when it all begins. I had a lot of confidence in the other doctor because he helped my brother-in-law. He had been very, very sick and he took him in and I stayed with him that night and I didn't think he'd make it through the night. The doctor come in, pair of cowboy boots on. I looked at him, looked at his chart and said what are they giving him that for? That's not what's wrong with him. I was busy with him, my sister was distraught out in the waiting room. He give him the medicine and the next morning, my brother-in-law woke up and said, what's all the fuss. But I had confidence, what I'm trying make my point, in this doctor.

Well, he sent me over to her and he examined her and looked all over and he says well, I think maybe you, with the osteoporosis and that and the operations you've had, you seem to be getting a little on the confused side. He said, I want to send you back home with B12.

And so he gave me a bottle of B12 vitamins to send home and he gave me some needles and he says give—once a month, give your wife a shot of this and this will help her. And it did. I tried to give my wife the B12 shot and she'd seen me vaccinate too many cattle and she said no, so that got to be a problem.

I tried to get a doctor or somebody, had to make an appointment and go wait to get a B12 shot. I asked some people that worked for the government if they were friends and they obliged me, I feel. They never said so but I believe, unless they were told they could give shots, not to do it on account of I assume insurance and responsibility.

Then that wasn't bad enough. We get that taken care of, then the doctor we were going to, they refused to take Medicare and they just like the other doctor would throw you out. I had no place to go because it was Medicare and we had put our faith in family doctors. And so with my wife, she'd had a lot of her female problems and we moved and I went to another doctor and he took her in and took care of her and helped her with her problems.

And then you get the B12 shot. I had to walk a long distance into the doctor's office to get it and pay him $10 to get a shot. And then the new doctor I went to, we could drive right up to the door and get the shots. And she has to have them. I could tell when she's out of it. She has to have it about every 3 weeks.

But that's where it all started from. And that's the reason I relate to that. And from that point on, as we come on down the path of life, you have to change your plans. You were having lots of fun and everything and all of a sudden—you have to excuse me a minute. So you learn in a hurry when you get in that kind of a situation, that as long as you're caregiving, you have to be a master chef, you've got to put meals on. You have to keep everything clean and make sure it don't get an infection. You have to—the world just comes down hard on you. And so with that in mind, your life

completely changes with what you've been doing and so you just make the best you can.

Well then the question was related to me then, the impact on your life. I've explained some of it. For a man to take over the house and most women don't care about you running the house anyhow, but you have to do it. And so you just busy yourself with your time, maintaining and keeping up and seeing that your wife is comfortable and try to find something that will make her better. And so this is one of the hardest things I've had to do is planning the meals and see that she gets a balanced diet.

I've always had to take care of myself. My father told me years ago, he said you learn how to cook because you may never have a woman along with you to take care of you. So we learned to take care of ourselves. But it's just a different way. And as it progressed along that path, we done pretty good. We changed the way of going to town. I got a van that has both a heater in it and an air conditioner in it now. A separate air conditioner, because I have to keep my wife with me 24 hours a day. So you change your whole status of life. You start just to fall apart and everything just concentrated on what's going on in life.

You have to—and you find out that though—when you take care of them, you have to simplify the toilets; you have to simplify the beds; you have to get everything as handy as you can. And also carry communication with you, particularly with myself, I carry my phone with me when I go out alone. With the hips, I can trip and go down. If there's a fence close by, if I'm all right, I'll crawl over to the fence and get up. But I can't get up.

Unfortunately, when you put the hips in you get—you get a spot that's kind of dead, a spot like the old steam engine. If you started it up with the piston on the wrong side you go faster backwards than you do forwards. But anyhow, if I go down I either crawl to a fence to get up, but that's because I know I have to go back to the house, because she can't help me. It does run into a 24 hour a day surveillance.

Other than that, your life changes. I'm not crying about it or anything because you do it because you want her to be comfortable. I put these in here because you can see, I get a little bit upset.

Now the next question that was brought into play was why did you want to keep her home and not take her to a nursing home. Unfortunately, I'm trying with my wife, if she's got any chance of getting better because I haven't had a doctor yet tell me exactly what's wrong with her but she's under treatment for deep depression at this time. And her Paxil, I gave it to her. I wasn't ready for the Paxil. I had another woman to contend with when she went on Paxil, but it was a lot better. She never had such long peaks and lows. More or less leveled out. Made my life much easier to work with her. And that, I see, improvement and we're going to go in June 20, and check on her with a neurologist to see what's going on.

But keeping her home, you keep her, in her particular case, in familiar surroundings. That helps a lot. I make sure she has fresh flowers in the house.

We talked to nursing homes. I've been around nursing homes, unfortunately, and I had my father in there and he was 90 years

old. And he got so he couldn't take care of himself. They're wonderful. They're wonderful and everything like that but unfortunately—I've been a clown for the shrine for years and we have put on clown suits and we've gone into nursing homes. We've gone into rest homes. We've worked with the retarded, the special kids. I'm sorry, I shouldn't have said retarded. The special kids down through the years and the crippled kids in the shrine hospital. I do this to bring some happiness to those people there.

But I find when you do something like that for them, you can make people on the happier side of everything. It gives them some ease when you give people a badge and a little sticker to put on them. And believe me, don't try to take it away from some of the older people. But I do—just the care giving, I've done that just to make people happy on things. It's a real lesson learning in that, to give and try to help people. But that's what we're here for is to make this a happier world and more pleasant and keep people comfortable.

But it's just one of those relations. And being a caregiver, that's what it comes from. You do it all the time. You can't even take care of your being a farmer and being a caregiver. You have to take care and feed stock, so you come by it naturally. And that takes it then to the training.

I've more or less had to train myself to do a lot of things and I've taken physical therapy and been that way. Thank goodness we have physical therapy. It's the best way to go. It's to keep moving, to keep exercising. I have a lot of respect for them. But you learn a lot, for the training part. That was in the question here. You learn to care, you learn to feed. And being a stockman, a cattleman, you learn to observe. And when you learn to observe—because the cattle, they can't tell you what's the matter with them. You have to see it. And you have to see it that they got a balanced diet. And so it's just being a good herdsman and that is the training that I've got down through the years to care for my family and caring for my land and care for the farms.

Now there's the question that comes up about the government programs and financial, social things. I really can't relate to much of the government programs as far as a lot of them. It's real complicated. But I do know this much, that if we didn't have some of these organizations, it would be real chaos at the older level. Because we're getting more older people all the time.

With this—I have been, with the homemakers here, the respite thing. I've gone into several of the meetings. It's a real awakening when you go into one of those meetings. The people, caregivers, what they do and what it is, the emotions that come to it. And you get to the point and listen and sit through there, what they're saying you can relate to but you can express yourself, you can let off some steam.

The unfortunate thing will come when you start being a caregiver in the home, is you lose your friends. They like you but they don't want to listen to you. You need somebody that you can talk to. And this respite deal is you can relate to people.

I have a lady that's been helping me with my accounting. Her husband's very sick; she has to feed him and everything's by tubes. Now, I'm not a nurse, I don't have to be a nurse, or anything, be-

cause the wife can pretty well take care of that. But this gal has—if she leaves somewhere, she has to have a nurse to stay with him. And I asked her why don't you put him in a rest home or something. She said well, it's $4 thousand and she says, I can't afford it. And she does a beautiful job of it. Her load is heavy but she told me, she says I had friends everywhere and I lose my friends. And this is where the lonely part comes.

Another question was asked here, what programs do you seek for treatment and things like that. Well, I mentioned we have the respite, but I did take and get into the physical therapy. And then another thing is you can't raise a family without getting some knowledge how to keep going. And then too, you get into programs. You have your churches and in my case, the lodge. And in my case, I can let off steam if I can get loose to put on my clown suit and put a smile on somebody's face.

When I was having my hips put in, I got a course in ventriloquism, just to pass the time. And it's fascinating. It's real fascinating and I wished I had time. I wished I was better at it. But you put the clown and the ventriloquist, you can put a lot of smiles and a lot of happiness in this world.

The other thing is that caregiving is a gift. And let's help the ones that can be treated at home with friends. Caregivers need your support. We will get more for our money and a lot less tape if you keep your loved ones where it's at home and put them in a peaceful surrounding.

I've noticed when I've gone into the rest homes and people like that, they're under locked doors. They keep them back; and I'm not about to do that, yet. And that's all I have to say. It's a rugged life and I'm glad I've got the homemakers to help me get out of tiring situations. That's all I have to say. I'm sorry.

Ms. WISSEL. Robert, thank you so much for sharing your story with us. And you mentioned earlier, the story you just said, it's what Congress also heard from around the country in regards to the needs. The need for the respite; the need for the counseling; the need for the support; the education; the training. But thank you so much for sharing that.

Mr. LUNDBLADE. Well, I hope I've helped somebody.

Ms. WISSEL. You have. Our next witness is Russ Spain, and Russ is the Area Agency Director in Area Six, and he will talk about where he is in the process of developing the respite program or the Family Caregiver program in his area. Russ?

STATEMENT OF RUSS SPAIN, DIRECTOR, AREA AGENCY ON AGING, AREA SIX, IDAHO FALLS, ID

Mr. SPAIN. Thank you. And thanks for the opportunity to testify this morning on the National Family Caregiver Support Program. As you're well aware; and as was mentioned yesterday at the hearing in Caldwell, the plan that I'm going to outline today is sitting at ICOA this morning, waiting for their approval. Let me begin by giving just a bit of demographic information.

The Area Six Agency on Aging covers the nine counties of eastern Idaho. Those nine counties comprise 20,000 square miles and have about 21,000 residents who are 60 years of age or older. So this area is definitely rural in nature. And as you are well aware,

just to provide service to a senior in Lemhi County, it's a 3-hour drive each way from our offices in Idaho Falls.

My remarks will focus on how we at the Area Six Agency on Aging plan to implement our portion of the Family Caregiver Support Program. Our program allotment of the funds amounted to $52,911. We have determined, and nationally that seems to be the case, that education is one of the needs of caregivers. To that end, 26.7 percent of the award will be used for information and assistance. That will allow the I&A director to be more involved in the community, providing the needed education components.

In addition, the Area Six Agency on Aging has had a caregiver support group in place for a number of years. And actually, Robert is part of that group and he referred to it and I have to add that I understand I was not there at the time but I understand he did put on his clown suit for one of the caregiver support group meetings, and it was one of the best meetings that they have had in a long time. He did bring some laughter to that group.

The National Family Caregiver Support dollars will allow us to do a bit of promotion of the fact that the group exists and to attract speakers and training on topics that will be of real use to this group of caregivers. We haven't had that in the past. So we've therefore designated 7.6 percent of the funds to support that group.

One of the opportunities that we took when we first learned that the National Family Caregiver Support Program was funded was to prepare a survey that we could give to our caregiver support group to obtain their input into the needs of the area. The overwhelming response was that there was a need for respite. Therefore, we're allocating 55.7 percent of our funds for respite to be added to the contract of our respite Provider Homemaker Services of Idaho. We are also requiring of them that at least 10 percent of those additional funds be used for after hours respite, weekend respite and emergency respite.

Our I&A program has been receiving calls for a number of years concerning grandparents as caregivers of young children and what services are available. The University of Idaho extension offices in the area have also been studying this phenomenon. We have opted to spend the full 10 percent allowed in the National Family Caregiver Support Program to establish a grandparents as caregivers of young children support group. The funds would be used to locate those individuals and solicit their participation in such a group.

In addition, we will use a portion of the 10 percent to add to our legal assistance contract with Idaho legal aid to give legal assistance specifically to grandparents as caregivers of young children. Legal concerns as they relate to caring for young children by a grandparent is the major issue we hear about from that group.

You should know that according to Child Protective Services, where young children have gone through the court system in some way, to end up with grandparents as caregivers. There are only 75 grandparents as caregivers in the nine counties of eastern Idaho. And only five of those grandparents are over age 60. We know there are more than that who are caring for young children but are lucky enough, if you want to say that, to not have had to go through the court system and are over 60 years of age. We will be turning to school districts to help us find those grandparents who

may need our help through the National Caregiver Support Program.

In closing, I would just like to applaud the Administration on Aging plan to allow States the maximum leeway in implementing the program in their States to do what will best serve their constituents. This is not a one size fits all situation. What works in an urban sitting may not work as well in rural areas and vice versa. If the AOA and State units on aging, like the Idaho Commission on Aging, allow our agency to implement what will work in Idaho Falls, in Salmon, and Rexburg, and Challis, while at the same time allowing Area Three to do what will work in Boise, and Nampa, and Caldwell, our citizens are the better for it.

Thank you for this again, for this opportunity to testify before you and let you know what we in eastern Idaho are doing with the very valuable program that you and your colleagues had the foresight to add to the Older Americans Act. Please continue it and the other Older Americans Act programs and adequately fund them so that we can serve those baby boomers who are going to be seeking services in the not too distant future, including myself, I might add. Thank you.

Ms. WISSEL. Russ, thank you. Now we have Ken Wilkes from the Idaho Commission on Aging. Ken.

STATEMENT OF KEN WILKES, IDAHO COMMISSION ON AGING

Mr. WILKES. Thank you, Lupe for the opportunity to testify this morning on this important new program. My remarks will focus on the implementation on the program here in Idaho, including the service package and time lines for beginning the delivery of these much needed services. I will also comment briefly on the assistance and guidance we've received from the Administration on Aging in implementing the program.

We received notification of Idaho's allotment of $564,300 and the first written guidance from the Administration on Aging on January 7 of this year, and our notification of grant award a little over a month later on February 20. Soon after receiving the information from AOA, the commission staff began discussions about how we would implement the program and we prepared a Power Point presentation for our upcoming commission meeting and meeting with our area agency directors, which was held February 14 and 15.

At the commission's business meeting February 15, we presented a plan for the design and implementation of the program and requested the support of our commission. Our plan called for the formation of a small work group that included three family caregivers, a member of our commission, one of our area agency directors and a representative from the Hispanic and Native American community.

Our work group met twice, once on February 28, and again on March 14. Our first meeting covered the following: We reviewed the 2000 Older Americans Act amendments pertaining to the Family Caregiver Program and also reviewed the guidance we'd received from the Administration on Aging. We included in that meeting a telephone conversation with the Region 10 Administration on Aging administrator and his staff in Seattle, to discuss

questions regarding the program and the questions were made official in a letter dated March 7 to the Administration on Aging. We listened to a presentation on grandparents raising grandchildren and also listened to some of the experiences of the three caregivers that were included in our work group.

Our second work group meeting focused on a review of concerns and issues raised by our area agencies on aging. We discussed some cultural caregiver issues presented by our Native American and Hispanic representatives and then we had a discussion of the most needed services identified by our three caregivers. And finally, we reviewed a draft application form that our staff had prepared for area agencies to submit to us in order to receive these funds.

The draft area agency application form was sent to the area agency directors and discussed with them on a telephone conference call on April 4, before it was finalized and mailed to them in mid-April. These applications are due today. I'm glad to hear Russ has submitted his. Until we receive the applications, we won't know exactly what service packages the area agencies are proposing. However, preliminary information indicates the area agencies will be proposing to use the funds primarily for information and assistance, case management, and respite.

The three caregivers in our work group identified respite, including adult day care, caregiver education and training and support groups as the services that would most benefit them directly. We plan to award funds to the area agencies by July 1, and shortly thereafter, services will begin.

So as you can see, Idaho has moved quickly to design and implement a program that we feel will be a model for other States. We've received telephone calls from a few other States asking how Idaho was planning to implement the program and it appears that we're well ahead of the implementation curve.

I'd like to close by saying that our regional administration agency on aging staff has been very responsive to questions we have raised, both in writing and by telephone. Our acting director attended a meeting in Seattle on the April 25, that included a video conference with Administration on Aging central office staff in Washington, DC., and in that conference, it addressed reporting requirements for the program and provided information on existing Family Caregiver programs, programs that were in existence prior to the Older Americans Act Family Caregiver Program.

At the Seattle meeting, AOA staff said they wanted to allow States maximum flexibility in implementing the program. In addition, they have provided a list of frequently asked questions and have provided answers to those questions. The AOA website has also been helpful and an AOA sponsored conference on the program is scheduled for September 6 and 7 in Washington, DC.

On behalf of the Idaho Commission on Aging, I'd like to thank Senator Craig for bringing the Senate Special Committee on Aging to Idaho and for the opportunity to testify here today. I think it's important that the committee come to see how it's going to be implemented in a rural State. As my testimony indicates, we are well on our way to providing solid support for Idaho's growing number of family caregivers.

Our goal of the Idaho Commission on Aging and its six Area Agencies on Aging is to provide the most needed supportive services to family caregivers that will enable them to continue to care for their elderly family members in their homes and to prevent or delay more costly institutional care. We are committed to meeting the congressional intent of this program and work with your committee to be responsible stewards of Idaho taxpayer dollars that support this program.

I would also like to thank Senator Craig for his support of the 2000 reauthorization of the Older Americans Act, including this new and important program. Thank you and I'd be happy to respond to any questions.

Ms. WISSEL. Ken, thank you. We heard from you yesterday and also from Russ and so both of you are becoming quite experienced. Thank you very much. It's been great to hear how far Idaho is in this process. I know many States are struggling. They're having a difficult time getting going, so it's nice to see that Idaho is this far along to get the program going.

We have some questions here, but we would like to also provide our audience with the opportunity to ask any questions themselves. We have a microphone here right in front of us. If anyone has a question for any of the three panelists up here or even for us in regards to the National Family Caregiver Program, please just come forward and do so.

And we'd like to keep the Q and A directed to the Family Caregiver program. And then what we're going to do, once we complete the Family Caregiver portion we will close the forum and we will then take any questions that you may have in regards to, anything, that has to do with the older population. Whether it's about Medicare, Medicaid, Social Security, prescription drugs. We'll have those discussions after we finish with the forum. So with that, if anyone has any questions for anyone up here, please come forward.

I will start with a question and it will go to Robert. Robert, your story was quite touching, but that's a story that we've heard from many caregivers. The struggles, you make your plans, and then something happens and the plans have to be changed. Of course it's a difficult change and there's so many things that are going on during those changes. If you could design the program yourself and you heard about the priorities, what would you see the most important component of the National Family Caregiver Program?

Mr. LUNDBLADE. Well, I still maintain that we should keep people at home and have proper people see that they're taken care of and keep them out of the system that we've unfortunately got in the hospitals and the care centers. And like you said, baby boomers are coming. I'm going to tell you, it's going to have to be looked after. But taking them out of the home and having somebody else take care of them, is a difficult thing. I don't know just how to express it.

With me, you just care too much. You try to do as much as you can for your loved one but I'm no fool either, when you can't take care of them. And I'm no nurse and thank God I don't have to be a nurse but you still have to be clean. You still have to have safety devices and you still have to have good food and balanced meals. And even if they don't want to eat it, you have to see that they eat

it. I'm lucky because my wife can take care of herself and can feed herself and everything like that.

But a lot of people aren't that—I tell you, when you run into people that some of the—they have to take care of them, I don't know how they hold up under it. But they do keep them home and they do help them. But if we don't get back and keep them where they're in more familiar surroundings rather than just a cold hard facts of care, government care, it's going to be a sad world. It's coming.

Ms. WISSEL. What service would help you continue doing the things you've been doing and providing the work that you've done, we want to keep you healthy as well.

Mr. LUNDBLADE. I find out with what I'm working with now, the health care social system here, they have things in line that can help you with, and that. I haven't had to use them because I feel like I could do a lot of it myself yet. I haven't had to call on a lot of other people because I've been trying to make sure. If anybody can make her happier and help her, I can, and I'm familiar with her. They've got in place, I've talked to the respite and they've got the things you need, as I get into it a little deeper. I'm not into it as deep as I've had to I just never had to do it because I figure I can take care of myself.

I'm an independent rancher. This respite deal, you can have somebody to talk to and somebody come in and guard the people and get some help. I think it's the way, as far as I'm concerned, it's the way to go, is keep them with the loved ones and give them some help. Shoving them off into a—I've been down that road. I've watched too many of them just come and get them and drag them off and put them in a hospital.

This respite—I'm just getting into it. I'm not too familiar with it and it's a lot deeper program than I thought it was. I just wanted someplace I could go and be with people and see if there's anything easier, make my life easier or make other people's life easier and how to handle a situation that comes to you.

I'm sorry. When I was a young man and the folks were around and that, we didn't have something like that to help them. But we were trained to take care of our folks and I stayed with them. They wanted for nothing with them. But now, it's just throwing away, let somebody else worry about it. But let's keep them—I realize that this program that they're working with is the right way to go. You get more bang for the bucks.

Ms. WISSEL. And you do. If we were to pay for all of the caregiving that's done by family members, the government could not afford it.

Ken, I have a question for you. Do you feel that you have gotten the appropriate assistance, technical assistance, from the Administration on Aging?

Mr. WILKES. For the most part, yes, particularly from our regional office. You know, you've asked me that question in prior hearings this week. I've thought a little bit more about it and you know, I guess what would really have been helpful is the bill was passed in what, late November, I believe, and as I thought about it, it wasn't until February before we ever received any guidance or information about the program. And now it's going to be July

1, before we will have money actually in the hands of the area agencies.

And we're ahead of a lot of States. So some States, it will probably be a year after the bill was passed that included this program before it's actually implemented. So I think once the guidance started coming out in February, we've received pretty good direction and information and answers to questions we had, that have been provided. But it took close to 3 months before that started to happen.

Ms. WISSEL. Now I know that Idaho received approximately $564,300, just over half a million dollars. And you say that program funding probably—when you look at the need, that may not be enough. You're looking at the program just being implemented. Do you believe that you're going to be able to spend all the money this fiscal year?

Mr. WILKES. No. I'm sure that the area agencies will be carrying over money from this year into the second year because of the delay in getting the program implemented.

Ms. WISSEL. OK.

Mr. WILKES. And we have discussed that with the area agencies. In fact, as you know before you moved on to Washington, DC., we had implemented a new policy that only allowed 10 percent carry over. I think with this program, because of the delay, it would make sense to limit that 10 percent because all six area agencies will have, I'm sure the, money unspent from this year and so we will allow them to carry that into the second year.

Ms. WISSEL. Did you need to add something to that, Russ?

Mr. SPAIN. No, other than just to agree with it.

Ms. WISSEL. You said in your testimony that you have elected to use the full 10 percent allowable for programs aimed at grandparents, grandparent caregiving. Why did you decide to use the money this way and how great is the demand for the grandparent caregiving assistance?

Mr. SPAIN. We decided to use it that way because actually, within the last several months we have begun to receive an awful lot of calls from grandparents, asking what programs might be available or they're calling our information assistance office with other questions. By the way I have my grandparent and my grandchildren with me. Is there anything that is available for me to help in that way? And we have also received some calls to our case management and adult protection concerning children who may need to go into grandparents' homes.

So we decided to at least use the money, the maximum amount here to find out what kind of—use it to survey the area, if you will, to find out what kind of numbers we're dealing with here, because we really don't know. We don't believe that those five people that I testified about that are over 60 are the only ones in the nine county area. From the calls that we've received, we know that there are a number more than that.

And we wanted to begin to set up some sort of support group for them, much like the caregiver support group, so that they can talk with one another and do some peer counseling to at least help one another find out what they may do to help one another solve indi-

vidual problems and to bring some people who have some expertise in various areas to help them.

And we're also going to use some of the money, some of that 10 percent to add, as I mentioned, to our contract with legal aid because the questions that we are getting, for the most part, are dealing with legal issues that grandparents as caregivers—that we can't answer. Only an attorney or the legal system can.

Ms. WISSEL. Ken, one more question for you. You heard Senator Craig talk about, this program just being implmented and of course, the interest is to make sure that it meets the intent. He also wants to make sure that you're getting the proper guidance. But he has also mentioned that this is a new program and has indicated an interest in revisiting the program once it's well on its way, maybe in another year from now. Do you or does the commission, have any plans to implement any type of outcome measures so that at the end you can actually show measurable performance outcomes on this particular program?

Mr. WILKES. Yes, Lupe. In fact, I think it was what, about a couple of weeks ago we, as staff, met to revisit the outcome measures that we have for the other programs and in that meeting we began some discussion about the need for outcome measures in this program. We have sort of general feel for what we might do in terms of outcomes but we really need some time to work on it.

I don't think we will have any to measure this first year but as we move into the second year, which as you know in our case is a calendar year, we'll have some outcomes in place come January. The Administration on Aging in the reporting is only asking to report outputs, units and unduplicated but I don't—although I've heard them talk about having outcomes, I don't anticipate that happening anytime soon. So we'll have to develop our own.

Ms. WISSEL. Russ.

Mr. SPAIN. I would just like to add, I think, and in this case I may be talking not only for this area but probably for other areas. I hope that Congress and the Senate and AOA and the Idaho Commission on Aging will realize that what we are putting together in this area agency, for instance, for this year, what that program is and what it may look like 2 years from now, may really be two very different things. Because we're going to learn through this process and things may or may not work and we may need to change directions and do something totally different, and I'm glad that we're given the flexibility within the context of the Family Caregiver support program to do that. If it doesn't work, let's not do it. Let's not throw that money away. Let's put it to where it is doing some good.

Ms. WISSEL. I think you heard yesterday, there's been a question at all the forums that we've attended concerning some inflexibility that you had heard Ken, from Administration on Aging in regards to funding the five different areas. Yesterday, if anything, this was clarified. You heard that this is not the case. That you do have the flexibility that you need and do not have to fund a program that is not needed. So I think something positive has come out of these forums this week that is to ensure that you do have that flexibility to tailor the program to meet the needs of your own community.

Mr. WILKES. Yes. That was really helpful to have Edwin there yesterday to clarify that for us.

Ms. WISSEL. Do we have any questions from the audience or did we pass out any cards? Are there's any questions that you want to write down? You might not want to come up to the microphone but feel more comfortable writing it. You can do so.

Mr. STEELE. Madam Chair, I have a question for Mr. Lundblade.

Ms. WISSEL. I'm not a chair, I'm the staff director. Senator Craig is the Chairman. But please come forward to the microphone.

Mr. STEELE. And this is a broad question and posed mainly to Mr. Lundblade. I've known Bob all my life and I know the personal problems that they've gone through. As a State legislator, I was never really involved in aging programs. We in fact never had programs starting out may or may not have been funded one year; they weren't funded the next year. As a county commissioner, I have found that there is a definite need here in Bonneville County. And personally, I have tried to find out why the elderly couples that are living alone won't ask for assistance and there are many of them that wait too late. It just seemed like until they reach indigent status, they don't want anybody to really bother them.

Probably the most thing that I have found, these elderly people cherish their independence. When they went through their family raising programs, it was you either did it or you did without. And the second is the fear of separation and the third, and I think Russ can explain this, is the lack of knowledge of a program.

I think those three programs and I don't know how to end it. As a director on the Seventh District Health and Welfare, I know that there are people that have approached these problems over and over again. And until the last few years, the funding wasn't available in the amount that it needed. And as Ken has indicated here today, we have funding available but we don't have a program to use it. And I think all of you understand that when you turn back funds in a program, the next year you've got to prove that you could have used it the prior year or there will be a deletion in the funds. That's just the way it works.

I applaud what Senator Craig is doing here, and this is a program, I feel, that has been long overlooked as far as the overall picture, in my role now as a county commissioner. We have received more indigent, more elderly people. They come in, they ask for help as indigents. They're embarrassed and perhaps even after they've made the application, they won't follow through. They go home and for some reason or another, it doesn't happen. I applaud you for being here and I applaud the program.

Ms. WISSEL. Mr. Steele; correct?

Mr. STEELE. Yes, ma'am.

Ms. WISSEL. You're absolutely right. And that's what I think Russ and Ken, need to hear. They need ideas, as to how to get the word out and how to get people to access the services, because that's been an issue. I've been a State director here in Idaho for the Aging Commission this has always been a big issue. The pride, comes into play. And we don't want to take the pride away because that's something that you need to keep.

What you're doing, caring for your loved one, is something you want to do yourself. In many cases and there are statistics out there that show the caregiver ends up dying before the person they're caring for because of the work, the stress, and all that they

go through. How can we get that word out? How can we get them to access this very needed program that everyone agrees is a very important program to care for the caregiver? The senior's being cared for but the caregiver also needs that care. How do we do that?

Mr. STEELE. I think Russ was absolutely right. I believe it's a process of elimination. When we start out, we find it didn't work; we do something else. This is the part, as Ken has indicated, where funding will be available. Some years we might not use it, some years we might not have enough. So this whole program, this whole program is dependent on finance. I think we all understand that. And if we can't get a program in place quickly enough to utilize the money that's being allocated to us, then we're going to lose part of the program. Because this is just natural politics. When you turn money back, you jeopardize that money that's turned back. Thank you very much.

Ms. WISSEL. Thank you. That was Ralph Steele, and he is a former State legislator and he is a county commissioner now. Anyone else that would like to ask a question or make a comment?

Mr. LUNDBLADE. I might make one statement. I'm from the old stock and I'm independent and with Ralph back there. Ralph and I know where we've been. We know each other. But I come from families that are independent. My grandmother, I guess, wouldn't even accept charity. It was an insult. And that's carried down through us. But we're a farming community here, we used to be. Not so much that anymore. And yesterday I watched some of the desert burn up. It's unfortunate but we're a strong people and we're a family people.

We're getting with the baby boomers. They have a little different—it's coming. I don't know how they're going to cope with it but because they're going to get hit into an area that they're going to be in the same shoes as I am, as I stated early on. I woke up and I was 75 years old and been married for 55 years. Hey, you're starting to waste away.

But in answer to his question, we are. We took care of ourselves, we took care of our stock. We took care of everything. We took care of our land and kept it private. You feel nervous about going and asking somebody for favors. I, fortunately, I haven't asked for—I don't need any particular money favors. I'm not asking for that. But you need some guidance is what, and the place to go without getting so wrapped up and somebody that will level with you and tell you what it is.

I, in my life, cannot believe the run around that we get from this new generation. And dammit, if the computer breaks down, they can't add. [Laughter]

Ms. MELGAARD. I'm Wendy, I'm with the Homemaker Services of Idaho. I'm the executive director and one of my goals right now is completely addressing what he was talking about, is promoting the programs that we run. My agency runs the homemaker program, respite program and outreach services for the visually impaired. And if anybody—you know, part of what I'm doing is there's been a little bit of a change in the board. I'm working on getting people that have media or those kind of backgrounds to help me with that promotion. And if you have ideas on that, I would love to hear

what your research is because I want to be able to connect to that senior population and let them know what our resources are out there because I do think that a lot of them don't know.

One of the things that we're looking at is maybe changing the name of our agency, which is Homemaker Services of Idaho, because we're finding that people think we are housewives or a church group or, you know, I'm hearing all kind of things. So if you have ideas on that, I'd love to hear anything from anybody here. And I do have one board opening, in case somebody's interested in helping me with that.

But any ideas that you have in—you know, maybe with Robert too, is how can we approach a senior citizen who is caring for a loved one, to let you know that we're not there to take over your independence, we're there to help promote your independence.

Mr. LUNDBLADE. Well, I don't know if I can answer that, but I can see—and I'm not as familiar with your group because listening here, you've got new things going. But I am familiar with some of the old tactics that were put up when we were younger and I don't want to subject me or my family to that kind of behavior. And if you can give us some guidance along the way and some help and give us a little relief as to some of the pressure that you get under—I feel badly because I break down up here, but it's just the pressure. But we need a place like you have. And honestly, the minister of our church is the one that sent me over to see you. And I just wanted somebody I could leave Marion with while I could get away for a few days. I've tried to get help.

I had a young lady come out and help me and she worked for me a few months and we got along real well, and I had the physical therapist come out. We felt with her that we could get the Medicare thing, people sent out the physical therapist. Done a wonderful job and showed it. But then that only can last so long and then somebody has to take time to be with her when they do that. And I'll be damned if the hospital found out she was out like that and then bam, you can't keep them. They're gone. And I'm sure that your agency might get somebody trained to find out and bang, they're gone, because there's a shortage of nurses here and there's a shortage of health people here and it's dynamite. I'm sorry, but.

Ms. MELGAARD. That's true. That's always an issue.

Mr. LUNDBLADE. And the gal, then she went to work—as a matter of fact, she said she needed to get some money to fix her car so she could go get a job. So I let her have some money to go get the car. Then she called back and said she would come and work it out. Fine. Then the day she was supposed to come out, she said that she had to take care of her grandmother. This is fine. I haven't seen the money or anything else since, you know, trying to work it out, but the point of it is if you get—it's difficult to find somebody that can do it.

I'm sorry, but as Mr. Steele says, we're independent people and we're living in an entirely different valley. I live out of here, on a ranch. I can look out and I can see everything. I don't have any neighbors around me. And to get tied down to what this—Seventeenth Street traffic and that, you know, it's a little nervous. I used to go down there in a horse and buggy, you know. And that shows you how far back.

And I'm sorry for taking the time but you're working with one class of people here and then you're working with another. And the baby boomers are coming on and I kind of have to smile about it. My daughter just graduated a couple of her children out of the university, you know. Right in the bloom of life and bing, they got a couple teetering old folks to slow her down.

This group of people, as Mr. Steele said, we're a different breed. And it's with the influx that's in here now, I kind of liked what I heard yesterday. I asked questions yesterday. I asked questions to Margo and what's all involved in this thing. And man, she about blew my mind away, how much they do do. And I just got mixed up in respite because I needed a place to go. I'd like to get away. And frankly, I had an awful lot of pleasure out of helping kids in the rest home and helping put a smile on people's face.

I get a big pleasure. If somebody I noticed lost a loved one, I put a clown suit on and give them a hug. You'd be surprised how many have told me I need it so much. But I can do that without coming on to them. It's just a clown, just a clown, they say. You know, but you see people's eyes in a different light when you got that clown face on. I'm sorry, but that's just the way it is. People are hurting for a friend and they're hurting for some kindness. And we're older and boy, you better keep up with somebody or they'll run you off the road. I'm sorry I'm taking your time.

Ms. WISSEL. No, no, it's quite alright.

Mr. LUNDBLADE. It's a real problem you got and if you can help keep people there and help them out—because I had no idea that it was so damn rigorous of a job to take care of everything, the nursing. I don't have to do any nursing but the housekeeping and keeping the things clean and everything like that. You're not used to it. I'm glad you're with us. I'm glad. I'm sorry I can't help you much.

Ms. WISSEL. Russ.

Mr. SPAIN. I think one of the things that Commissioner Steele hit right on the head when he mentioned that we are dealing with an independent group of folks, and we're not well known and Wendy alluded to that as well. But what he is doing as a county commissioner, being involved in District Seven Health, he is also on our umbrella agency, Eastern Idaho Special Services Agency Board of Directors. That involvement and learning what agencies are and what agencies do will go a long way toward getting our message out, if you will. And what the Senator is doing as Chair of the Senate Special Aging Committee. All of that will help.

Ms. WISSEL. Any other questions?

Mr. PARK. I'm Darren Park from the Social Security Administration, and I kind of had a comment and then a question. We get a lot of calls on a daily basis from this aged population that want to know where to go, where to turn next to. And so any information that we could be given as a Federal agency to know where to refer these people to and any training that could be provided by State organizations or whatever that could come in and give that information to our employees can be greatly helped. And this would be, throughout our State and throughout the country. I'm sure they appreciate any information we could get.

And then my second question, I guess, we've talked a lot today right now, how to help these people right now. And Mr. Lundblade really brought up this subject several times, the baby boomers. As the Social Security Administration, we're scared to death what's going to happen.

Mr. LUNDBLADE. It's coming.

Mr. STEELE. It is. What I want to know is, what's Congress looking at into the future, because it's not much further down the road. These people start to retire in 6 to 7 years. And what we're looking at down the future because this whole aging agency is going to get a lot more important to the community, if it's not now. And it is now.

Ms. WISSEL. Darren, that is something that is currently being discussed. We will be discussing it here in just a few minutes. We will talk about Social Security and Medicare. The two need to be modernized. There is also the prescription drug programs issue that is also being discussed.

We're talking about services and we're talking about a population that does not, ask for anything. They do for themselves. They're very independent. They take care of themselves. They don't ask anyone for any help. In just a few years you get the other spectrum, which is the french fry, drive-through generation. The generation that wants it now, wants it fast and feels entitled to it. And so it's two totally different populations needs that we need to address and plan for. So yeah, you're right. It's going to change everything and the way we do things.

Mr. PARK. Thank you.

Ms. WISSEL. We will be talking about all those issues in just a couple of minutes. We will talk about to what is happening with all other services. Thank you.

Mr. WILKES. Lupe, may I just respond quickly to one of his comments?

Ms. WISSEL. Certainly.

Mr. WILKES. We have a State conference on aging scheduled in September I think would be helpful to provide information to the Social Security office staff around the State. So I'll make a point to get the information to your Social Security offices, that you may be interested in attending that conference.

Mr. PARK. Thank you very much.

Ms. WISSEL. Any other questions or comments in regards to Family Caregiver?

Ms. HEDGES. My name is Marsha Hedges, I'm with the SCIBA program. I think information and somehow getting this out to those seniors—we serve a 16 county area. We get a lot of phone calls and people have no idea where to turn to. And in Idaho Falls and of course our area agency in Pocatello and the people just have no idea it's out there. Unless they go to a senior center or something like that, they're getting that information. But not all of the people are at the senior centers.

And I think that's one of the things that we need to address is how to get that information into their hands. Idaho is a very religious State and I know we don't mix government and religion, but maybe some church bulletin board—you know, bulletins at church-

es and things. Somehow we need to reach the people and let them know that information is out there.

I'm a baby boomer, I just kind of comment here. I have parents that are World War II veterans and the same as Robert, we won't turn to the government for help. That we have been taught, you know, by our parents that we will be self sustaining. And yes, our parents live next door. My father-in-law has congestive heart failure and as children we are stepping in and helping them right now. I think I see that in Idaho as you know, we take care of our families and we're taught that way. And so I think you might see more of that in Idaho than you do other places. But that's my comment on that, is you know, we are preparing and we are ready and getting things in place to take care of our parents. So thank you.

Ms. WISSEL. Thank you. Any other questions? Then what we'll do is we'll conclude the forum and we'll go right into discussing the Senate Special Committee on Aging, the agenda that Senator Craig has set, what's going on in regards to aging programs and give you the opportunity to just ask any questions that you may have in regards to what's going on in Washington when it comes to services and programs for the aging population.

[Whereupon at 11:30 a.m., the forum was concluded.]

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