

**MEALS, RIDES, AND CAREGIVERS: WHAT MAKES  
THE OLDER AMERICANS ACT SO VITAL TO  
AMERICA'S SENIORS**

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
ONE HUNDRED TWELFTH CONGRESS

FIRST SESSION

WASHINGTON, DC

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**THURSDAY, MAY 26, 2011**

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

The Committee met, pursuant to notice, at 2:03 p.m., in Room SD-106, Dirksen Senate Office Building, Hon. Herb Kohl, Chairman of the Committee, presiding.

Present: Senators Kohl [presiding], Nelson, Casey, Udall, Manchin, and Corker.

**OPENING STATEMENT OF SENATOR HERB KOHL, CHAIRMAN**

The CHAIRMAN. Good afternoon. We'd like to thank all of you for being with us today.

In 1965, the same year Medicare was created, President Johnson signed another landmark bill for America's seniors, the Older Americans Act. Today the programs authorized by the OAA serve more than 10 million older Americans nationwide and over 386,000 in my State of Wisconsin. They help seniors live independently in their communities through home care, home-delivered and group meals, family caregiver support, transportation, as well as other services.

While the need for such vital OAA services has increased during these difficult economic times, Federal funding for OAA programs has not. This year OAA programs were cut by 17 percent from last year.

Every five years, Congress takes a fresh look at OAA programs to assess whether they are meeting the needs of the people they serve. Last September I held a field hearing in Milwaukee to gather ideas for strengthening and improving OAA programs. Since then we've incorporated many of the recommendations we received into priorities, and we will work with our colleagues to include these priorities in the new bill.

One of our priorities will address helping the nearly 44 million family members providing care to an older relative by simply asking them: "What do you need?" By permitting States to assess whether family caregivers need services such as respite care and counseling, we can delay more costly institutional placements of frail and disabled seniors.

We also believe we must strengthen the long-term care ombudsman program, which provides an advocate for elderly and disabled

patients to help resolve complaints of abuse and neglect in long-term care settings. We will work to expand the capacity of the National Ombudsman Resource Center and increase the ombudsmen's access to resident health care records so they can be more efficient as well as more effective.

Once again, we'd like to thank you all for being here. We look forward to your remarks, particularly those who are testifying, on how we can improve the Older Americans Act.

We turn now to Senator Bob Corker.

#### **STATEMENT OF SENATOR BOB CORKER**

Senator CORKER. Thank you, Mr. Chairman. As always, thanks for calling the hearing on the Older Americans Act. We want to thank the witnesses here today to share your expertise and experience, and I want to especially thank Rosalynn Carter, our First Lady, for sharing her experience, and Tim Howell with the Senior Citizen Home Assistance Services in Knoxville, for coming to Washington to testify on the good work that they are doing for seniors of East Tennessee. I look forward to learning more about Older Americans Act programs today.

When the Older Americans Act was passed in 1965, it was designed to be the human services support for seniors and complement the health support offered by the brand-new Medicare-Medicaid programs. This non-medical support envisioned by the Older Americans Act was proven to be what seniors need to stay in their own homes and independent as long as possible.

These services, like home-delivered meals, rides to appointments and activities, housekeeping and personal care, case management, caregiver support, and senior centers, are the first—are the sort of home and community-based services that seniors and their families across the country rely upon.

In Tennessee Older Americans Act home- and community-based service programs serve about 159,000 people. Almost 2,000 people are working and learning new skills for future sustainable employment because of the senior community service employment program. The service providers in Tennessee work hard to help seniors maintain dignity and independence with the latest innovations and programs.

For example, Tennessee has started to get in place aging and disability resource centers. These centers are to serve as a single point of entry for all services a senior may be eligible for. I look forward to reviewing the upcoming evaluation by the U.S. Administration on Aging of these centers and to see if any necessary improvements in the information and referral—in this information and referral innovation.

In 2020—and this is something that I think all of us are focused on as we look at future budgets—there will be more than 75 million people over the age of 60 and thereby eligible for the Older Americans Act programs. With our population growing older, these programs become more and more important. But at the same time, we are experiencing a fiscal crisis and need to seriously review spending on all government programs. This means that Older Americans Act programs will have to continue to innovate and increase efficiencies to meet increasing demand.

I look forward to working with my colleagues and with our panelists to continue to modernize the Older Americans Act so that it can be flexible and appropriate to serve the needs of our Nation's seniors.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Corker.  
Senator Nelson of Florida.

#### **STATEMENT OF SENATOR BILL NELSON**

Senator NELSON. Thank you, Mr. Chairman. I want to take this opportunity to thank you for your long and distinguished career. This is the first opportunity publicly that I could say that to you, as we have already discussed privately, because last week you announced that you are going to retire from public service. Your 24-year career in the United States Senate is most distinguished and most appreciated by a lot of folks who never get a chance to tell you.

Like most citizens of the United States that have a connection one way or another with Florida, so you do as well. The Senator's brother is one of our distinguished citizens in Palm Beach.

I want to, Ms. Carter, thank you for you just keeping on keeping on. It was a long time ago when you and your husband were campaigning in the Florida primary in 1976, and you have been his partner every step of the word in the best sense of that word, and you continue today rendering service to our country and to our people. So thank you very much.

Mr. Chairman, I just wanted to mention that, on this subject that we are discussing today, that a good example is a bill that I've had to file. I say had to file because, for example, in all the good stuff that programs like community development block grants do, CDBGs, but it has, for example, a limitation of 15 percent of the funds that can go to feeding programs for seniors. In one particular case, the City of Miami wants so desperately to use those, the remaining CDBG funds, for assistance to seniors in the feeding programs. But they're limited to 15 percent.

So I filed a bill to raise that a modest amount to 25 percent, that would give the recipients of CDBGs that flexibility to tailor their particular needs of the community, in this particular case the needs of senior citizens. I just wanted to get that out on the record for the committee.

The CHAIRMAN. Very good. Thank you, Senator Nelson.  
Senator Mark Udall.

#### **STATEMENT OF SENATOR MARK UDALL**

Senator UDALL. Thank you, Mr. Chairman. Good afternoon to everybody. I too want to associate myself with Senator Nelson's remarks about your leadership. I haven't forgiven you yet, Senator Kohl. I want that to be on the record.

The CHAIRMAN. I have your note.

Senator UDALL. But I wanted to welcome our panelists. I unfortunately have to step out. I serve on the Intelligence Committee, and we're having an important debate on the Patriot Act and its reauthorization.

But I did want to acknowledge the First Lady. The Udall and Carter families have been intertwined for many decades and we have great respect for their commitment to public service, and it's wonderful to see you here today.

Ms. Greenlee, you were a hit in Pueblo last summer. You were a real crowd-pleaser. I can't say the same about myself, but thank you for holding a hearing with us in Pueblo. I know the chairman and many members of the committee have been holding hearings all over our great country on the OAA.

We have a real opportunity in my opinion to modernize the act for a new and unique generation of seniors. I'm a member of the baby boom cohort. These Americans, my remarks say, which are my people, are fast approaching Medicare eligibility, and I think we have different expectations, different experiences, about how we can make our golden years really meaningful.

So this is an important hearing. Mr. Chairman, I look forward to working with you to modernize the act in ways that take advantage of the potential and the contributions that every American can make regardless of their age. So thank you again.

The CHAIRMAN. Thank you, Senator Udall.  
Senator Casey.

#### **STATEMENT OF SENATOR BOB CASEY**

Senator CASEY. Mr. Chairman, thank you. I'll be brief, and I'll add a statement to the record. But we want to commend you, not only for today's hearing, but of course for your great service to the United States Senate. You've been—you've been a great leader of this committee, and we'll miss you. We know you're going to be here for a while yet. We're not saying goodbye yet, but we want to commend you for that.

To Rosalynn Carter, former First Lady, we're grateful that you're here and appreciate your important witness on these issues over many years and your leadership and your testimony today.

Assistant Secretary Greenlee, we're grateful to have your testimony today as well.

On the second panel, I'm honored to say as a Pennsylvanian we have a former Mayor of York, Pennsylvania, Elizabeth Marshall, who is here. We will say hello to her in a more personal way a little later, but I am grateful she's here.

Just a couple words about why we're here. This legislation, of course, the Older Americans Act, has often been described as the glue that holds a whole series of programs that benefit older citizens together. I think what brings us into this room today is not just legislation and policy, but a shared commitment that we have more work to do as it relates to older citizens, those who have fought our wars, worked in our factories, taught our children, built our economy, and gave us life and love; that we've got an obligation, an enduring, abiding obligation, to do all we can. And one of the ways to fulfil that obligation is to make sure that we make the right choices on legislation and policy, and I'm happy to be part of this hearing today.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Casey.



We're honored to have with us today former First Lady Rosalynn Carter. We're all familiar with Ms. Carter's tireless advocacy alongside her husband, President Carter, on behalf of human rights and conflict resolution around the world. She is also a dedicated advocate for caregivers and mental health issues here at home.

Mrs. Carter is President of the Rosalynn Carter Institute for Caregiving at Georgia Southwestern State University, where she leads the institute's efforts to promote the well-being of family caregivers throughout our country. She is an inspiration for many and a legend in her own right.

Next we'll be hearing from Kathy Greenlee, the Assistant Secretary for Aging at the U.S. Department of Health and Human Services. Ms. Greenlee has a wealth of experience advancing the health and the independence of seniors and their families. Previously Ms. Greenlee served as Secretary for Aging for the State of Kansas, as well as the Kansas State Long-Term Care Ombudsman.

We thank you very much for being here, and we'll take your comments and testimony, Mrs. Carter.

**STATEMENT OF ROSALYNN CARTER, PRESIDENT, ROSALYNN CARTER INSTITUTE FOR CAREGIVING, AMERICUS, GA**

Mrs. CARTER. I'm very pleased to be here this afternoon to speak about caregiving, an issue that is very important to me. It has been part of my life since I was 12 years old and my father was diagnosed with leukemia at age 44. We lived in a very small town and all the neighbors rallied around. But I still vividly remember going to my secret hiding place, the outdoor privy, if you can believe that, to cry. That's where I could be alone.

I was the oldest child, and I felt the burden of needing to help care for my father and my three younger siblings. Yet I was afraid and didn't always feel like being strong. But my mother depended on me.

Less than a year after my father died, my mother's mother died, and my grandfather came to live with us. He was 70 and lived to be 95. My mother cared for him at home until he died. I helped as much as I could, but I was married and living away much of the time. During the last few years of his life he was bedridden and totally dependent on her, our family members, neighbors, and friends for all his needs.

My story is not unique, but today the informal support networks that were so much a part of my life in a small town—neighbors, extended family, the church—are not there for millions of Americans. Families are fractured and dispersed. Women, the traditional caregivers, are now an integral part of the work force. Advances in medical science mean we are living much longer, yet resources to enable us to live independently are sorely lacking.

We face a national crisis in caregiving, especially for our elderly citizens. Most frail elderly and disabled people live at home today. About 90 percent of the care they need is provided by unpaid, informal caregivers, most often family members, providing tasks that only skilled nurses performed just a decade ago, and with minimal preparation and training.

Many of these caregivers are frail and elderly themselves and find the burdens of caregiving overwhelming. Consider these facts:

Older people caring for their spouses have a 63 percent higher mortality rate than those of similar age without caregiving responsibilities; the stress of caring for a person with dementia negatively impacts the caregiver's immune system for up to 3 years after caregiving ends, making them more susceptible to all kinds of illnesses; caregivers report chronic conditions such as heart disease, cancer, and diabetes at twice the rates of noncaregivers; and up to 50 percent report struggling with depression. It's even higher when caring for a loved one with dementia.

While experts estimate the value of care provided by unpaid informal caregivers to be more than \$375 billion annually, many caregivers have to reduce their working hours or even quit their jobs, losing health and retirement benefits worth hundreds of thousands of dollars.

The economic consequences are devastating. Our nation's family caregivers are enduring both physical and mental problems and even dying sooner because of the responsibilities in caring for a loved one.

Mr. Chairman, there are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregiving. That's all of us. Caregiving knows no geographic or political boundaries.

The Rosalynn Carter Institute for Caregiving at Georgia Southwestern State University near my home town is doing groundbreaking work to help Americans with their challenging caregiving responsibilities. In one of our programs, with support from our corporate partner Johnson and Johnson, we undertook a national assessment of the state of caregiving in our country. We discovered innovative programs proven to be effective, but they were not and are not reaching people in need.

One of them focuses on the spouses of people with Alzheimer's disease. It provides concrete advice on how to deal with difficult behaviors like wandering, repeatedly asking questions, and agitation. It also focuses on taking care of oneself and on simple techniques to reduce stress. A woman at home who's been through our program told me that it changed her life. She said she was overwhelmed by difficulties and stresses of assuming care for her mother after her father died unexpectedly. She now is proud of being able to allow her mother to stay in her home. Just think what a difference this kind of program would make in lives of caregivers across this country.

The RCI, which is what we call the Rosalynn Carter Institute, has been working in Georgia and in demonstration sites around the country to introduce these interventions at the community level. But much more needs to be done.

There must be a fundamental shift in how this nation values and supports caregivers and caregiving. Last October the Rosalynn Carter Institute released a very important report, "Averting the Caregiving Crisis: Why We Must Act Now." This report is the result of 3 years of intensive study which involved hundreds of experts. I urge each of you to read it carefully, for it contains a blueprint for a national initiative to support family caregivers.

Its recommendations include: better assessments of caregiver health; increased use of evidence-based interventions in communities across the country; and greater flexibility in both public and private insurance programs to provide training and support for family caregivers. Its most important recommendation, however, is a call for leadership. We propose a National Quality Caregiving Task Force in the President's office, with shared leadership between the Secretary of Health and Human Services and the Secretary of Veterans Affairs. We have the knowledge base to solve the caregiver crisis, and we are already spending billions of dollars which can be used much more effectively.

These are challenging times for our country, with extreme pressure on federal, state, and local resources. Families and communities are struggling to cope. Yet if we fail to act now, the consequences for those in need of care will be increased rates of institutionalization, higher risk of abuse and neglect, unnecessary isolation, and perhaps even premature death. For family caregivers it will mean much greater burden, increased risk of physical or mental health problems, and more financial hardships. For our already overtaxed health care system, it would be impossible to find the work force to deliver high-quality institutionalized care.

The overall impact would be an unprecedented burden. In human terms, it will lead to unparalleled suffering for millions of older Americans and their family caregivers. We cannot let this happen.

Thank you for the opportunity to speak with you about this most significant national issue. Mr. Kohl, thank you.

[The prepared statement of Rosalynn Carter appears in the Appendix on page 32.]

The CHAIRMAN. Thank you very much, Mrs. Carter.  
We'll hear from Ms. Greenlee.

**STATEMENT OF KATHY GREENLEE, ASSISTANT SECRETARY,  
ADMINISTRATION ON AGING, DEPARTMENT OF HEALTH AND  
HUMAN SERVICES, WASHINGTON, DC**

Ms. GREENLEE. Thank you. Senator Kohl, it's good to see you again. Senator Corker. Members of the Special Committee on Aging: Thank you for the opportunity today to talk about the reauthorization of the Older Americans Act. In preparation for this process, at the Administration on Aging we went through the most extensive outreach effort in the history of the agency to seek input from all across the country, from family caregivers, seniors, and other individuals providing support. We have a lot of information that we have gathered about the value of these programs and look forward to continuing to work with this committee as we take up the challenge of reauthorization.

Senator Kohl, I would like to join your colleagues in commending you in your service on behalf of older Americans. I think I have mentioned to you before I first heard of you from our mutual friend George Petrosky, the former Wisconsin long-term care ombudsman. Not only have you been instrumental in helping seniors; you have paid particular attention to those seniors in nursing homes in this country. And many of us—I think I can speak on behalf of the whole aging network—have valued your contributions and will miss your leadership. So thank you for your service.

It's also wonderful to appear today with Mrs. Carter, a tremendous honor to be here. I met Mrs. Carter last fall when I traveled to Americus to the Rosalynn Carter Institute to talk specifically about what we need to do to continue to advance the cause and the supports for caregivers. She had released her report about that same time.

Mrs. Carter is a leader in the field of caregiving. The work that they're doing at the institute is innovative. The leadership she is asking for she is herself providing. I also want to acknowledge her work in the field of mental health, not something we will spend as much time on at this hearing. But Mrs. Carter's work in mental health is really important for individuals dealing with mental health and their family members.

So I applaud your work, Mrs. Carter. It's an honor to be here.

As you know and mentioned, I was the Secretary of Aging in the State of Kansas. I have served now for 2 years as the U.S. Assistant Secretary for Aging, and in both of those capacities I have listened to and spoken to thousands of individuals and families in a variety of settings. And I have seen first-hand how the Older Americans Act reflects the values that we have in this country: supporting independence, helping people maintain their health and well-being so they are better able to live with dignity, protecting the most vulnerable among us, and providing basic respite care and other supports for families so that they are better able to take care of loved ones in their homes and their communities for as long as possible. This is what Americans of all ages overwhelmingly tell us they prefer, to age at home in their communities.

One of the real strengths of the Older Americans Act is that it doesn't matter if an individual lives in a rural area, a frontier area, or an urban center. The programs and the community-based supports are flexible enough to meet the needs of individuals in all of these diverse communities and settings.

Over the past year alone, nearly 11 million older Americans and their family caregivers have been supported through the Older Americans Act comprehensive community-based system. These services, as you mentioned, Senator Kohl, complement medical and health care systems. They help to prevent hospital readmissions. They provide transportation to doctor's appointments and support some of life's most basic functions, such as bathing or having a home-delivered meal.

This assistance is especially critical for nearly 3 million seniors who receive intensive in-home services, half a million of whom would otherwise qualify for nursing home admission.

For more than a year, as I have mentioned, we have received reports from more than 60 reauthorization listening sessions around the country, and have received on-line input from a variety of sectors, individuals, and organizations and their caregivers. This input represents the interests of thousands of individuals with regard to the Older Americans Act's services.

During this process we heard an overriding issue that Mrs. Carter has already spoken to today, and which was also advanced through the Vice President's Middle Class Task Force, and that is the issue with regard to families. Families are doing the best that they can, but they're struggling between balancing the demands of

work, child care, and elder care. Families tell us that they need some basic assistance in supporting their care for their loved ones.

During our process of soliciting input, we heard that the Older Americans Act is working and it needs to continue to be flexible. We also heard two particular themes that I want to suggest in terms of further conversation. One suggestion or recommendation that we have heard is that we continue to improve the program outcomes by embedding evidence-based interventions and disease prevention programs, encouraging comprehensive person-centered approaches, providing flexibility to respond to local nutrition needs, and increasing efforts to fight fraud and abuse.

Second, we need to remove barriers and enhance access, extending caregiver supports to parents who care for their adult children with disabilities, providing ombudsman services to all residents of nursing facilities, not just seniors, and using aging and disability resource centers as single access points to provide information regarding public and private resources for long-term supports and services.

Let me give you three brief examples we would like to discuss as we continue our work: One, we should ensure that we utilize the best evidence-based interventions for helping older individuals manage chronic disease. These have been effective in helping people adopt healthy lifestyles, improve their health status, and reduce their use of hospitals and emergency room visits.

We want to improve the Senior Community Services Employment Program by integrating it with other senior programs. As you know, the President has recommended in 2012 through this budget process that we transfer the older workers program from the Department of Labor to the Administration on Aging.

We would also like to continue to combat fraud and abuse of both Medicare and Medicaid by permanently establishing the authority for the operation of the senior Medicare patrol program as a basic component of the Older Americans Act, so we can continue to use retired volunteers to help us detect and deter fraud in the area of Medicare and Medicaid.

The Older Americans Act has historically enjoyed widespread bipartisan support. Based in part on this extensive public input, we believe that reauthorization can strengthen the Older Americans Act and put it on solid footing to meet the challenges of a growing population of seniors, while continuing to carry out the critical mission of helping elderly individuals maintain their health and independence in their homes and communities.

Thank you again, Senator Kohl and Senator Corker, for your leadership. I look forward to working with you and the rest of your committee. Thank you.

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

[The prepared statement of Kathy Greenlee appears in the Appendix on page 64.]

We'll now commence questioning. We'll start with Senator Corker.

Senator CORKER. Thank you, Mr. Chairman. I'll be brief.

Again, thank you both for your testimony. Mrs. Carter, I notice the chairman said you were a legend in your own right. Certainly

not in relation to anybody up on this panel, we serve with a lot of folks here that are a legend in their own mind.

[Laughter.]

Senator CORKER [continuing]. So we thank you so much for having earned that and certainly bringing such focus on this issue. But thank you very much for your testimony.

I have a few organizational issues to ask Ms. Greenlee about. I know the President's budget this year transfers some additional responsibilities into your agency, the Title V Senior Community Services Employment Program, the State Health Insurance Assistance Program, the CLASS Act. I know you were talking about some of the flexibilities and other kind of things that need to happen within your organization. Is that going to, in your opinion, distract at all from your ability to efficiently carry out the other responsibilities of the organization?

Ms. GREENLEE. No, Senator Corker. The agency has a 45-year history and experience in providing community supports to individuals. One of those components is the economic security of seniors, and we have a variety of programs that have worked on pension counseling, benefits outreach. Bringing the older workers program to AOA will help strengthen our mission, not detract from it. It is the only one of the Older Americans Act programs that we do not administer.

The senior health insurance assistance programs are primarily delivered at the local level through our area agencies on aging. And the reason for the CLASS Act, the underlying need for the CLASS Act, is to provide a different type of option for individuals to maintain their independence in the community. We feel like we have a wealth of knowledge to support these other programs and can make them all work to help individuals, people with disabilities, and seniors remain independent.

Senator CORKER. I know that Secretary Sebelius has mentioned that the CLASS Act is an unsustainable program unless numbers of changes are made. I know that you are probably closest to it since, as you mentioned, you're going to be involved in implementing it. Are there things that you are already looking at, major structural changes to actually cause the CLASS Act to be sustainable? I know there are people on both sides of the aisle who have a lot of concerns about that.

Ms. GREENLEE. Senator, as you have referenced, I was designated officially in January as the administrator of the CLASS program at the Administration on Aging. The Secretary and I have both had opportunity to testify, most specifically on the House side, and committed ourselves and our efforts to the financial solvency of this program.

We both agree that there are reforms that need to be made to the program in order to sustain the program and make it financially sound for 75 years, as required by the law. We will this fall issue preliminary regulations with regard to the program and at that time be able to provide more information about the kinds of things that we need to do through a regulatory process to strengthen the program.

There are things that we were looking at, considered by the Senate before the bill was passed, that we will return to first as we find ways to support the program for its financial solvency.

Senator CORKER. As you go about looking at implementing it, I know there has to be some investments made, if you will, through your organization to begin that implementation. How are we accounting for that? Is that something that goes into the actual cost of the CLASS Act itself or is that something—how is that being accounted for?

Ms. GREENLEE. Senator, as you know, the Department of Health and Human Services was given money to implement the Affordable Care Act. It is from those funds that we have currently been paying for our operational costs. We have made sure that we can identify all the staff who are working on the CLASS program full time and those of us who split our time between CLASS and the Administration on Aging's traditional work, so that we can fairly account for the work that we're doing. I believe we're adequately handling the accounting that needs to be done.

Senator CORKER. I know there's going to be a tremendous amount of focus on Medicare and its sustainability over the course of this summer. My hope is that we will in a bipartisan way figure out a way to make it solvent. We all know it's going to be insolvent as is. The trustees are stating by the year 2024.

As you move ahead with the CLASS Act, I think people believe it's already at that stage as it's been set up, and I do hope you'll let us know of some of the major frailties that exist there and continue to keep us apprised of that.

We thank you for your service, and I look forward to having several questions for the second panel.

Thank you, Mr. Chairman.

Ms. GREENLEE. Thank you, Senator.

The CHAIRMAN. Thank you, Senator Corker.

Senator Casey.

Senator CASEY. Thank you, Mr. Chairman.

I want to thank you both for your testimony and the personal witness that you bring to these issues.

I wanted to start with our former First Lady, Mrs. Carter, on a question that relates to the specialized training that is often needed in these circumstances. I have been over many years as a State public official for a decade and now in my fifth year in the Senate overwhelmed by the kind of care that's delivered by direct care workers, how strong they are, how dedicated they are, willing to do backbreaking and sometimes impossible, seemingly impossible work on behalf of those who need that care and on behalf of their families.

But I wanted to ask you about it. I noted in your testimony on the four recommendations that you made, as well as Assistant Secretary Greenlee, about evidence-based programs. I wanted to get your sense of that, based upon your experience, as to evidence-based programs on this question of specialized training and preparing folks for doing that difficult work. What can you tell us about that in your experience?

Mrs. CARTER. Well, we've been working with evidence-based programs for a good while now at the Rosalynn Carter Institute. One

that we are working on—we're doing six in all—with Johnson and Johnson. Johnson and Johnson has been great, because they were the first ones that did clinical trials in nursing homes working with those who were suffering from mental disorders. So they've been very good to us.

But we have six programs and a couple of them are Alzheimer's. We are actually doing an Alzheimer's one at home. We train people to go into the homes. They don't have to come in. When we were trying to get them to come to the Institute for training they didn't want to. Caregivers don't want to come in, and they don't want to admit they're caregivers. So many of them don't want to admit they have to have help; it's just their job to do what they should do for a family member.

But we send them into the houses. When they find out that this person can come to the house, they welcome them. So we go I think 6 weeks, go in a couple times a week. And it's just made—we have found that it increases the time people can stay at home without being institutionalized. The depression is lifted to a certain degree, and it just—it's working.

We're also trying this in other places around the country. But we're working with three different ones now, and we're kind of comparing them to see which is best for Alzheimer's. We've done one with cancer. And we've had—at the Rosalynn Carter Institute, we had everybody that we knew of, I think, in the United States who was working on evidence-based programs. I think we had one person from Ireland that came to that meeting.

We have had great reports, and actually it just helps the caregiver so much when the program works. It's cost-effective because they don't have to try things and try things. They just know what works, and if they will follow the guidelines of the program it can help.

So we just need evidence-based programs in the whole country. It's going to be a long time before we get there. But we're really working and doing research right now on those programs in many parts of the country.

Senator CASEY. I thank you for that. I know that part of what we're trying to do is to not only improve care and provide the kind of highest level of care we can, but also to provide options for the work force. Sometimes I guess they're described as career ladders, ways for people to move up if they're at entry level, in an entry level position.

So I think that evidence-based, evidence-based research and the care that can come from that is going to be critically important.

I know I've got about 20 seconds, but, Assistant Secretary Greenlee, anything that you wanted to add on this question of training or the evidence-based methods?

Ms. GREENLEE. This will state the obvious. It's such a broad topic that it will take many different Federal organizations working together. We have a community living initiative within HHS that looks at issues with regard to people with disabilities, as well as seniors. Senator Corker mentioned the CLASS Act. This was identified even in the law of the CLASS Act, how will we support the public programs that we will have in the future, such as the CLASS Act; the Medicaid and Medicare programs; the programs



that we have under the Older Americans Act; and disability programs, with a paid work force that allows them to have meaningful career ladders, as well as a skill set necessary to serve an increasingly aging population. It will take both a paid and unpaid workforce to provide the care that's needed in this country.

Senator CASEY. Thank you very much.

The CHAIRMAN. Thank you, Senator Casey.

Senator Manchin.

Senator MANCHIN. Thank you, Mr. Chairman, and thank both of you for being here and we appreciate it very much. The State of West Virginia appreciates the work that you have done and also the assistance that we get in the Older Americans Act and what it's done for our State.

As you know, we have the second most aged State in the Nation per population and probably one of the most rural States. So it's quite costly for us to give the services that are needed. But we've expanded those, and I think the word that you mentioned earlier was "flexibility." I can't explain enough how much flexibility that we need in some of these States so that the money is not sliced to where transportation is one, meals on wheels is another.

The formula that's used for small States and rural States such as myself, and there's more populated States—and I know that the funding mechanism is based on population. It should be based on the services that are given, if you could just consider that. We serve an awful lot of people in West Virginia and our funding is much lower, but we're feeding many, many, many more than other States that might not have the need as we have.

With that, I think you might be aware of some of the programs we've expanded, the FAIR programs and the Lighthouse programs. We did some things and during the most difficult recession times we expanded programs because it was a priority of ours to allow our seniors to live in dignity in their own homes, with a little bit of assistance.

Need-based is a big thing in West Virginia because we have a lot of seniors who want to be able to contribute and pay their way or pay part of their way if they can. So we try to develop flexible plans to where they felt like they were still contributing, but yet they just couldn't find the service anywhere. A lot of times if you're on a certain cuff and you get—if you're not within certain guidelines as far as income, the service is not even offered. I think that's something that should be considered, too, because it's not for a lack of need. They just can't find anyone else to provide those services, and they're willing to pay. So we hope those flexibilities are taken into consideration.

But in transportation, that's the one that we're having some concerns about. I don't know if—I support the OAA lock, stock, and barrel. So tell me what you think you can do to help us help ourselves more?

Ms. GREENLEE. Senator, we have transportation support that we can provide through the Older Americans Act. Transportation is such a huge issue that I don't think there's a way to completely address transportation needs with such a program of this size. We need to talk to other partners at the Federal level and at the State

and community level to figure out what is the best way to provide transportation services.

I think one of the best things that we can do—and for this answer I'm actually relying on my Kansas experience—is to make sure that we remove any barriers, so that if we provided support for, say, a van at any level with government funds, we use it to the best ability in serving all populations.

So I think we need to be innovative, work with our transportation partners, and figure out how we can make sure that we're not in the way of what needs to happen in the community to get the job done.

Senator MANCHIN. What recommendation do you have—I know, Mrs. Carter, from your experience. What recommendation would either one of you have, how we can be more efficient with the dollars we have? As you know, the budget constraints are going to be tough on all of us. But by setting the priorities we can make sure that the dollars we have are in place, but yet they go further. And we're all growing older and in need of the services, I'm sure.

But is there anything that we can do that would give you the efficiencies or help you have more efficiencies? Have we tied your hands in any way, Mrs. Carter?

Mrs. CARTER. One of the greatest helps would be to have data so we could know how to allocate the resources. One of the recommendations that our study has made is that we use the Behavior Risk Factor Surveillance System that the Centers for Disease Control has developed. They have developed a caregiving module. If we could use that in the states in the OAA, it wouldn't cost very much, because the question is not—it's not on the survey—all surveys—and you have to ask for it.

So we checked to see—Georgia doesn't have it in their survey. So we checked to see how much it would cost, and it would cost just \$21,000 a year to get that data in Georgia, and that would be so helpful in cutting costs.

Ms. GREENLEE. For about a decade now, the Administration on Aging has been focused on evidence-based practices. We do this a lot in the field of Alzheimer's support for individuals and their family members, the evidence-based practices that I mention in my testimony.

Those of us who work in the social services arena understand that science is not just for people who are in the laboratory, that good evidence, good outcomes in science is a critical part of delivering quality and effective social service programs. That's why we're suggesting that we continue to work in this effort with real regard to the health programs in the Older Americans Act, to make sure that we've got good outcomes.

I agree with Mrs. Carter about the global issue of data. Our ability to continue to research our programs makes the case with regard to their effectiveness. Their ability to provide cost savings to other programs such as Medicare and Medicaid is also a critical component of this conversation as we figure out, as we go forward, how to balance the supports that are needed with the increasing pressures of more seniors and the struggling budgets at the Federal and State level.

Senator MANCHIN. I'll wait until my second round. Thank you very much, both of you.

The CHAIRMAN. Thank you very much, Senator Manchin, and we'd like to thank you both profusely for being here today. You have made tremendous contributions today, as you have in the past, and again we appreciate your being here. Thank you so much.

Ms. GREENLEE. Thank you, Senators.

The CHAIRMAN. We'll turn now to the second panel, if you'll step up to the table, please. First we'll be hearing from Elizabeth Marshall, a recipient of home-delivered meals. Ms. Marshall was elected as the first female Mayor of York, Pennsylvania, in 1977. She also served as a member of the York City Council.

Next we'll be hearing from Max Richtman, who serves as Chairman of the Leadership Council of Aging Organizations, a coalition of 66 national aging organizations. Mr. Richtman is a former staff director at this committee and is currently the Acting CEO of the National Committee to Preserve Social Security and Medicare. Welcome.

Next we'll be hearing from Heather Bruemmer, who is the Executive Director and State Ombudsman for the Wisconsin Board on Aging and Long-Term Care. She also chairs the State's Long-Term Care Council and serves on the Coalition of Wisconsin Aging Groups' Advisory Council.

Senator Corker has a witness from Tennessee.

Senator CORKER. Yes, sir. I'd like to introduce Timothy Howell, who is the Chief Executive Officer of the Senior Citizen Home Assistance Services, a nonprofit that provides in-home caregiving in East Tennessee. SCHAS aims to improve the lives of seniors and persons with disabilities while maintaining their independence and dignity. Mr. Howell has worked for SCHAS for 10 years, has been the CEO since 2008.

As CEO, Mr. Howell oversaw the completion of Renaissance Towers, an assisted living community targeted to low-income seniors who wish to pay for their own care. He's President of the Tennessee Association of Homemaker Services Providers, a member of the National Council on Aging, and the Downtown Rotary.

Thank you for traveling all the way from East Tennessee to be here.

The CHAIRMAN. Thank you.

We'll hear now from Mrs. Marshall.

**STATEMENT OF ELIZABETH MARSHALL, OAA SERVICE  
RECIPIENT, YORK, PA**

Ms. MARSHALL. Thank you very much.

This is addressed to you, Chairman Kohl, and to Senator Casey and other members of the committee. Thank you for inviting me to testify before you today. I am pleased to be able to share with you my thoughts on the Older Americans Act. Throughout my life I have always strived to be an independent woman. Born in 1918, I'm a child of the Great Depression and have continued to live by the values of economy, thrift, and self-reliance that I learned during my formative years.

My husband Howard and I married after he returned from serving overseas. We moved to York, Pennsylvania, in 1948 and we

bought our first and only home there in 1954. This is the same house I live in today. Our two sons still live near me, and my daughter resides in New Hampshire.

An old song by Joseph Burke called "A Little Bit Independent" is my theme song, if you will: "A little bit independent in your walk, a little bit independent in your style." I have worked throughout my life to be an independent woman, to find my strengths and use them, whether in service to my family, community, or country.

In the early 1960s I increasingly became involved in the York community, which was undergoing a turbulent time, and eventually in 1971 I was elected the first member of city council and later served—oh, I'm sorry. It led to my election to York City Council in 1971, and then I was elected as the first female Mayor of York in 1977. I later served as Deputy Comptroller for the City of York. So I know something about government and the challenging choices faced by decisionmakers as to the best use of taxpayer dollars.

After my public service career, I worked as a real estate agent for 18 years. I retired just 11 years ago at 81 years of age. I have been on my own now for 10 years since my husband passed away in 2001.

Many of us in our neighborhood are long-time residents. Our tight-knit community is essentially aging in place and helping each other remain in our homes for as long as possible. I am proud to still be an independent woman. I want to be able to stay in my home, near my family and neighbors.

I am grateful that the York County Area Agency on Aging is there for me and for thousands of other seniors in my community. I have a care manager at the Area Agency on Aging. She was able to connect me to the home-delivered meals program and if I need additional support, services, or even just information, she will be ready to assist me and my family.

Three times a week a volunteer from the local senior center delivers both hot and cold meals to me in my home. I appreciate the meals service, and it's also nice to have a friendly visitor check in to make sure I'm safe and doing well.

I understand that the home-delivered meals service is funded in part through the Older Americans Act. The act allows the coordination and provision of many other in-home and community programs. There's even a part of the act focused on family caregivers, to help them help us.

And we can't forget our senior centers, which are more important than ever to help older adults stay connected to their community. Many recipients of services are like me; they just need one or two little bits of help. Others may need more services. But the act allows seniors to receive just what they want to stay healthy. Even if you need a high level of support, receiving this care in your home is still more affordable for you and the taxpayers than care in a nursing home.

As our leaders struggle to balance the budget and reduce the deficit, the cost savings that Older Americans Act programs generate are even more critical.

My story—my story is not necessarily a unique one. My peers and I have served our families, communities, and country for many

years, and with the right balance of help we can continue to remain contributing members of our society and maintain our health, independence, and dignity for as long as possible. I'm glad to be able to continue living in my home of 57 years, where I can still be, quote, "a little bit independent in my walk."

The Older Americans Act allows you to retain your dignity, health, and independence with just a little bit of support. I urge this committee and your colleagues in the Senate and House to understand how vital these little bits of support are to millions of older Americans determined to age in place. We need to reauthorize the Older Americans Act in a timely and bipartisan fashion and prepare our country for the wave of baby boomers standing behind my generation.

Thank you, Senator Kohl and members of the Aging Committee, for inviting me to share my thoughts about the Older Americans Act with you here today.

[The prepared statement of Elizabeth Marshall appears in the Appendix on page 71.]

The CHAIRMAN. Thank you, Mrs. Marshall. That was a beautiful statement.

Ms. MARSHALL. I'm sorry, I didn't hear that.

The CHAIRMAN. That was a beautiful statement. Thank you so much.

Ms. MARSHALL. Oh, thank you.

The CHAIRMAN. Mr. Richtman.

**STATEMENT OF MAX RICHTMAN, CHAIR, LEADERSHIP  
COUNCIL OF AGING ORGANIZATIONS, WASHINGTON, DC**

Mr. RICHTMAN. Mr. Chairman, members of the committee: First of all, let me say to Mrs. Marshall: You're a tough act to follow, but I'll do my best.

On behalf of the Leadership Council of Aging Organizations, I'm honored to testify before the Special Committee on Aging about the LCAO Older Americans Act reauthorization consensus document. LCAO is a 66-member coalition of diverse national nonprofit organizations dedicated to preserving and strengthening the well-being of America's older population. Historically, LCAO has played a significant leadership role in past reauthorizations of the Older Americans Act.

In preparation for this year's reauthorization, we've worked for over 6 months to develop the consensus document that we have submitted to the committee. Under the leadership of the LCAO community services committee, individual organizations presented their ideas and suggestions for improving the Older Americans Act. These ideas were incorporated into the consensus document, which was enthusiastically endorsed by the full LCAO at our April 6th meeting.

The LCAO Older Americans Act reauthorization document contains 98 recommendations. They do a number of things. They reinforce key existing priorities in the current statute and seek to address challenges and opportunities brought about by the exponential growth of our older population. We agree that the Older Americans Act continues to work very well for older adults across the country. The act's core mission, infrastructure, and programs

remain relevant, effective, and very much relied upon by older adults and caregivers.

The problem we face, of course, is insufficient funding, which makes it difficult for the aging network to carry out Older Americans Act priorities as established by Congress in past reauthorizations. There simply is not enough money for all the needs that exist.

On that note, I'd like to thank you, on behalf of our organization, Mr. Chairman, for your request to the General Accounting Office to examine the true magnitude of this unmet need. We also acknowledge that the Older Americans Act, like other statutes, is a dynamic document that can and must change to address emerging needs and embrace new innovations.

It's notable that the Older Americans Act is up for reauthorization the same year that the first of the baby boomers turn 65. Not only are the numbers of older adults increasing at a historic rate, but this population is becoming much more diverse. Additionally, as older Americans live longer they face growing health and economic challenges. All of these issues are converging to place tremendous strain on the aging network, a network that is already overburdened, but eager to expand capacity and enhance planning to meet the demands and opportunities presented by our aging population.

Particularly in times of fiscal restraint, times such as now, we acknowledge that improvements can be made in the efficiency and effectiveness of the Older Americans Act in its delivery of core services and how it interacts and coordinates with other Federal programs that serve older adults. There are recommendations throughout the document we presented that call for improved coordination of services and identification and dissemination of best practices that already occur in local communities in order to strengthen the aging network nationwide.

LCAO also believes it is crucial to strengthen evaluation, research, and demonstration of aging services. This will not only empower the aging network to continue implementing best practices but will also state with authority the degree to which the Older Americans Act provides a cost-effective way for older adults to remain in their own homes with health and economic security.

The Older Americans Act programs, such as in-home assistance, home-delivered and congregate meals, and respite for family caregivers, benefit individuals and their families. They also save Federal and State government resources from being spent on otherwise unnecessary care in hospitals and nursing homes.

On behalf of LCAO, I applaud this committee for its leadership in calling attention to the upcoming Older Americans Act reauthorization. We urge Congress to continue the long tradition of bipartisan and timely reauthorization of this important statute while providing the funding needed for Older Americans Act programs to keep older Americans independent and productive.

Thank you again for the opportunity to testify today on behalf of the 66 members of the LCAO, and I welcome your questions and comments. Thank you.

[The prepared statement of Max Richtman appears in the Appendix on page 76.]

The CHAIRMAN. Thank you, Mr. Richtman.  
Heather Bruemmer.

**STATEMENT OF HEATHER BRUEMMER, STATE OF WISCONSIN  
LONG-TERM CARE OMBUDSMAN, MADISON, WI**

Ms. BRUEMMER. Chairman Kohl, Ranking Member Corker, and members of the committee: Thank you so much for this opportunity to testify today. I'm the State Long-Term Care Ombudsman of Wisconsin and also represent the National Association of State Long-Term Care Ombudsman Programs, better known as NASOP.

It is a privilege and honor to be here on behalf of the ombudsman advocates who work daily tirelessly to assure the rights and well-being of hundreds of thousands of vulnerable residents living in long-term care settings throughout the Nation. The significance of this effort to reauthorize the Older Americans Act cannot be overestimated. It is a primary duty of this Nation to protect our most vulnerable individuals and to preserve their pride and dignity.

Everyone has a history, a story. We all create memories. So it's our responsibility to assure that all members of our rapidly aging population have the proper access to services that will respect their right to be who they are and who they've been.

The Older Americans Act provides critically needed home- and community-based services that allow older adults to remain for as long as possible in the community with needed support. Since 1978, the ombudsman program has been a core component of the Older Americans Act. It is the only program in that act that specifically serves consumers provided by residential care facilities.

I think that we all appreciate and value the importance of living in our own home. We heard from Elizabeth today it's very special, and as a result there has been a remarkable growth in the amount of home- and community-based services available for seniors in Wisconsin. In November of 2008 we had a significant trend happen. We have more assisted living beds in the State of Wisconsin than we do nursing home beds.

Wisconsin was one of the original pilot States when the long-term care ombudsman was first created by Congress, and our State has continuously relied and improved the advocacy resources available to aging consumers. The Board on Aging formed in 1981. We had five ombudsmen. Today we have 15 outstanding regional ombudsmen and over 100 volunteers serving 95,000 clients in nursing homes and assisted living facilities, and we also provide services through the Medicaid waiver programs.

Nationally, ombudsmen visited 79 percent of all nursing homes on a quarterly basis last year, yet only 46 percent of assisted living facilities and similar homes. Throughout the country, it has become increasingly more difficult for ombudsmen to participate in visits for assisted living. The inability of Congress to provide sufficient funding is certainly not the result of trying by the champions of the long-term care ombudsman program, such as yourself, Chairman Kohl, and the members of this committee. Each year the program resolves hundreds and thousands of complaints and, interestingly, 77 percent of these complaints are resolved to the satisfaction or partially resolved to the client's needs.

We spend time in nursing homes. If we are able to address the needs of people living in assisted living with the same intensity as we do the concerns in nursing homes, our numbers would be astronomical.

The long-term care program offers significant protections to residents. The complexity and diversity of consumers today who live in these facilities is growing. We have falls, medical mismanagement, medication errors, pressure ulcers, and abuse situations, and unfortunately they are on the rise. We spend a tremendous amount of time investigating these incidents and also provide education and guidance to facility staff to help prevent reoccurrences of these problems.

Unfortunately, we are still confronted with the reality of inadequate resources, but we keep moving forward and protecting our most vulnerable.

Resident and family councils are vehicles by which open communications are really important in order to deliver excellent quality of life and care. When considering this reauthorization, it is important with this requirement to maintain resident and family involvement with the assistance of the ombudsman program.

Access to confidential information for ombudsman is critically important. We are recommending that this reauthorization ensure the private and unimpeded access by individuals to ombudsman service in a confidential setting, that it is not compromised. The sections of this act relating to the process of and limitations and disclosure of client information needs clarification and emphasis. It is important that the text of the Older Americans Act clarifies that the privacy provisions of the Health Insurance Portability and Accountability Act, better known as HIPPA, do not impede the access to resident health records by the ombudsman and representatives of the program.

The Administration on Aging had declared in a memo that the ombudsman program representatives are performing a health care oversight function and they are not impacted by the HIPPA privacy rules. Throughout the country we have more and more people that can't speak for themselves and who have no legally authorized representative to speak on their behalf. It's really our duty, and we recommend that we add language to this act to encourage States to intensify their efforts to educate the public on the value and importance of completing documents to establish a trustee relationship.

The Board on Aging and NASOP also support the recommendation to amend Title 2 to provide a base appropriation beginning at \$1 million to the National Ombudsman Resource Center. It has proven to be a valuable site for ombudsman programs to obtain training resources and technical assistance. It would be extremely helpful to expand the center's training capacity and ability to work with State regulators to improve the investigative process used to deal with resident complaints.

The Older Americans Act gives us a strong foundation and reauthorization gives us a window of opportunity to build an even more robust demonstration of the Nation's concern for our well-being of our elders. It is extremely important that Congress and the aging



network come together to strengthen our long-term care ombudsman programs to provide a safe and home-like environment.

On behalf of Wisconsin's long-term care ombudsman program and NASOP as advocates for the Nation's most vulnerable facility residents and consumers of long-term care, I thank you, Senator Kohl, Ranking Member Corker, and the members of the committee for allowing me to share our thoughts on the reauthorization. Thank you.

[The prepared statement of Heather Bruemmer appears in the Appendix on page 98.]

The CHAIRMAN. Thank you very much, Ms. Bruemmer.  
Mr. Howell.

**STATEMENT OF TIMOTHY HOWELL, CEO, SENIOR CITIZEN  
HOME ASSISTANCE SERVICES, KNOXVILLE, TN**

Mr. HOWELL. Thank you, Senators on the Special Committee on Aging, for allowing me to address you today. As the CEO of Senior Citizens Home Assistance Services that provides homemaker and personal care to 20 counties in East Tennessee, I see elders and people with disabilities every day that come to me with different situations. Although their stories are different, their goal is the same: to maintain their dignity. Their health may be fading and all their mental status diminishing, but they are still human beings, and their dignity should not be diminished over time.

Senior Citizens Home Assistance Services was formed in 1970 with a grant from the Older Americans Act as a study to see if people could use homemaker services to stay in their homes. Since then we have been on the battle of the forefront of maintaining dignity for our elders.

The majority of the work that we do is through our homemaker and personal care services. We screen, hire, and train caregivers to travel to the home and provide light housekeeping, laundry, shopping, companionship, transportation, and personal care like bathing, feeding, toileting, and grooming. This year we will help over 2,500 people with over 300,000 hours of one on one care to stay in their home.

The good news of this story is that the agency receives funding from many different sources. We have a full fee private pay system so those that can afford to pay for the services can, and then we also receive money from Federal, State, Veterans Administration programs. But I think one of the best things that we have and something that we could have helped Senator Manchin with with his question is that we have a sliding scale fee for people that do not qualify for those government programs, but also may not have the ability to pay the full fee. We have a sliding scale fee because we are able to have fundraisers and we get United Way funding. So if somebody comes to us that does not have—that has a gross income that keeps them from the government programs, then we are still able to help them even though they may have expenses such as a home mortgage or medicines or things like that. So we are still able to help them with a sliding scale fee, and they can pay us like \$7 an hour, \$9 an hour, or \$11 an hour, and so they can still get the help that they need to stay in their homes.

Partnerships are key, we have found, in the battle to provide dignity. We get cleaning supplies donated to us from a local office company so that—for those that cannot afford to purchase them, and we also receive nonperishable foods from Second Harvest, which is another 501[c][3] in our county, and that allows us to give food to those that may not have the ability or the money to pay for their bills at the end of the month, and we can still get them food.

So if you're looking for employment opportunities—and I understand, Mr. Kohl, that you might be since you're retiring—we can hire you; we can train you to be a caregiver. In fact, our oldest caregiver was born in 1921. She is 90 years old and she brings an aspect to caregiving that a person my age cannot do. She is unique with her companionship. She works about 20 hours a week, and she's able to talk to people and relate to them while she's cleaning their homes and helping them stay in their homes. So even on your worst days, she can give you a smile that can brighten up your life.

In fact, over 50 percent of our 310 employees are older than 50. We have a great caregiver training program that our RN and nurse trainer uses to teach people to be a caregiver.

Even with all our programs to keep people in their homes, we realize that the cost does become expensive at times as their need increases. This is why we built Renaissance Terrace, a 48-unit assisted living facility that charges \$2200 per month for all the services of an assisted living facility in the State of Tennessee. We are able to keep the monthly fee low because we receive Federal, State, and local government funding from Knox County and from the City of Knoxville, as well as private donors and foundations to construct the building. With the construction cost funded, we only have to charge enough to pay for the operating costs, such as payroll and supplies.

The people that live in our facility are able to pay for their help, or the VA may help, or in some cases family members may help pay for the fee. The important fact is that I am not here asking you for more money to pay for my assisted living for the residents of Renaissance Terrace. Through combining your one-time investment with other partners, we developed a program that can sustain itself, sustain itself through the residents paying for their care.

I want to thank you for taking this challenge of providing care to the elders and persons with disabilities while keeping their dignity intact. I encourage you to look for solutions that can maintain and support themselves with an investment from you, but I realize that this will not always be the situation.

Again, I thank you for allowing me to be here, and I will answer any questions that you may have.

[The prepared statement of Timothy Howell appears in the Appendix on page 103.]

The CHAIRMAN. Thank you, Mr. Howell.

I'd like to ask you, Mrs. Marshall. Your home-delivered meals, how important is that in your day and in your week? What would you do if you didn't have the home-delivered meals system?

Ms. MARSHALL. Well, it's hard to know, because I have been able through my whole life to be independent. My son is worried about the fact that I'm alone a lot of the time and he thought that there

should be somebody looking in on me every day. So I ordered the meals on wheels. I get it Monday, Wednesday, and Friday, and there's always someone there in case I should fall or some accident of that sort.

So that takes care of 3 days a week, and it also helps me as far as shopping and cooking for myself. The various foods that I get are well-balanced and healthy. They sometimes need seasoning or fixing up a little bit before you put them in the micro. But it's a very well-balanced, healthy diet, really, and I'm very grateful for it.

On Tuesday and Thursday I'm on my own, and Saturday and Sunday. But I have been very grateful for the fact that I have wonderful sons handy to me and a daughter in New Hampshire who has been a boon to me. I'm very grateful for the help of my children. It may be a burden on them. I'm sure in many ways it is. But I don't hear about it.

The CHAIRMAN. How often do you talk to your daughter in New Hampshire?

Ms. MARSHALL. Well, I really grew up in two communities. I had a grandmother in New Hampshire who had a stroke in her 60s and she lived—she could not speak very well, but she lived at home. And my mother went up to New Hampshire in June every year after school was done and took care of her or helped take care of her, because she was in a wheelchair and completely unable to do anything for herself.

In fact, I never really got to know her because she wouldn't talk very much. She would say "How be ya?" and that was about it. But she was very much beloved by her family, and I have many pictures of her in the wheelchair surrounded by family members.

There wasn't such a thing as meals on wheels at that time. Generally, there were people, and in New Hampshire many country people, because this was in the White Mountains, a village in the White Mountains. So we really had two residences growing up. It was a wonderful, wonderful experience.

The CHAIRMAN. Good.

To the other members of the panel, what is your principal recommendation to us as we go about reauthorizing OAA? Mr. Richtman, would you like to give us your opinion?

Mr. RICHTMAN. Well, I think, as I mentioned in the testimony, we feel it is very important that the committee take into account ways to improve coordination of services, to identify the best practices, things that work in local communities, and make sure that all of the agencies involved have the resources to replicate these best practices around the country.

If I could, Mr. Chairman, to follow up on the question you asked about home-delivered meals, and I hope this isn't presumptuous, but I could give this as a recommendation. You mentioned that I was staff director of this committee in the 1980s and I was involved in previous reauthorizations. There was a member of this committee who was, shall we say, cynical about the Older Americans Act activities, and one of the nutrition service providers from that Senator's State arranged to take that member of the Senate to deliver meals on a truck. The reaction that the Senator had when he met people who had no other way to get a hot meal or

have any interaction with anybody turned him around, and he became a strong advocate for the program.

So I would recommend some first-hand experience by members of the committee with some of these programs.

The CHAIRMAN. That's very good.

Mrs. Bruemmer.

Ms. BRUEMMER. Thank you. I think it's really important that our vulnerable residents in long-term care facilities have access to our ombudsman services, which I addressed in my testimony. We have so many people who are living in long-term care facilities that don't have family, and it's important that the ombudsman, who is their advocate, be able to express their best interests.

Secondly, I think we all know—and you recently had a wonderful hearing on elder abuse. It is occurring in our world, unfortunately, and it's our duty to protect our most vulnerable people that we serve. So it would be wonderful if we could get additional supports and funding to provide training and prevention.

You know, we talk about prevention frequently, and it really does make a considerable difference if we can educate people on how to prevent. We provide prevention services in nursing homes and assisted living to staff, and it really has a positive impact for the people that they serve. And also supporting the National Ombudsman Resource Center, which is such a tremendous support to all the States in the Nation and really benefits our wonderful residents that we serve.

Thank you.

The CHAIRMAN. Thank you, Ms. Bruemmer.

Mr. Howell, what's your principal recommendation?

Mr. HOWELL. I would suggest looking for partnerships and funding opportunities that could be a one-time investment for the government, and then maybe those programs could sustain themselves over time through private pay.

Then also I'd like to say that through the single point of entry system we need more case management from the providers at the time that the help is being asked for. People go through many questions to get into the enrollment process, at least I know in the State of Tennessee they do, and they get asked those questions several different times. So I think we need a system to where once you are asked those questions once it is shared among the service providers and the case managers and the MCOs, so that you don't have to keep going back and asking that elderly person again and again and again, now, what is your income, what is the help that you need, and so forth. Because I know we are going to go out and do an intake and we're looking for things like, does that person have a pet, because I don't need to send somebody as a caregiver into a home that has cat allergies when that person has a cat. Or if they smoke I don't need to send somebody in that home that has asthma.

So if we don't know those things up front, we're already setting ourselves up for disaster in helping that person stay in their home when we don't get all the information that we need.

So those are my two recommendations, just shared information among everyone and look for partnerships so that programs can sustain themselves over time.

The CHAIRMAN. Thank you very much, Mr. Howell.  
Senator CORKER.

Senator CORKER. Thank you, Mr. Chairman.

Ms. Marshall, thank you so much for being here. You mentioned you hope you weren't a burden for your children or grandchildren. I know that's not the case. I'm sure you're a blessing, and there's probably a whole line of people in your community willing to adopt you if they ever felt that was the case. We thank you very much for being here and putting a face on an issue that all of us care about. So thank you very much.

Mr. Richtman, I know as director of the National Committee to Preserve Social Security and Medicare you've been very critical of some legislation I've offered to get spending back to historic norms over the next decade. I understand that, and that's the world we live in today.

Also, it seems you've been very resistant to changes to Medicare that might make it sustainable. There are a lot of people in this town that know Medicare is going to be insolvent or bankrupt in the year 2024. There's no getting around that. CBO even says by 2020. I'm wondering if you have put forth your own innovations or changes to cause Medicare to be solvent and to cause it to be there for seniors down the road?

Mr. RICHTMAN. Well, of course this isn't the subject of this hearing, but I will respond. I think the legislation you're talking about is the bill you authored with Senator McCaskill; is that correct?

Senator CORKER. That's correct, yes.

Mr. RICHTMAN. The concern we have is we feel that some of the process that legislation deals with will lead to dramatic cuts in the programs we advocate for, and will do so in a way that—a more indirect way that maybe politically is easier, but nevertheless the impact would be the same.

On Medicare, you're right, opposed to the bill that was defeated yesterday in the Senate. It had passed the House. We feel that Chairman Ryan's proposal to deal with Medicare in effect eliminates the program, turns it into something entirely different.

Senator CORKER. That really wasn't what I asked, and I understand that and I've read some of the things you've said about that. But my question is have you offered your own solution, since putting our head in the sand would mean that future wonderful people like Mrs. Marshall would not be able to benefit from the program.

Mr. RICHTMAN. I was going to get around to that. We supported the Affordable Care Act, which has some very significant improvements in Medicare, and—

Senator CORKER. Even with the Affordable Care Act, it's insolvent in the year 2024. So I'm trying to ask—

Mr. RICHTMAN. Well, you know, were it not for the Affordable Care Act, the Medicare program would be insolvent much earlier than 2025, which is the date that the trustees have issued. It's true that the date of insolvency went back 4 or 5 years from previous—

Senator CORKER. Closer to today.

Mr. RICHTMAN. Closer to today. Now, a lot of that has to do with the recession, less revenue coming into the program.

Senator CORKER. Mr. Richtman, are you going to answer my question?

Mr. RICHTMAN. I'm trying to, Senator.

Senator CORKER. Well, I wish you'd just get—have you offered solutions to the program? I haven't heard any. Instead of sandbagging people that are, have you offered solutions?

Mr. RICHTMAN. Our solution, which I was trying to explain, included the Affordable Care Act. That is a very positive improvement of Medicare; added 12 years—I'd say that's a pretty good solution—added 12 years to the solvency of the program, added benefits for seniors that they did not have before, such as preventive care without any out-of-pocket costs. So I offer that as a solution. I think it's becoming more and more popular.

Senator CORKER. It's very disappointing that someone in your position would stonewall a situation so important as this.

Let me ask you this. Chairman Kohl and I have both been very fortunate in life, he far more than me, but we both have.

Mr. RICHTMAN. Me too.

Senator CORKER. Would you agree that it would be an appropriate thing for folks like Mr. Kohl and myself to have minimal, if almost no, benefit, where, in other words, Medicare would be more based on ability to pay, where we would have to pay far more for the benefits of Medicare than someone else who might not have been as fortunate? Would you agree that that would be at least a portion of a solution, even though that would not solve it? Would that be something that your organization would support?

Mr. RICHTMAN. No, we would not—you're talking about, I assume, means testing.

Senator CORKER. That's exactly right.

Mr. RICHTMAN. We are opposed to means testing both Medicare and Social Security, and I'll tell you why. These programs, all the polling shows that they are tremendously popular, because they're insurance programs. People pay into them while they're working, and they receive the benefits. Means testing these programs turns these programs into welfare. That's what welfare is, a means-tested program.

I've said this at many events that I participated in. If you ask a group of seniors, how many of you are on Social Security, how many of you are on Medicare, and usually at my meetings they all are. And you say, how many of you are ashamed to be on these programs, nobody is. But if you ask them, would you be proud to be on welfare, they wouldn't. And I think turning these programs into welfare programs, which is what means testing does, puts them in a whole different category, and the support, tremendous majority support for these programs, would dissipate.

So we're opposed to that.

Senator CORKER. Well, portions of Medicare already are means-tested. What I hear you saying is you're more interested in generational theft than you are in—

Mr. RICHTMAN. That's really not fair, Senator. Most of the surveys we've done—in fact, we just did one with Celinda Lake—our members, who are almost all on the program, they are just as concerned that these programs be there for their children and their grandchildren. And I feel that we reflect that, and really, I take

issue with the charge that we're interested in that kind of generational warfare.

Senator CORKER. Well, I'm very disappointed that you've offered no real solutions. But I look forward to talking with you in another venue with that.

Mr. Howell, thank you so much for traveling up here. I notice that, on the other hand, your organization does have a sliding scale ability to pay, and you've found that to be something that's very useful. I wonder if you might describe that in a little bit more detail?

Mr. HOWELL. I'd be glad to. When our board set up the nonprofit in 1970 they wanted to be able to help everyone that came for assistance to the agency. So the sliding scale fee was one good way to do that. I think we have found many benefits from that, and one of them being if we are going to United Way and asking them for funds and let's say they appropriate to us in Knox County somewhere around \$120,000 and then we provide help to a person over here and they are able to pay \$7 an hour and that help costs us somewhere around \$18, \$19 an hour, then we really only have to come up with about another \$11 per hour to get that funding.

So what that does is that allows that money to be stretched out further and to help more people. So we don't usually have a waiting list for services, so if someone calls me I can usually get the help out to them as quickly as they need it. I think that telephone call is important because it's saying, I've given up my ability to do something in my life and so now I need help; will you come do that? So we don't have to put them on a waiting list to do so. We can be there and help them.

I also think in a lot of ways it makes us more accountable because those people are paying for that service. So even—and that sliding scale fee has increased over time. But even if they're paying \$7 an hour, to a person that is in their 80s or in their 90s that's a lot of money to something that they consider to be a maid service come in and helping them clean or getting them transportation or helping them go grocery shopping, getting their medicines, and so forth.

So that is a lot of money to them, and I think some of our proudest moments are when we get a check issued to us from someone and it's for \$28, and that's basically 4 hours of service, but on the bottom of it it says "Thank you," because how many people write "Thank you" on the bottom of their checks when they pay their bills? They do that because they know we are keeping them in their homes with some help. Just a little bit of help will keep them there.

So I think the sliding scale fee has been a great system for the people that we serve.

Senator CORKER. Thank you. And has there been any stigma attached to that, as Mr. Richtman just alluded to?

Mr. HOWELL. In the services that we provide, no, sir, I don't know of any stigma attached to that. We do help people that qualify for the government programs and they're in those and the government is paying for them, and we also help people that have the ability to pay the full fee. So our caregiver may go into the home of a very wealthy person one day and then be in the home of a poor

person the next day. We train them to treat them with the same dignity across the board and with the same help when they go in that home and provide that service to them.

Senator CORKER. Well, listen; thank you very much for being here, and I look forward to the rest of your testimony.

Thank you.

The CHAIRMAN. Thank you very much, Senator Corker.

Senator Casey.

Senator CASEY. Thank you, Mr. Chairman.

What I'll do, for the record, is to submit questions for Mr. Howell, Ms. Bruemmer, and Max Richtman because I have a constituent on the left there, the Mayor, former Mayor of York, and I wanted to speak directly to her for a couple of minutes. You three don't mind, I don't think, but I'm grateful. I appreciate all of your testimony and the work that you do. I've known Max Richtman a long time, and I appreciate his advocacy for many years on behalf of older citizens.

But I did want to direct my maybe just a comment or two, Mayor. First of all, once a mayor always a mayor, and we appreciate your public service to the city of York. Being a Mayor, being a member of City Council at any time, is a difficult job, and we appreciate what you did and what you continue to do for the community in York, and for your testimony today.

I was struck by some, a couple of lines in your testimony which in some ways really summarized or encapsulated what we're talking about today, the Older Americans Act. I was looking at your testimony, the last page of your testimony, when you say, and I'm quoting: "Many recipients of services are like me. They just need one or two little bits of help." A pretty good summary of what a lot of people need, and sometimes it varies.

Then you go on to say, and I'm quoting again just a line or two beyond that, quote: "The act is flexible that way and allows the senior to customize their care plan to just what they need to stay healthy," unquote.

We can often talk and talk in this town describing legislation paragraph after paragraph. Rarely do we have a witness who's able to sum it up very directly and with the personal experience that you have brought to this. You've been able to, through your testimony today and I know in other ways, bring to life and be—in a sense, bear witness to the benefits of these services. And we're greatly, greatly appreciative of that, because you didn't have to do that. You could have just lived with the benefit of these services, but to travel here and to bring your story and your witness to this is very, very important, and we're truly grateful.

I know that the whole audience fell in love with you today. I don't think anyone who knows you is surprised by that. But we especially appreciate your testimony and your public service.

I guess the last thing I'd say is, again quoting you, you say a paragraph later, quote: "The beauty of the Older Americans Act is that it allows you to retain your dignity, health, and independence," unquote. You have defined "independence," and we're grateful that you're willing to share your story with us today. And if I can think of an intelligent question I'll write it down and send it



to you, but I think the answer to most of our questions is through your testimony and through your personal witness.

Thank you very much.

Ms. MARSHALL. Thank you so much.

The CHAIRMAN. Thank you, Senator Casey.

I have also one last question for you, Mrs. Marshall. Might you consider making a comeback in politics and running for Mayor?

[Laughter.]

Ms. MARSHALL. Well, I have been active in the grassroots, a grassroots group, and I helped to rejuvenate the Democratic Party because I'm a Roosevelt Democrat. I have always felt that when people needed help they should have some programs that help them, and it just shouldn't be such a matter of who has wealth and who hasn't. Human life is precious.

The CHAIRMAN. Thank you.

Well, we thank all of you for being here today. This has been very important to us as we continue with the reauthorization of OAA. You have made an effort to be here today and it's important and you've made a big contribution. Thank you so much.

Thank you all for being here.

[Whereupon, at 3:38 p.m., the hearing was adjourned.]



# APPENDIX

**Written Testimony of  
Former First Lady Rosalynn Carter  
Rosalynn Carter Institute for Caregiving  
Georgia Southwestern State University  
Americus, Georgia**

**Before the Senate Special Committee on Aging  
Thursday, May 26, 2011**

**“Family Caregiving Issues and the National Family Caregiver Support Program”**

Chairman Kohl and members of the committee,

I am pleased to be here this afternoon and to have this opportunity to speak about caregiving. My interest in the issue goes back to my childhood when I was deeply influenced by how chronic illness affected and shaped my family and by the dedicated and selfless efforts of family caregivers.

Caregiving has been an integral part of my life since I was twelve years old and my father was diagnosed with leukemia at the age of 44. We lived in a very small town – Plains has about 600 residents – and all the neighbors rallied round; but I still vividly remember going to my secret hiding place – the outdoor privy – to cry. I was the oldest child, I felt the burden of needing to help care for my father and my three younger siblings; yet I was scared and didn’t always feel like being strong.

Less than a year after my father died, my grandmother passed away unexpectedly, and my grandfather came to live with us. As he grew older, his needs increased. My mother cared for him at home until he died at 95. During the last few years of his life, he was bedridden and totally dependent on her, me and other family members, neighbors and friends for all his needs.

I like to say that there are only four kinds of people in the world- those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers. Valuing caregiving as a critical component of our nation’s healthcare system is the impetus behind the work that we do at the Rosalynn Carter Institute for Caregiving (RCI).

The Institute was established in 1987 on the campus of Georgia Southwestern State University in Americus, Georgia. We were really charting new ground when the RCI was formed. Our mission targets supporting caregivers and their loved ones who are coping with chronic illnesses and disabilities across the lifespan as well as limitations due to aging.

In the past 3 years, with the corporate support of Johnson & Johnson, we have convened groups of experts in research, program planning, and policy development to examine the evidence-base for caregiver support interventions and the initial efforts to translate evidence-based clinical

research into a community setting. These evidence-based programs have been tested through randomized-controlled clinical trials with the results published in peer-reviewed journals. We as a nation cannot afford for our valuable caregiver support research to sit on a shelf - these programs must be translated into a community setting so that our caregivers can benefit from them. Without these supports, caregivers will experience significantly increased burden as well as psychological and physical ill health, resulting in an increased likelihood of premature institutionalization of the care recipient and additional disability for the caregivers themselves. Even with these early beginnings, we have found that evidence-based caregiver support programs are effective and result in helping caregivers cope with the demands upon them, reducing feelings of burden and stress, improving mental health, and delaying institutionalization.<sup>1-12</sup> More efforts are needed to promote evidence-based programs into the communities to support all caregivers.

Our nation is in need of a fundamental shift in how it values and recognizes caregivers especially in view of the rapidly escalating number of older adults, many of whom live with chronic illness and disabilities. There are 39 million older adults in the U.S. today. By 2030, when all of the baby boomers have reached age 65, the projected number of older Americans is expected to reach 72 million, or roughly 20 percent (1 in 5) of the U.S. population. Approximately 6 million adults over age 65 need daily assistance to live and that number is expected to double by 2030. Approximately 80 percent of older Americans are living with at least one chronic condition, and 50 percent have at least two chronic conditions.<sup>13</sup>

Most frail, elderly and disabled people live at home; and about 90 percent of the care they need is provided by unpaid, informal caregivers. Many of these caregivers are frail and elderly themselves. For many, the burdens of caregiving are enormous. Research studies have repeatedly shown that family caregivers have an increased risk of experiencing depression, grief, fatigue, and physical health problems secondary to exhaustion and self-neglect.<sup>14-16</sup> Consider these facts:

- Older people caring for spouses have a 63 percent higher mortality rate than those of a similar age without caregiving responsibilities;
- The stress of caring for a person with dementia negatively impacts the caregiver's immune system for up to three years after caregiving ends, making them much more susceptible to all kinds of illnesses;
- Caregivers report chronic conditions such as heart disease, cancer and diabetes at twice the rates of non-caregivers;
- Up to 50 percent of caregivers report struggling with depression; and the rates are even higher when caring for a loved one with dementia.

Our nation's family caregivers are enduring both physical and mental problems --- and even dying sooner -- because of the responsibilities they have shouldered to care for their loved ones. Yet without them, where would our country be? The demand for institutional care would increase dramatically; and so would the overall costs. Our already over-taxed health care system would be hard pressed to find the work force necessary to deliver high quality institutionalized

care. And millions more older people would have to live out their final days deprived of the comfort and security of being in their own homes.

The economic value of family caregivers is substantial. Experts have estimated that the services provided by family caregivers are in excess of \$375 billion annually. Benchmarks exist that may help put this value in perspective. This figure is (1) more than total spending for Medicaid, including both federal and state contributions for medical and long-term care (\$311 billion in 2007) and (2); approaching the total expenditures for the Medicare program (\$432 billion in 2007).<sup>17</sup>

The RCI strongly advocates for re-envisioning support for the 65 million family caregivers in our country. We recognize both a moral and economic imperative to fix the broken pipeline between caregiving research and practice in this country. Should we fail to act now, the consequences for care recipients will include increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life. For family caregivers, the consequences will involve declining health and quality of life as well as reduced financial security. The overall impact on our healthcare system will be to bear an unparalleled cost burden for expensive long-term care management with less capacity due to lack of adequate resources.

We can avert this oncoming caregiving crisis. In order to do so, we must address the most pressing unmet needs of family caregivers, including assessment of caregiver health, a lack of adequate training, additional respite care, and greater access to support programs.

Last October the RCI released a very important report, *Averting the Caregiving Crisis: Why We Must Act Now*. This report is the result of three years of intensive study which involved hundreds of experts from around the country. I urge each of you to read it carefully, for it contains a blueprint for a new national initiative to support family caregivers. I want to highlight just four recommendations that are relevant to this Committee's work:

- 1) A National Quality Caregiving Task Force should be created to oversee the caregiving initiative in the President's Office with the possibility of shared leadership between the Secretary of Health & Human Services and the Secretary of Veterans Affairs. The group should include government and private sector leaders and be adequately staffed. Specific activities to be undertaken by this Task Force should include: (1) developing a work plan with priority goals and target achievement dates that focus on communicating a clear vision of the caregiver support system to be created, its components and underlying principles, role in the overall Home and Community-based System, and as a critical part of overall healthcare reform; (2) formalizing and defining agency-specific roles in the evidence-based program product/service development "pipeline" and creating a coordinating body to guide the development and subsequent evaluation of evidence-based programs for caregivers from basic research to implementation and sustainability in the community; (3) defining responsibilities of national, state, and local entities in carrying out the initiative; (4) identifying all related initiatives and their relevance to the current effort; (5) developing public communication and liaison strategies to assure public

awareness and input; and (6) facilitating public-private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

- 2) Assess and monitor caregiver health. We need to establish state-level systems to assess and monitor caregiver health. One way to do this may be to utilize the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of the Older Americans Act funding. If states are required to collect BRFSS data with the caregiver module every two years, they will be able to identify populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, and have data to inform the allocation of resources and the development of programs to support caregivers.
- 3) Ensure the provision of evidence-based programs for caregivers. There is a need for immersion of evidence-based caregiver support intervention programs into current state and private agencies that provide services to older Americans. Knowledge about the effectiveness of caregiver support programs should be rapidly generated and include information about success in serving diverse communities, costs, and cost-effectiveness. Following a public health model, systems of care within states and communities can be augmented to assure that caregivers receive evidence-based interventions tailored to their unique needs and level of risk. Specifically, a menu of services should be available to support each caregiver at a level that is appropriate for that caregiver – much like one might need a more intense dosage of a medication for a more severe illness.

My dream is that one day all programs for caregivers will be evidence-based, but I know that this will not be easy to accomplish. At the RCI, we are building the expertise to do so. Our corporate partner, Johnson & Johnson has a long history of working in this field to better understand late life mental disorders. They were the first to conduct clinical trials in nursing homes at a time when there was virtually little or no research being done in these settings where the prevalence of depression and dementia is so significant. Today they are investing to ensure that knowledge gained about dementia through academic research is made easily available to the 15 million caregivers in communities across the country dealing with this problem.

With Johnson & Johnson's support, the RCI is arming caregivers with information and tools that have proven to improve quality of life. We have introduced evidence-based interventions in ten communities across the country. We also developed a technical assistance program to make sure that participating organizations have the skills and training necessary to ensure successful adoption of the new methods. Today we are expanding this effort in partnership with the Georgia Department of Aging Services and are very grateful for the support provided by AoA for this work. We are eager to share the knowledge we have gained with you.

- 4) Continue funding for the National Family Caregiving Support program. Medicaid home and community-based waiver programs should be expanded to allow for maximum flexibility to support family caregivers with "wrap-around" services and supports that

achieve cost-effectiveness. Additionally, after grant funding by the Administration on Aging ends for successful demonstrations (that is those demonstrations that are cost effective and achieve the desired outcomes), the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. One such legislation that may be able to provide the needed support is the "CLASS Act" (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, to support the development of a new national long-term care insurance program, with inclusion of caregiver support, education and training as components of plan benefits.

As RCI looks to the future to successfully avert the caregiving crisis facing our nation, it is our position that all sectors of government work together to develop timely and effective solutions. To that end, the RCI has met with representatives from the Administration on Aging, (AoA), the Centers for Medicare & Medicaid Services (CMS), Department of Health and Human Services, Office of Disabilities (OD), and the Veterans Administration (VA). RCI has upcoming meetings with these key federal agencies and would be delighted to come back before the committee to update you on outcome oriented recommendations that have evolved from these meetings. I applaud the Senate Special Committee on Aging for its efforts to focus on ways to help our health and long-term care system to support and sustain America's family caregivers.

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AVERTING THE  
CAREGIVING CRISIS

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## I. PROLOGUE

The Rosalynn Carter Institute for Caregiving (RCI) was established in 1987 at Georgia Southwestern State University (GSW) in Americus, Georgia. RCI was formed in honor of former First Lady Rosalynn Carter, an alumna of GSW, to enhance her long-standing commitments to human development, caregiving and mental health. At its core, the mission of RCI is to foster local, state and national partnerships committed to building quality long-term, home and community- based services. RCI's focus includes supporting caregivers and their loved ones who are coping with chronic illnesses and disabilities across the lifespan.

This report is based on RCI's more than three years of intensive study of the caregiving process, evidence-based programs to help family caregivers, and current translational strategies for making effective programs widely available to caregivers. Our efforts began in 2007, with funding from one of our corporate partners, Johnson & Johnson. We endeavored to bring together experts in research, program planning, and policy development in support of family caregivers. A national summit was convened with over 300 leading caregiver researchers and agency leaders from around the country to examine the evidence-base for caregiver support interventions and the extent to which it was being applied in practice. One of the summit's key findings was that although many interventions with proven positive outcomes for caregivers have already been developed, most have not been translated into programs at the community level. Without these supports, caregivers will experience significantly increased burden as well as psychological and physical ill health, resulting in an increased likelihood of premature institutionalization of the care recipient and additional disability for the caregivers themselves.

The consensus reached among summit participants was that our nation is in need of a fundamental shift in how it values and recognizes caregivers. Following the summit, RCI convened six national meetings to share findings across key stakeholders and develop consensus about recommendations for change. Additionally, RCI launched several other key initiatives. The first was the development of a network of community coalitions (CARE-NETS) that provides a forum for addressing the needs of caregivers in a concerted and coordinated way. The second was embarking on a new venture called the National Quality Care Network (NQC�N) as a vehicle for innovation, information sharing, and stimulating partnerships for action in our communities. The NQC�N is a learning collaborative comprised of community-based demonstration sites and program developers working to implement, disseminate, and maintain effective translational strategies. Ultimately, the NQC�N aims to create supportive policies and secure long-term, sustainable funding for the integration of caregiver programs within community systems. The third initiative was the distribution of more than \$1 million in grants to the NQC�N to support the timely dissemination and wide accessibility of effective caregiver interventions. The fourth initiative is RCI's CARE Report that will share the translational experiences of providers who have successfully integrated evidence-based programs for caregivers into their respective healthcare settings.

RCI strongly believes that a **National Caregiving Initiative** is necessary to provide an umbrella for disparate caregiving efforts across Federal, state, and local agencies, the private sector, voluntary health organizations, corporations, and private philanthropy. To avert the caregiving crisis, it is critical for us to begin the dialogue that will create momentum and focus to address family caregiver issues as part of overall healthcare reform. The recommendations delineated in this paper represent RCI's effort to launch this national dialogue.

## II. EXECUTIVE SUMMARY

While there is no universally agreed-upon definition, the terms “informal caregiver,” “unpaid caregiver,” and “family caregiver” are often used interchangeably to refer to the estimated 65.7 million Americans who have provided unpaid assistance to an adult or child with functional and/or cognitive limitations. These dedicated caregivers provide between 80 to 90% of the long-term care provided at home to over nine million elderly or disabled individuals.

Today’s caregivers are responsible for providing a wide range of assistance to their loved ones, often involving complex nursing care (e.g., respiratory care, medication management and dispensing, medical monitoring), cognitive support (e.g., management of delirium or agitation, ensuring safety), and care management, both in home (e.g., supervision) and out of home (e.g., arranging medical care appointments). Although the amount of weekly care provided by family caregivers varies greatly, reports have consistently documented that a “typical” caregiver provides an average of 21 hours of care per week. For care recipients who require extensive dependent care, such as persons with Alzheimer’s disease, the estimated 9.8 million caregivers provide 8.4 billion hours of care each year.

Estimates have consistently projected that the need for family caregiving in the United States (U.S.) will escalate significantly in the coming decades. This increase in demand can be attributed to several key trends, including an aging demographic, increased longevity, the growing burden of chronic illnesses, and an overburdened formal healthcare system. Not only are more Americans living longer but the proportion of older adults in the U.S. population (i.e., 65 years or older) is growing rapidly. There are 35 million older adults in the U.S. today. By 2030, when all of the baby boomers have reached age 65, the projected number of older Americans is expected to reach 71 million, or roughly 20 percent (1 in 5) of the U.S. population. Approximately 6,000,000 adults over age 65 need daily assistance to live and that number is expected to double by 2030. About 80 percent of older adults have at least one chronic condition such as arthritis, hypertension, heart disease, diabetes, and respiratory disorders. Over 50 percent of older adults have at least two chronic conditions. Although chronic conditions can often be controlled or alleviated with medications, healthy lifestyle choices (e.g., smoking cessation, physical activity and good nutrition), and other therapies, many chronically ill adults become frail or incapacitated, resulting in an increased need for dependent care.

Experts have estimated that the economic value of services provided by family caregivers is in excess of \$375 billion annually. This figure is (1) as much as the total expenditures for the Medicare program (\$342 billion in 2005); (2) more than total spending for Medicaid, including both federal and state contributions for medical and long-term care (\$300 billion in 2005); (3) far more than the total spending (public and private funds) for nursing home and home healthcare in the U. S. (\$206.6 billion in 2005); and (4) more than four times the total amount spent on formal (paid) home care services (\$76.8 billion in 2005).

Although we know that many caregivers experience no adverse health effects related to caregiving, 20% to 30% fare very poorly. These caregivers are often more prone to depression, grief, fatigue, and physical health problems, all of which may have roots in stress, exhaustion, and self-neglect. Increased use of alcohol, smoking and other drugs are not uncommon, as are poor health behaviors such as inadequate diet, exercise, and sleep. Additional risks are a suppressed immune system leading to frequent infection and an increased risk of heart disease, diabetes, stroke and premature mortality. Caregivers experience chronic conditions at nearly twice the rate of noncaregivers. Although individuals who take on the caregiving role are generally physically healthier than those who do not, evidence suggests that at least one in ten caregivers report caregiving as the cause of their physical health’s deterioration.

It is imperative that we recognize that the confluence of our overburdened healthcare system with an aging population has created both a moral and economic imperative to fix the broken pipeline between caregiving research and practice in this country. Should we fail to act now, the consequences for care recipients will include increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life. For family caregivers, the consequences will involve declining health and quality of life as well as reduced financial security. The overall impact on our healthcare system will be to bear an unparalleled cost burden for expensive long-term care management with less capacity due to lack of adequate resources.

We can avert this oncoming caregiving crisis by re-envisioning support for family caregivers. In order to do so, we must address the most pressing unmet needs of family caregivers, including a lack of adequate training, additional respite care, and greater access to support programs. To address these unmet needs, RCI strongly advocates that the following twelve imperative actions across three focus areas, including (a) Research and Development, (b) System Design, and (c) Public and Tax Policy, are adopted through a **National Caregiving Initiative**:

#### A. RESEARCH AND DEVELOPMENT

**Recommendation 1: Leadership and Coordination.** There must be top-level direction that promotes integrated planning and action in order to increase the efficiency and speed of development of this proposed system, to minimize conflicts and duplication of efforts, and to assure accountability for outcomes. A National Quality Caregiving Task Force should be created to oversee this initiative in the President's Office with the possibility of shared leadership between the Secretary of Health & Human Services and the Secretary of Veterans Affairs. The group should include government and private sector leaders and be adequately staffed. Specific activities to be undertaken by this Task Force should include: (1) developing a work plan with priority goals and target achievement dates that focus on communicating a clear vision of the caregiver support system to be created, its components and underlying principles, role in the overall Home and Community-based System, and as a critical part of overall healthcare reform; (2) formalizing and defining agency-specific roles in the evidence-based program product/service development "pipeline" and creating a coordinating body to guide the development and subsequent evaluation of evidence-based programs for caregivers from basic research to implementation and sustainability in the community; (3) defining responsibilities of national, state, and local entities in carrying out the initiative; (4) identifying all related initiatives and their relevance to the current effort; (5) developing public communication and liaison strategies to assure public awareness and input; and (6) facilitating public-private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

**Recommendation 2: Monitor Caregiver Health.** We need to establish state-level systems to monitor caregiver health by requiring states to adopt the Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of Older Americans Act funding. If states are required to collect BRFSS data every two years, they will be able to identify sub-populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, better allocate Older Americans Act funding and other resources, and begin to develop programs that are in line with strategic priorities.

**Recommendation 3: Outreach and Public Education.** We need to reach caregivers at risk of ill health due to high burden. We must educate the public about the critical and often difficult role of caregiving and empower communities to assist caregivers in their work. A national outreach and public education campaign

should be funded by the Department of Health and Human Services using resources of the Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, and Administration on Aging.

**Recommendation 4: Professional Development.** It is imperative that persons who actively work with family caregivers (e.g., professionals, paraprofessionals and volunteers), be equipped with the skills necessary to assure an effective and successful working relationship. Skills training should encompass implementation protocols specific to culturally-sensitive, evidence-based programs for family caregivers. The provision of licensing and certification in evidence-based program implementation should be made affordable and widely available.

**Recommendation 5: Accelerate Research and Development.** Knowledge about the effectiveness of different systems of caregiver support should be rapidly generated, and include information about success in serving diverse communities, costs, and cost-effectiveness. Multi-site demonstration projects should be initiated to test the effectiveness of different configurations of evidence-based programs within the Center for Innovation at the Centers for Medicare and Medicaid Services. All future caregiver demonstration projects should be encouraged to examine and publish comparable cost-effectiveness and cost-efficiency data.

#### **B. SYSTEM DESIGN**

**Recommendation 6: Establish Services in Natural Settings to Improve Access.** We need to facilitate access to support programs for caregivers. Caregivers are more likely to access needed services in the course of their normal activities and responsibilities, such as while visiting their doctor or taking their loved one to the doctor, upon hospital admission and discharge, through the faith community, and while at work. We recommend providing opportunity grants, training and technical assistance to help diverse agencies and organizations build capacity to provide evidence-based programs for caregivers.

**Recommendation 7: Make Professional Assessment and Triage Available to All Caregivers.** Caregivers should be provided access to skilled professionals who can routinely perform culturally competent caregiver risk and needs assessments. Assessments should result in a care plan specifically related to the level of risk identified and should contain specific and measurable outcomes. Routine assessments already being conducted by healthcare providers (hospital discharge, home care, outpatient rehabilitation) or government-funded (Area Agencies on Aging) should be revised to include a caregiver component. Moreover, government and other third-party payers should reimburse healthcare providers for conducting a caregiver assessment.

**Recommendation 8: Assure Caregiver Services are Evidence-Based, Culturally-Sensitive, and Tied to Caregiver Programs.** A standard of care within the aging network should be adopted that offers a menu of service options and interventions of increasing intensity to address the varying needs of caregivers based on their levels of risk. One approach would be to revamp the National Family Caregiver Support Program to ensure the provision of evidence-based programs.

**Recommendation 9: Establish a National Resource Center on Evidence-Based Caregiver Programs.** Information on implementing and translating evidence-based programs for caregivers should be centralized to support widespread adoption across communities. A National Resource Center should be authorized and funded to track successful implementation and translation activities and assure that guidance and training processes are in place. A special focus at the National Resource Center should be placed on culturally appropriate programming.



**Recommendation 10: Technical Assistance for Providers.** Affordable and culturally-sensitive technical assistance networks should be created to ensure widespread and effective implementation of evidence-based programs for caregivers. These networks could be university or community-based that tap into local and national expertise in capacity building, evaluation, and systems design.

### C. PUBLIC AND TAX POLICY

**Recommendation 11: Tax and Public Policy Changes.** It should be a national goal to preserve family caregiving as a viable option by protecting families from economic hardship associated with caregiving, and to create incentives for family caregivers to increase their skill level to provide sustained higher-quality care. A caregiver credit should be designed under the Social Security System as suggested by the General Accounting Office. Such a credit would: (1) allow a specified amount of caregiving time (3 to 4 years), to count as covered employment, and assign a wage to that time; (2) exclude a limited number of caregiving years from the benefit calculation so that earnings are averaged over fewer years; or (3) supplement caregivers' retired worker benefits directly, in proportion to the time they took time out of the workforce for caregiving. Tax credits should be made available to family caregivers, such as those proposed in the CARE Act in the 110th Congress and currently under consideration in several states (Caregiver Assistance and Relief Act, 2007). To combat caregivers leaving the workforce, there should be a policy mandate for flexible work arrangements wherever feasible. Incentives should be created for family caregivers to participate in evidence-based programs that increase their skills and knowledge. Tying tax credits to caregiver participation in such programs also should be strongly considered. Additionally, government entities and other payors should provide vouchers for care recipients to pay minimum wage to family caregivers upon completion of required training.

**Recommendation 12: Targeted Investments and Sustainable Funding.** It should be a national priority to support the development of an essential infrastructure to serve family caregivers, and to promote adoption, implementation, and maintenance of the most effective programs. Investment should be made in an expanded nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible. Funding for the Alzheimer's Disease Supportive Services Program of the Administration on Aging should be expanded, and additional funding should be provided for the National Family Caregiver Support Program for program expansion. Medicaid home and community-based waiver programs should be expanded to allow for maximum flexibility to support family caregivers with "wrap-around" services and supports that achieve cost-effectiveness. Additionally, after grant funding by the Administration on Aging ends for successful demonstrations, the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. Moreover, the "CLASS Act" (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, should be quickly implemented to support the development of a new national long-term care insurance program, with inclusion of caregiver support, education and training as components of plan benefits.

As RCI looks to the future, to successfully avert the caregiving crisis facing our nation, it is our position that all sectors of society must come together in new ways to develop effective and timely solutions. The broad and coordinated response outlined in RCI's **National Caregiving Initiative** will require a fundamental shift in how we, as a country, recognize the invaluable contributions of family caregivers as the true backbone of our nation's long-term care system.

### III. THE EMERGING CAREGIVER CRISIS

#### A. Who Are Family Caregivers: An At-A-Glance Look

While there is no universally agreed-upon definition, the terms “informal caregiver,” “unpaid caregiver,” and “family caregiver” are often used interchangeably to refer to adults who provide assistance to relatives, neighbors or family members who are frail, ill or disabled.<sup>1</sup> Today, an estimated 65.7 million Americans serve as unpaid family caregivers<sup>2</sup>, providing approximately 80 to 90% of the long-term care at home to over nine million elderly or disabled individuals.<sup>3-6</sup>

Although the majority of family caregivers are women (66%), the proportion of men serving as caregivers is growing.<sup>2</sup> While most family caregivers are spouses of care recipients<sup>2</sup>, others may be the care recipient’s child, sibling, grandchild, or close friend. Caregivers are culturally diverse, representing a milieu of racial and ethnic backgrounds including non-Hispanic White (72%), African-American (13%), Hispanic (2%) and Asian-American (2%).<sup>2</sup> With regards to education level, four in ten caregivers are college graduates (43%), although three in ten have had a high school level education or less (29%).<sup>2</sup>

A “typical” family caregiver is an average age of 49.2 years and has served as a caregiver for about 4.6 years.<sup>2</sup> An estimated 13% of caregivers caring for older adults are themselves aged 65 or older.<sup>7</sup> Over 73% of caregivers report being employed while providing care to a loved one, 50% of whom have had to make work-related adjustment (e.g., taking frequent time off, reducing to part-time work hours, or taking a leave of absence) in order to be a caregiver.<sup>2,8</sup> Employed caregivers are evenly split between blue- and white-collar workers,<sup>9</sup> with four in ten caregivers reporting a household income of \$50,000 or less.<sup>2</sup>

#### B. What Do Family Caregivers Do: An Overview of Activities

Family caregivers are responsible for providing a wide range of assistance to their loved ones. An estimated 56% of caregivers provide hands-on assistance with one or more activities of daily living (ADLs), such as eating, bathing, dressing, toileting, and transferring.<sup>2</sup> In addition, caregivers often help the care recipient with instrumental activities of daily living (IADLs) including transportation, housework, grocery shopping, meal preparation, managing finances, and performing medical therapies or treatments. On average, family caregivers help with at least two ADLs and four IADLs.<sup>2</sup>

When defining the work of caregiving in the context of ADLs and IADLs, it is important to acknowledge that such tasks are not simple in nature. Rather, they often require complex nursing skills (e.g., respiratory care, medication management and dispensing, medical monitoring), cognitive support (e.g., management of delirium or agitation, ensuring safety), and care management, both in home (e.g., supervision) and out of home (e.g., arranging medical care appointments). In fact, a growing number of researchers and advocates in the field of caregiving have expressed that ADLs and IADLs fail to adequately capture the true work of family caregivers by ignoring the context of caregiving.<sup>10</sup> To address this gap, researchers have proposed that the following additional contextual features of caregiving be considered when assessing a caregiver’s true workload: (1) *frequency of care provision* – whether care is required rarely, frequently but with predictability, or frequently in unpredictable ways; (2) *caregiver’s proximity to the care recipient* – whether the caregiver resides in the same household as the care recipient, or within a close distance, or whether they are distant caregivers; (3) *effort* – how much effort is required to provide care, from

persuading to complete guidance and control; and (4) *participation level of the care recipient* – whether it is active, passive or resistant.<sup>11</sup>

Although the amount of weekly care provided by family caregivers varies greatly, reports have consistently documented that most caregivers provide an average of 21 hours of care per week.<sup>2,12,13</sup> For care recipients who require extensive dependent care, such as persons suffering from Alzheimer's disease, an estimated 12.5 billion hours of care are delivered each year by approximately 10.9 million caregivers.<sup>14</sup> While most caregivers take on the brunt of caregiving themselves, many require additional hands-on support to meet the daily needs of the care recipient. Reports documenting the prevalence of secondary support sources indicate that 66% of family caregivers say at least one other unpaid caregiver helps their care recipient and another 35% of caregivers rely on paid help from aides, housekeepers, or others to help their care recipient.<sup>2</sup>

Regardless of the approach used to capture the extent and activities of caregiving, it is irrefutable that family caregivers constitute one of the most pervasive sources of support for people who need assistance due to frailty, illness or disability. Simply put, the enormous and valuable contributions of family caregivers is unquestionably helping to sustain our nation's long-term care system.<sup>15</sup>

### **C. Why Are Family Members Invaluable but Neglected Partners in the Healthcare Paradigm**

#### **1. Escalating Need for Family Caregiver Services**

Estimates have consistently projected that the need for family caregiving in the U.S. will escalate significantly in the coming decades.<sup>4,16</sup> This increase in demand can be attributed to several key trends, including an aging demographic, increased longevity, the growing burden of chronic illnesses, and an overburdened formal healthcare system.<sup>2,4,16</sup>

##### **i. Aging Demographic, Increased Longevity and the Growing Burden of Chronic Illnesses**

Not only are more Americans living longer but the proportion of older adults in the U.S. population (i.e., 65 years or older) is growing rapidly.<sup>16</sup> Today, there are 35 million older adults in the U.S.<sup>17</sup> By 2030, when all of the baby boomers have reached age 65, the projected number of older Americans is expected to reach 71 million, or roughly 20 percent (1 in 5) of the U.S. population<sup>4</sup>.

Approximately 6,000,000 adults over age 65 need assistance with activities of daily living, a number expected to double by 2030.<sup>4,16</sup> Among the U.S. population, there has been an increase in the number of individuals with a reported disability from 44.1 million in 1999 to 47.5 million in 2005, comprising 21.8% of all Americans.<sup>16</sup> Over one-third of those reporting a disability are from the aging baby boomers.<sup>16</sup> It has been speculated that these higher rates of disability may be due to the rapid population growth among African-American and Hispanic communities, where higher proportions of conditions such as obesity and diabetes adversely impact functional abilities and health status.<sup>16,18</sup>

About 80% of older Americans have at least one chronic condition such as arthritis, hypertension, heart disease, diabetes, and respiratory disorders.<sup>18,19</sup> Over 50% of older adults have at least two chronic

conditions to manage. While chronic conditions can often be controlled or alleviated with medications, healthy lifestyle choices (e.g., smoking cessation, physical activity and good nutrition), and other therapies, many chronically ill adults become frail or incapacitated, resulting in an increased need for dependent care.<sup>4,16,20</sup>

## ii. Overburdened Formal Healthcare System

With an aging population, an increase in disability rates, and the pressing need to effectively manage care for Americans living longer with chronic illnesses, there are growing concerns about our formal healthcare system's capacity to meet the needs of the public. One of the primary concerns is the lack of sufficient numbers of healthcare professionals needed to render care. By 2030, the U.S. will need an additional 3.5 million formal healthcare providers, a 35% increase from current levels, just to maintain the current ratio of providers to the total population.<sup>4</sup>

Among healthcare professionals, nurses are at the forefront of providing long-term care at both institutional settings and the care recipient's home. Since the late 1990s, our nation has faced a shortage of qualified nurses.<sup>21</sup> Today, there are nearly 20,000 nurse vacancies in long-term care settings.<sup>22</sup> The current nursing shortage is projected to affect healthcare until 2020.<sup>23</sup> Unlike past shortages, this one results from a broad set of factors, including an aging population, fewer young workers entering the healthcare workforce, an aging nursing workforce, increased employment options for women, and increased dissatisfaction with the workplace.<sup>23-25</sup>

Another resource limitation causing concern is institutional capacity. According to national surveys, the overall occupancy rate for the 1.7 million beds across nursing homes is about 86%, with wait lists being common place at many institutions given the average length of stay is 835 days for a typical nursing home resident.<sup>26,27</sup> In addition to nursing home capacity limitations, home health agencies are projected to experience significant challenges in meeting the needs of care recipients. Recent reports from the Visiting Nurse Agencies (VNAs) indicated a 10% vacancy rate for registered nurse positions, and 59% of VNAs report that they are forced to decline patient referrals weekly due to staffing limitations.<sup>28</sup>

## 2. Recognizing the Unparallel Contributions of Family Caregivers

Healthcare expenditures in the U.S. are currently about 18% of the Gross Domestic Product (GDP), and this share is projected to rise sharply.<sup>29</sup> The total amount our nation spends on long-term care services alone is about \$206.6 billion.<sup>30</sup> If healthcare costs continue to grow at historical rates, the share of GDP devoted to healthcare in the U.S. is projected to reach 34% by 2040.<sup>31</sup> At present, the U.S. spends about \$7,400 per person on healthcare each year. Adults aged 65 and older have the highest healthcare spending, averaging \$8,776 per person in 2006. Experts estimate that chronic diseases are responsible for 83% of all healthcare spending.<sup>32</sup> Approximately 96% of Medicare spending and 83% of Medicaid spending is for people with chronic conditions.<sup>32</sup> Healthcare spending for a person with one chronic condition, on average, is two and a half times greater than spending for someone without any chronic conditions. The average annual healthcare coverage cost for people with a chronic condition is \$6,032, five times higher than for people without such a condition.<sup>33</sup> Nationwide, the median nursing home cost is \$74,000 a year, but costs can easily reach \$100,000 a year in some parts of the country. Assisted living facilities average \$36,000 per year, and home health services average \$29 per hour.<sup>34</sup>

Without the unparalleled contributions of family caregivers, our formal healthcare system would be completely bankrupt. The unpaid services provided by family caregivers have a substantial economic value that vastly exceeds the value of paid care. The estimated unpaid contributions of family caregiving was valued at about \$375 billion (2007 dollars), up from an estimated \$350 billion (2006 dollars).<sup>35</sup> A few benchmarks can help put this figure in meaningful context. The estimated \$375 billion is:

1. As much as the total expenditures for the Medicare program (\$342 billion in 2005).
2. More than total spending for Medicaid, including both federal and state contributions and both medical and long-term care (\$300 billion in 2005).
3. Far more than the total spending (public and private funds) for nursing home and home healthcare in the U. S. (\$206.6 billion in 2005).
4. More than four times the total amount spent on formal (paid) home care services (\$76.8 billion in 2005).

Although family caregivers are saving our economy billions annually, caregiving can be financially devastating. Caregivers may be forced to dramatically cut their work hours or quit their jobs in order to continue to provide care to their loved ones, resulting in not only lost wages for caregivers but also lost Social Security benefits. Over their lifetime, it is estimated that a family caregiver will experience about \$659,000 in lost wages, pensions, earned interest, employer-matched retirement savings and Social Security benefits.<sup>19,36</sup> In addition, many family caregivers struggle financially as they spend their own money for home modifications, medications, groceries, and other expenses.<sup>2,8</sup> Recent studies have documented that about half of caregivers contribute financially to their loved ones, spending an average of \$200 per month (\$2,400 per year). Caregivers who have the greatest level of caregiving burden report spending approximately \$324 per month (\$3,888 per year) out of pocket.<sup>12</sup>

### **3. The Plight of Family Caregivers: Impact of Caregiving on the Caregiver's Health and Quality of Life**

Today's family caregivers face an array of new challenges, including smaller, more geographically dispersed families, competing childrearing duties, and the need to balance work and caregiving. In addition, the type of assistance that caregivers provide has changed considerably. Today's care is of longer duration, often lasting five or more years. Caregiving is more technically and physically demanding, requiring performance of tasks that only skilled nurses performed just a decade ago.<sup>2</sup> Care recipients are often released from hospitals "quicker and sicker", resulting in family members being responsible for skilled nursing care with minimal preparation or training.<sup>37,38</sup> Thus, the "home hospital" has become a reality. These circumstances create additional physical and emotional stress for caregivers, thereby adversely impacting their overall health, well-being and quality of life.

The impact of caregiving on the caregiver has become the subject of heightened concern. Research studies have repeatedly shown that family caregivers have an increased risk of experiencing depression, grief, fatigue, and physical health problems secondary to exhaustion and self-neglect.<sup>2,11,39</sup> In general, women caregivers report more stress and suffer from greater morbidity as a result of caregiving than men caregivers.<sup>40,41</sup> Moreover, the increased use of alcohol, smoking and other drugs are common as coping strategies among caregivers, as is poor health behaviors such as inadequate diet, exercise, and sleep.<sup>42</sup>

Additional health risks associated with caregiving include a suppressed immune system leading to frequent infections, and an increased risk of heart disease, diabetes, stroke and other chronic conditions.<sup>2,16,19,43,44</sup>

The plight of family caregivers has been acknowledged as a critical public health issue because caregiving impacts both the care recipient and the caregiver.<sup>16</sup> To avert caregivers becoming care recipients themselves, the need for supportive action is pressing.<sup>45,46</sup>

#### **D. When Should We Act: Averting the Family Caregiver Crisis Now**

It is imperative that we recognize that the confluence of our overburdened healthcare system with an aging population has created both a moral and economic imperative to translate caregiving research into effective community programming in our country. Should we fail to act now, the consequences will be multi-fold for care recipients, family caregivers, and our nation's formal healthcare system.

The inability to successfully support family caregivers will likely have disastrous consequences. The consequences for care recipients will be increased rates of institutionalization, higher risks of abuse and neglect, and decreased quality of life.<sup>38,47-51</sup> The consequences for family caregivers will involve declining health and reduced financial security.<sup>2,16,52</sup> There will also be overall consequences for our healthcare system including an unparalleled cost increases for expensive long-term care management.

With the recent enactment of the Patient Protection and Affordable Care Act (PPACA), our nation has taken a promising step toward recognizing the need for inclusion of family caregivers as valued partners to formal home and community-based service providers.<sup>53</sup> The PPACA emphasizes the importance of care coordination between family and formal caregivers as a means of removing barriers to accessing care. Furthermore, it requires programs to facilitate shared decision-making between patients, their formal health care providers, and their family caregivers. Moreover, the PPACA mandates provisions for family caregiver instruction and training on the management of psychological and behavioral aspects of dementia, communication techniques for working with individuals who have dementia, and proper medication management. Although the impact of the PPACA on addressing the many support needs of family caregivers remains unknown, it is an encouraging component of health care reform legislation.

### **IV. RE-ENVISIONING SUPPORT FOR FAMILY CAREGIVERS**

#### **A. The Unmet Needs of Family Caregivers**

As a nation, we must re-envision support for family caregivers if we are to sustain the backbone of our long-term healthcare system. In order to do so, we must address the most pressing unmet needs of family caregivers, including the lack of adequate training, respite, and access to support programs.

Despite home-based medical technologies becoming more widely available, to date little attention has been directed toward identifying, developing, and disseminating the education and training needed to provide care recipients and their caregivers with the skills they need to manage complex technologies and treatment regimens.<sup>52,54-58</sup> Family caregivers often need to perform complex medical tasks such as wound care and coordinate patient care, make decisions and solve problems while they prepare meals, provide assistance with toileting and bathing, and run the household. Difficulties in care provision are frequently compounded if the care recipient has cognitive or neuropsychological symptoms.<sup>37</sup> Today's caregivers not

only face physical and emotional health risks, but many also do not feel prepared with the skills and knowledge they need to provide sustained care for a person with a chronic illness.<sup>37</sup> To be successful in their roles, caregivers require information, access to resources and support to facilitate their role.

Research has consistently shown that family caregivers have concerns in five areas: (1) dealing with change, (2) managing competing responsibilities and stressors, (3) providing a broad spectrum of care, (4) finding and using resources, and (5) addressing emotional and physical responses to care.<sup>59-63</sup> Many studies have documented that these areas of concern remain inadequately addressed.<sup>62,63</sup> Unfortunately, far too often, caregivers report receiving insufficient guidance from their healthcare providers, not knowing how to perform caregiver roles or access and utilize existing resources, and lack of familiarity with the type and amount of care needed.<sup>48,49</sup> As a response, the Institute of Medicine has recommended that family caregivers receive training to improve the care received by older adults and to lessen the strain on these caregivers.<sup>4</sup> Similarly, the American College of Physicians has issued recommendations that physicians develop care plans that are patient- and caregiver-specific and provide information, training, and referrals to support those plans.<sup>61</sup> Office visits and hospitalizations are opportunities for physicians to assess caregiver well-being and listen to their concerns. Physicians may provide appropriate education and social service referrals and identify needs for future patient placement or respite care. When caregivers become skilled in their responsibilities, they are able to acknowledge and accept the changes in their lives and transform their attitudes and experiences into something more positive, even if they do not necessarily like those changes.<sup>48</sup> Although skilled caregivers are still often stressed, they are also able to better balance their personal, family, and caregiving responsibilities.

## **B. Strategies for Addressing the Needs of Family Caregivers**

### **1. Implementing Evidence-Based Programs**

During the past decade, research has led to a better understanding of the processes by which the stresses and demands of caregiving can adversely affect the caregiver's health and lead to nursing home placement for the care recipient. On the basis of this research, substantial headway has been made in developing interventions that result in improved caregiver outcomes. These interventions are multi-dimensional and typically include family and community support groups, respite care, skill training and individual counseling. A growing number of these interventions have undergone rigorous randomized controlled trials to be considered evidence-based programs (EBPs). Collectively, EBPs for family caregivers have been found effective in helping caregivers cope with the demands of caregiving, reducing feelings of burden and stress, improving mental health, increasing satisfaction with social support, enhancing feelings of self-efficacy, successfully managing problem behaviors of care recipients, and in delaying institutionalization of care recipients, and reducing the cost of care.<sup>64-73</sup>

Taken together, the literature highlights the following key attributes as important dimensions of successful EBPs for family caregivers<sup>74</sup>:

1. A heavier "dosage" of treatment over a longer period of time is more effective than shorter, lower dose interventions
2. Periodic caregiver contact with a professional who delivers specific intervention protocols is important in achieving positive outcomes

3. Interventions and care plans must be tailored to the caregiver's specific needs and risk factors with flexibility to meet the changing demands of care
4. The most successful interventions are those that are multi-component including a combination of education, skill building, problem solving training, counseling, direct services and altering the physical environment to address priority needs
5. Rigorous scientific evaluation (i.e., randomized controlled trials) is necessary to test programmatic efficacy
6. Demonstrated results of the intervention (e.g., improved mental health, better quality of life, reduced caregiver burden and strain, delayed nursing home use) have been published in a peer-reviewed scientific journal

Although EBPs have proven effectiveness for family caregivers, little effort has gone into deploying these programs widely in the community. For the most part, EBPs have not been viewed as a vital public health resource to be embedded in the community and made widely available. Instead, they have been viewed as limited efforts offered primarily to those caregivers who seek assistance on their own. To date, none of the EBPs for family caregivers have been integrated into the aging network of services, the National Family Caregiver Program, health and long-term care services, or sustainable funding streams such as health insurance, HMOs, Medicaid and Medicare programs.

RCI's experience indicates many reasons why these EBPs are not being widely implemented. These include a lack of awareness that effective programs exist, inadequate funding to sustain the programs, and a dearth of available and affordable training and technical assistance to implement these programs.

## 2. Lessons Learned from Evidence-Based Programs

The widespread adoption of EBPs would significantly enhance the overall health and well-being of caregivers, extend community living for many seniors and people with disabilities, and improve the quality of care delivered. Ideally, the process of creating, implementing, and sustaining EBPs for caregivers would be seamless and efficient. However, it is clear that the transition from research to service is very uncoordinated and disenfranchised. As a result, promising research is shelved rather than put into practice at the community level where it could benefit family caregivers and their care recipients.

The collective experiences of RCI's community partners reveal that translational processes involved in successfully implementing, disseminating, and maintaining EBPs for family caregivers are not well understood. We have identified *three key lessons* learned and a series of questions that need to be addressed in order to enhance the timely integration of EBPs across healthcare delivery settings:

1. Interventions that show efficacy in research settings are rarely ready for translation in practice settings without further refinement, modification and development of support materials (e.g., training manuals). Key questions to be answered include:
  - How much "change" is allowable before the integrity of the intervention is compromised?
  - How do we adapt an intervention and maintain its essential programmatic elements?



- How do we develop and design interventions that are more compatible with healthcare delivery systems?
  - Who decides and how?
  - How do we balance program modification and the needs of real-world settings while maintaining treatment fidelity of the program?
2. Agencies, although motivated and in need, are typically not ready to adopt and implement a complex intervention without building additional internal capacity. Key translational tactics that require attention include:
- Changing organizational “culture” to embrace evidence-based programs.
  - Enhancing institutional infrastructure for data collection, fidelity measurement, staff recruitment, supervision and training.
  - Building capacity to deliver a specific intervention by developing expertise; referral, intake and tracking systems; and heightened awareness through public education and outreach campaigns.
  - Developing a common set of programmatic outcomes linked to potential reimbursement streams.
3. Host Systems may not support new service and care provision models without fundamental changes in policies, funding, and thinking. Key translational tactics that require attention include:
- Agency may have capacity to deliver the intervention, but the funding, policies and procedures, hiring restrictions, regulations, etc. of the Host System may be incompatible with integration of new or enhanced service delivery models.
  - Host System and agency goals and priorities may be out of alignment and not permissive of seamless program integration and translation.

A growing body of evidence strongly suggests that the window of opportunity to effectively address the emerging caregiving crisis in our nation is closing quickly. Therefore, business as usual is no longer a viable option.

## V. TWELVE RECOMMENDED ACTIONS FOR IMPLEMENTING A NATIONAL CAREGIVING INITIATIVE

To avert the oncoming caregiving crisis, RCI believes that our nation must re-envision support to family caregivers. In order to do so effectively, we must address the most pressing unmet needs of family caregivers, including a lack of adequate training, additional respite care, and greater access to support programs.

RCI strongly advocates for a **National Caregiving Initiative** to provide an umbrella for disparate caregiving efforts within the Federal government level, state agencies, the private sector, voluntary health organizations, corporations, and private philanthropy. As a nation, we must provide a blueprint for building an evidence-based system of support in a timely manner such that focused momentum is created to incorporate family caregiving as a critical component of healthcare reform.

RCI recommends the following twelve imperative actions across three focus areas, including (a) Research and Development, (b) System Design, and (c) Public and Tax Policy, which would collectively serve as the foundation for a **National Caregiving Initiative**:

### **A. Research and Development**

**Recommendation 1: Leadership and Coordination.** There must be top-level direction that promotes integrated planning and action in order to increase the efficiency and speed of development of this proposed system, to minimize conflicts and duplication of efforts, and to assure accountability for outcomes. A National Quality Caregiving Task Force should be created to oversee this initiative in the President's Office with the possibility of shared leadership between the Secretary of Health & Human Services and the Secretary of Veterans Affairs. The group should include government and private sector leaders and be adequately staffed. Specific activities to be undertaken by this Task Force should include: (1) developing a work plan with priority goals and target achievement dates that focus on communicating a clear vision of the caregiver support system to be created, its components and underlying principles, role in the overall Home and Community-based System, and as a critical part of overall healthcare reform; (2) formalizing and defining agency-specific roles in the evidence-based program product/service development "pipeline" and creating a coordinating body to guide the development and subsequent evaluation of evidence-based programs for caregivers from basic research to implementation and sustainability in the community; (3) defining responsibilities of national, state, and local entities in carrying out the initiative; (4) identifying all related initiatives and their relevance to the current effort; (5) developing public communication and liaison strategies to assure public awareness and input; and (6) facilitating public-private partnerships, the involvement of faith communities, corporations and voluntary associations, in the work.

**Recommendation 2: Monitor Caregiver Health.** We need to establish state-level systems to monitor caregiver health by requiring states to adopt the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System's (BRFSS) caregiver module as part of Older Americans Act funding. If states are required to collect BRFSS data every two years, they will be able to identify sub-populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, better allocate Older Americans Act funding and other resources, and begin to develop programs that are in line with strategic priorities. Through monitoring at regular intervals, we can ensure that problems of public health importance related to caregiving are detected in order to identify existing and emerging health concerns and target resources towards their prevention and treatment.

**Recommendation 3: Outreach and Public Education.** We need to reach caregivers at risk of ill health due to high burden. We must educate the public about the critical and often difficult role of caregiving and empower communities to assist caregivers in their work. We recommend developing and launching a national outreach and public education campaign to reach caregivers most in need. The campaign should be funded and led by the Department of Health and Human Services using resources of the Centers for Medicare and Medicaid Services, Centers for Disease Control and Prevention, and Administration on Aging. The goals of the campaign would be to: (1) help family caregivers recognize, locate and accept assistance

and, (2) inform the public about the needs of family caregivers and how individuals, communities, employers, and faith communities can best offer help.

**Recommendation 4: Professional Development.** It is imperative that persons who actively work with family caregivers (e.g., professionals, para-professionals and volunteers), be equipped with the skills necessary to assure an effective and successful working relationship. Professional skills training should encompass education on how to assess the needs of family caregivers in a culturally-sensitive manner, how to effectively partner with them, and how to implement protocols specific to evidence-based programs for family caregivers. The provision of licensing and certification in evidence-based program implementation should be made affordable and widely available.

**Recommendation 5: Accelerate Research and Development.** Knowledge about the effectiveness of different systems of caregiver support should be rapidly generated, and include information about success in serving diverse communities, costs, and cost-effectiveness. Multi-site demonstration projects should be initiated to test the effectiveness of different configurations of evidence-based programs within the Center for Innovation at the Centers for Medicare and Medicaid Services. All future caregiver demonstration projects should be encouraged to examine and publish comparable cost-effectiveness and cost-efficiency data.

## **B. System Design**

**Recommendation 6: Establish Services in Natural Settings to Improve Access.** We need to facilitate access to support programs for caregivers. Caregivers are more likely to successfully access needed services in “natural settings” which they encounter in the course of their normal activities and responsibilities. Such natural settings include the doctor’s office where caregivers often visit with their care recipients, the hospital where caregivers are frequently engaged during admission and discharge of the care recipient, faith-based community settings, and employers. We recommend providing opportunity grants, training and technical assistance to help diverse agencies and organizations build capacity to provide evidence-based programs for caregivers.

**Recommendation 7: Make Professional Assessment and Triage Available to All Caregivers.** Caregivers should be provided access to skilled professionals who can routinely perform culturally competent caregiver risk and needs assessments. Assessments should result in a care plan specifically related to the level of risk identified and should contain specific and measurable outcomes. Routine assessments already being conducted by healthcare providers (hospital discharge, home care, outpatient rehabilitation) or government-funded (Area Agencies on Aging) should be revised to include a caregiver component. Moreover, government and other third-party payers should reimburse healthcare providers for conducting a caregiver assessment.

**Recommendation 8: Assure Caregiver Services are Evidence-Based, Culturally-Sensitive, and Tied to Caregiver Programs.** A standard of care within the aging network should be adopted that offers a menu of

service options and interventions of increasing intensity to address the varying needs of caregivers based on their levels of risk. One approach would be to revamp the National Family Caregiver Support Program to ensure the provision of evidence-based programs.

Following a public health model, systems of care within states and communities can be augmented to assure caregivers receive evidence-based interventions tailored to their unique needs and level of risk. Specifically, intervention intensity should be based on increasing caregiver risk burden at three levels:

1. **Universal** interventions, such as information and education, for all caregivers;
2. **Selective** interventions, such as skills training, for families at elevated risk for future health and stress-related problems stemming from the demands of caregiving; and
3. **Indicated** interventions, such as intensive counseling, to further address heterogeneity in risk factors and severity among the high-risk groups.

**Recommendation 9: Establish a National Resource Center on Evidence-Based Caregiver Programs.** Information on implementing and translating evidence-based programs for caregivers should be centralized to support widespread adoption across communities. A National Resource Center should be authorized and funded to track successful implementation and translation activities and assure that guidance and training processes are in place. A special focus at the National Resource Center should be placed on culturally appropriate programming.

**Recommendation 10: Technical Assistance for Providers.** Affordable technical assistance networks should be created to ensure widespread and effective implementation of evidence-based programs for caregivers. These networks could be university or community-based that tap into local and national expertise in capacity building, evaluation, and systems design.

### C. Public and Tax Policy

**Recommendation 11: Tax and Public Policy Changes.** It should be a national goal to preserve family caregiving as a viable option by protecting families from economic hardship associated with caregiving, and to create incentives for family caregivers to increase their skill level to provide sustained higher-quality care. A caregiver credit should be designed under the Social Security System as suggested by the General Accounting Office. Such a credit would: (1) allow a specified amount of caregiving time (3 to 4 years), to count as covered employment, and assign a wage to that time; (2) exclude a limited number of caregiving years from the benefit calculation so that earnings are averaged over fewer years; or (3) supplement caregivers' retired worker benefits directly, in proportion to the time they took time out of the workforce for caregiving. Tax credits should be made available to family caregivers, such as those proposed in the CARE Act in the 110th Congress and currently under consideration in several states (Caregiver Assistance and Relief Act, 2007). To combat caregivers leaving the workforce, there should be a policy mandate for flexible work arrangements wherever feasible. Incentives should be created for family caregivers to participate in evidence-based programs that increase their skills and knowledge. Tying tax credits to caregiver participation in such programs also should be strongly considered. Additionally, government entities and

other payors should provide vouchers for care recipients to pay minimum wage to family caregivers upon completion of required training.

**Recommendation 12: Targeted Investments and Sustainable Funding.** It should be a national priority to support the development of an essential infrastructure to serve family caregivers, and to promote adoption, implementation, and maintenance of the most effective programs. Investment should be made in an expanded nationwide caregiver support system that makes evidence-based programs for caregivers widely available and easily accessible. Funding for the Alzheimer’s Disease Supportive Services Program of the Administration on Aging should be expanded, and additional funding should be provided for the National Family Caregiver Support Program for program expansion. Medicaid home and community-based waiver programs should be expanded to allow for maximum flexibility to support family caregivers with “wrap-around” services and supports that achieve cost-effectiveness. Additionally, after grant funding by the Administration on Aging ends for successful demonstrations, the Centers for Medicare and Medicaid Services should continue funding these programs through a waiver or other mechanism. Moreover, the “CLASS Act” (Community Living Assistance Services and Supports Act), a provision under the enacted Patient Protection and Affordable Care Act, should be quickly implemented to support the development of a new national long-term care insurance program, with inclusion of caregiver support, education and training as components of plan benefits.<sup>53</sup>

## VI. FUTURE DIRECTIONS

As RCI looks to the future, we envision sustaining our strong commitment to supporting family caregivers. We will continue to foster the development of the network of community coalitions (CARE-NETS) that provide a forum for addressing the needs of caregivers in a concerted and coordinated way. Moreover, we will work toward expanding the National Quality Care Network (NQC�N) as a vehicle for innovation, information sharing, and stimulating partnerships for action in our communities. Our efforts with the NQC�N will focus on working to implement, disseminate, and maintain effective translational strategies of evidence-based programs for family caregivers. Ultimately, through RCI’s partnership with the NQC�N, we will aim to create supportive policies and secure long-term, sustainable funding for the integration of caregiver programs within community systems.

With the launch of a new RCI publication, the CARE Report, we will broadly share the translational experiences of providers in integrating evidence-based programs for caregivers. This bi-annual report will showcase the widespread adoption of evidence-based programs in order to increase awareness about the many positive outcomes of these programs. Among other endeavors, we will continue sponsoring RCI’s annual summit in Americus, GA, as a forum to bring together the diverse groups of health policy leaders, program planners, researchers, and other key stakeholders with vested interests in family caregiving issues. Furthermore, commencing with this year’s annual summit, a summary monograph of the key topics addressed at the sessions will be issued to interested parties at large. It is our hope that the monograph will help broadly disseminate summit activities and facilitate information-sharing.

Other future activities at RCI will include ongoing sponsorship of our Professional Development Webinars that provide technical assistance to agencies wanting to implement evidence-based programs for

family caregivers. And lastly, we will maintain our strong presence as advocates of family caregivers at the Federal, state and local level.

In closing, to successfully avert the caregiving crisis facing our nation, it is RCI's position that all sectors of society must come together in new ways to develop effective and timely solutions. The broad and coordinated response outlined in RCI's **National Caregiving Initiative** will require a fundamental shift in how we, as a country, recognize the invaluable contributions of family caregivers as the true backbone of our nation's long-term care system.

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Testimony of  
Kathy Greenlee  
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U.S. Department of Health and Human Services

Before the  
Special Committee on Aging  
United States Senate

on

“Meals, Rides, and Caregivers:  
What Makes the Older Americans Act so Vital to America's Seniors”

May 26, 2011

Thank you, Senator Kohl, Senator Corker, and Members of the Special Committee on Aging, for the opportunity to testify today at this hearing on the reauthorization of the Older Americans Act (OAA). Over the past year, the Administration on Aging (AoA) has conducted the most open process for seeking input on the reauthorization of the OAA in its history. I am pleased to discuss the input we received from across the country on this important legislation that provides vital home and community-based services to older adults and their caregivers, to summarize the important themes we have heard, and to highlight a few of the priority areas we would like to discuss with this Committee and the Congress as the reauthorization process moves forward.

At the outset, I would like to commend you, Senator Kohl, for your leadership as Chairman of the Special Committee on Aging, and for your many years of public service as an astute and effective advocate for policies that better protect and serve vulnerable Americans of all ages. We are particularly grateful for your many insights and for your stalwart support in shaping and improving our community- and family-based Older Americans Act programs, which play a vital role in helping to maintain the health and well-being of millions of older Americans.

For more than 45 years, the OAA has quietly but effectively provided nutrition and community support to millions of people across the nation. As the former Secretary of Aging from Kansas, and now having the honor to serve as the Assistant Secretary for Aging and listening to individuals and families in a variety of settings, I have seen and heard firsthand how the OAA reflects the American values we all share:

- Supporting freedom and independence;
- Helping people maintain their health and well-being so they are better able to live with dignity;
- Protecting the most vulnerable among us; and
- Providing basic respite care and other supports for families so that they are better able to take care of loved ones in their homes and communities for as long as possible, which is what Americans of all ages overwhelmingly tell us they prefer.

One of the real strengths of the OAA is that it doesn't matter if an individual lives in a very rural or frontier area, or in an urban center – the programs and community-based supports it provides are flexible enough to meet the needs of individuals in diverse communities and settings. Over the past year alone, nearly 11 million older Americans and their family caregivers have been supported through the OAA's comprehensive home and community-based system. These services complement medical and health care systems, help to prevent hospital readmissions, provide transport to doctor appointments, and support some of life's most basic functions, such as assistance to elders in their homes by delivering or preparing meals, or helping them with bathing. This assistance is especially critical for the nearly three million seniors who receive intensive in-home services, half a million of whom meet the disability criteria for nursing home admission but are able to remain in their homes, in part, due to these community supports.

What is more, the need for this support is growing rapidly. Every day, more than 9,000 baby boomers turn 65. In just four years, the population aged 60 and older will increase

by 15 percent, from 57 million to 65.7 million. During this period, the number of seniors with severe disabilities who are at greatest risk of nursing home admission and Medicaid eligibility will increase by more than 13 percent.

The reauthorization of the Older Americans Act provides us with the opportunity to strengthen and build upon a long record of success in serving our families and communities, and to help meet the growing need. To support this discussion, over the past year the Administration on Aging received reports from more than 60 reauthorization listening sessions held throughout the country, and received online input from interested individuals and organizations, as well as from seniors and their caregivers. This input represented the interests of thousands of consumers of the OAA's services. We continue to encourage ongoing input and discussions.

During this process, we heard an overriding issue that was also raised during the conversations and activities of the Vice President's Middle Class Task Force, and that is that many families are doing the best that they can, but that they are often struggling between balancing the demands of child care and elder care. Families tell us that when they may need some help in supporting their efforts to care for loved ones, they don't want assistance that is confusing or frustrating. They simply want to know where they can turn for some help. Something that's easily accessible, without a lot of strings attached or hoops to jump through. And that, essentially, is what the OAA has been about since its enactment – listening to what our seniors and families need, and providing critical and cost-effective supports that help maintain the independence they want.

During our input process we were consistently told that, as it's currently structured, the OAA is very helpful, flexible and responsive to people's needs. During this process, we heard a few themes:

Improve program outcomes by:

- Embedding evidence-based interventions in disease prevention programs;
- Encouraging broader partnerships and alliances that result in comprehensive, person-centered approaches;
- Providing flexibility to respond to local nutrition needs; and
- Increasing efforts to fight fraud and abuse in Medicare and Medicaid.

Remove barriers and enhancing access by:

- Enhancing caregiver supports to parents caring for their adult children with disabilities;
- Ensuring that ombudsman services are available for all nursing facility residents, not just older residents; and
- Utilizing Aging and Disability Resource Centers as single access points for long-term care information and to public and private services;

The following are some examples of areas that we would like to discuss with the Congress as you consider legislation:

- **Ensuring that the best evidence-based interventions for helping older individuals manage chronic diseases are utilized.** A number of evidence-based programs have shown to be effective in helping participants adopt healthy



behaviors, improve their health status, and reduce their use of hospital services and emergency room visits.

- **Improving the Senior Community Service Employment Program (SCSEP) by integrating it with other seniors programs.** The President's FY 2012 budget proposes to move this program from the Department of Labor to the Administration on Aging within HHS. The goal of this move is to better integrate this program with other senior services provided by AoA. We would like to discuss adopting new models of community service for this program, including programs that engage seniors in providing community service by assisting other seniors so they can remain independent in their homes.
- **Combating fraud and abuse in Medicare and Medicaid by making permanent the authority for the Senior Medicare Patrol Program (SMP) as an ongoing consumer-based fraud prevention and detection program.** The SMP program serves a unique role in the Department's fight to identify and prevent healthcare fraud by using the skills of retired professionals as volunteers to conduct community outreach and education so that seniors and families are better able to recognize and report suspected cases of Medicare and Medicaid fraud and abuse.

The Older Americans Act has historically enjoyed widespread, bipartisan support. Based in part upon this extensive public input process, we think that reauthorization can

strengthen the Older Americans Act and put it on a solid footing to meet the challenges of a growing population of seniors and continue to carry out its important mission of helping elderly individuals maintain their health and independence in their homes and communities.

Thank you again, Senator Kohl and Senator Corker, for your leadership on these important issues and for the invitation to testify here today. I would be happy to answer any questions.

**Testimony of**

**Elizabeth N. Marshall  
York, Pennsylvania**

**Before the  
U.S. Special Committee on Aging**

**On the  
Reauthorization of the  
Older Americans Act**

**May 26, 2011**

Chairman Kohl, Senator Casey and other Members of the Committee:

Thank you for inviting me to testify before you today. I am pleased to be able to share with you my thoughts on the Older Americans Act and how the programs it created help me manage my health and independence and remain living alone in my home at 92 years of age.

Throughout my life, I have always strived to be an independent woman. I was born in 1918 in Methuen, Massachusetts, graduated from Chelmsford High School, and then from Lowell Commercial College in 1937. I consider myself very much a child of the Great Depression and have continued to live by the values of economy, thrift and self-reliance that I learned during my formative years.

During World War II, I supported the war effort by serving as a Red Cross volunteer, working in the Remington ammunition factory, and faithfully purchasing the war bonds that supported our efforts. My husband and I married once he returned from serving overseas, and he took advantage of furthering his education with the help of the GI Bill of Rights. We moved to York, Pennsylvania in 1948, and bought our first and only home there in 1954. This is the same home I live in today. Our two sons still live near me in Pennsylvania, and our daughter resides in New Hampshire, where our family has traditionally spent every summer.

An old song by Joseph Burke called "A Little Bit Independent" is my theme song, if you will. "A little bit independent in your walk, a little bit independent in your talk...a little bit independent in your smile, a little bit independent in your style...and yet you're easy on the eyes". I have worked throughout my life to be an independent woman, to find my strengths and use them, whether in service to my family, community or country; or simply as a self-reliant individual in my own right.

In addition to raising my three children, I also helped my husband start up his own advertising business and worked at several of my own jobs over the years. In the early 1960s, I increasingly became involved in the York community, which was undergoing a turbulent time, with tensions high over racial issues. I was sensitive to the issues of prejudice and had friends with similar concerns and motivation. In conjunction with the YWCA, a program was initiated to mentor inner-city adolescent girls. I actively worked with that program, called the Cookes' Club, for six years, devoting time each week to provide support and diverse experiences to these vulnerable young women.

I was also heavily involved in the preparation and planning for the York “Charette”, which was held in 1970. The Charette was a weeklong process engaging community participation and national expertise to examine barriers to positive community relations and serious gaps in equitable service. The result was the development of a blueprint for community change at a time when challenges were extensive and tensions were high.

Eventually, my community service activities led to my election to the York City Council in 1971. I went on to serve six years on the Council, and then was elected as the first female mayor of York in 1977. I later served as Deputy Controller for the City of York for several years. So I know something about management, government, and the challenging choices faced by decision makers as to the best use of taxpayer dollars.

After my public service career, when many people consider retirement, I acquired a real estate license and spent the next eighteen years facilitating the purchase of commercial and residential properties. I retired just 11 years ago at 81 years of age. I have been on my own now for 10 years, since my husband, Howard Marshall, passed away in 2001.

I am grateful for the companionship and support of my children and my neighbors. Many of us in my neighborhood are long-time residents. Our tight-knit community is essentially “aging in place” together and helping each other remain in our homes for as long as possible. My sons do not live in the same town, but coordinate schedules so that one of them visits me daily. When I was battling cancer three years ago, I sought medical treatment near my daughter in New Hampshire.

I am proud to still be an independent woman. I want to be able to stay in my home, near my family and neighbors. It is important to maintain my physical health to ensure I can continue to live on my own. I make it a priority to exercise, eat well balanced meals, take medications as prescribed, and follow up with my physicians. And stay active.

I have seen first hand— as a volunteer, community leader, elected official and businesswoman— how important it is for a community to maximize its human and financial resources; create efficient systems; leverage other funding, whether that’s federal, state or private dollars; and support its most vulnerable members. It was hard for me to ask for and accept assistance, but I can’t do all of the things that I used to. I have the love and support of my three children, but we still needed to reach out beyond our family for some assistance. I am truly grateful that the York County Area Agency on Aging and the providers they work with are there for me and thousands of other seniors in my community.

So how does this work in my case? I have a care manager at the Area Agency on Aging who helps me and my family figure out what things we need to put in place to maintain my health and independence. She was able to connect me to the home-delivered meals program; and if, in the future, I need additional supports, services or even just information, she will be ready and able to assist me.

Three times a week, a volunteer from the local senior center delivers meals to me in my home. On Monday and Wednesday, they bring a hot meal for that day and a cold one for the next day. On Fridays, I just get one hot meal for that day, because there's limited funding to provide the service on the weekends. Since good nutrition is essential to health and wellness and I cannot cook for myself the way I used to, I appreciate the meal service. But it's also nice to have a friendly visitor check in to make sure I am safe and doing well. It's too easy for older adults living alone like me to become socially isolated or to suffer sudden health deterioration and not be able to access help.

I understand that the home-delivered meal service is funded in part by federal dollars through the Older Americans Act, which leverages state and county funding, as well as voluntary contributions by participants or other private donors. Working under guidance from the U.S. Administration on Aging and the Pennsylvania Department on Aging, the county-based Area Agencies on Aging in my state then customizes a host of home and community-based services and supports to meet the needs of older adults and caregivers in that area. The Area Agency on Aging then contracts the delivery of many of these services out to local providers, such as senior centers, other aging services programs, or even for-profit companies such as the one that makes and packages the meals I receive.

What's fascinating to me is the range of services and supports that older adults can receive under the Older Americans Act. While the nutrition programs are a core element, the Act also allows the coordination and provision of senior transportation, in-home care, help with home maintenance and modification, care managers like the one I have, legal services, health and wellness programs, public information and referral services, and the list goes on and on. There's even a part of the Act focused on the family caregivers who give so much of their time, love and money to help older relatives. To help them help us!

And we can't forget senior centers, which are more important than ever to help older adults stay connected to their community. Senior centers offer opportunities for good nutrition in a social setting as well as opportunities to engage in active and educational programs. From aerobic classes to learning how to use a computer to communicate by e-mail, seniors depend on this link in their communities across this nation.


Many recipients of services are like me—they just need one or two little bits of help. Others may need a more intensive set of services to maintain their independence, but the Act is flexible that way and allows the senior to customize their care plan to just what they need to stay healthy. Even if you need a high level of supports and services, odds are that receiving this care in your home is still more affordable for you and the taxpayers than if you end up in a nursing home. As our leaders struggle to balance the budget and reduce the deficit, the cost savings that Older Americans Act programs generate are even more critical.

The beauty of the Older Americans Act is that it allows you to retain your dignity, health and independence with just a little bit of support. It forms the critical glue that holds together all the other supports I have: my adult children, my friends and neighbors, and my own determination to age in place. Without those key pieces of the puzzle, I would not be able to still be living well and in my home of 57 years. So I can still be “a little bit independent in my walk”!

My story is not necessarily a unique one. My peers and I have served our families, communities and country for many years and, with the right balance of help, we can continue to remain contributing members of society and maintain our health, independence and dignity for as long as possible.

With the reauthorization of the Act before Congress this year, I urge this committee and your colleagues in the Senate and House to understand how vital these “little bits of support” are to millions of older Americans determined to age in place. We need to reauthorize this landmark legislation in a timely and bipartisan fashion in order to modernize what needs updating, strengthen what is already working so well, and prepare our country for the wave of Baby Boomers standing behind my generation.

Thank you, Senator Kohl and Members of the Aging Committee, for inviting me to share my thoughts about the Older Americans Act with you here today.



# Leadership Council of Aging Organizations

Testimony of Max Richtman  
 Chair, Leadership Council of Aging Organizations  
 Acting CEO, National Committee to Preserve Social Security and Medicare  
 U.S. Senate Special Committee on Aging  
 Hearing on the Reauthorization of the Older Americans Act  
 May 26, 2011

On behalf of the Leadership Council of Aging Organizations (LCOA), I am honored to testify before the Senate Special Committee on Aging to share the LCAO Older Americans Act (OAA) Reauthorization Consensus Document. I have provided a copy of the document with my written testimony.

LCAO is a 66-member coalition of diverse national nonprofit organizations dedicated to preserving and strengthening the well-being of America's older population. We provide a voice for seniors and their families in the ongoing national debate on aging policy.

As the Committee is aware, the OAA expires this September at the end of fiscal year 2011. LCAO has historically played a significant leadership role in past reauthorizations. To support a bipartisan, efficient and effective reauthorization in 2011, last summer the LCAO Community Services Committee initiated the process to reach consensus on a set of recommendations for OAA reauthorization. Individual organizations' ideas and recommendations were presented throughout the fall; from December 2010 through March 2011, the Committee met almost weekly to shape the Consensus Document. The full LCAO enthusiastically endorsed the Document on April 6.

The LCAO OAA Reauthorization Consensus Document contains 98 recommendations that both reinforce key existing priorities in the current statute and seek to address challenges and opportunities brought by the exponential growth in the older adult population. As our colleagues explored potential changes to the OAA over the past several months, it became very clear that the Act continues to work very well for older adults across the country. The Act's core mission, infrastructure and programs remain relevant, effective and very much relied upon by older adults and caregivers. The greatest obstacle the OAA and the Aging Network it supports face in meeting their full potential, however, remains insufficient funding for the priorities established by Congress in past reauthorizations.

We also must acknowledge that the OAA, like other statutes, is a living document that can and must change to address emerging needs and embrace new innovations. It is notable that the OAA is up for reauthorization the same year that the first of the Baby Boomers turn 65 years old. Not only are the numbers of older adults increasing at an historic rate, but this population is

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becoming much more diverse. Additionally, as older Americans live longer, they face growing health and economic challenges. All these issues are converging to place additional strain on an Aging Network that is already overtaxed, but eager to expand capacity and enhance planning to meet the demands and seize the opportunities of the aging of the population.

It should be noted that LCAO's recommended improvements do not require major changes to the OAA's core services or eligibility requirements. We continue to prioritize the Act's focus on person- and family-centered care, targeted to those with greatest economic and social need, with local flexibility to serve unique communities and populations. Nevertheless, we do acknowledge, particularly in times of fiscal restraint, that improvements can be made in the efficiency and effectiveness of the OAA in its delivery of core services and how it interacts and coordinates with other federal programs that serve older adults. There are recommendations throughout the Consensus Document that call for improved coordination of services and identification and dissemination of best practices already occurring in local communities to strengthen the Aging Network nationwide.

LCAO also believes it is crucial to strengthen evaluation, and research and demonstration, of aging services. This will not only empower the Aging Network to continue implementing best practices, but also state with authority the degree to which the OAA provides a cost-effective way for older adults to remain in their own homes with health and economic security.

On behalf of LCAO, I applaud the Aging Committee for its leadership in calling attention to the upcoming OAA reauthorization. We urge Congress to continue the tradition of bipartisan and timely reauthorization of this important statute, while providing the funding needed for OAA programs to keep older Americans independent and productive. OAA programs – such as in-home assistance, home-delivered and congregate meals, and respite for family caregivers - benefit individuals and their families and save federal and state government resources from being spent on otherwise unnecessary care in hospitals and nursing homes (institutional care).

Thank you again for the opportunity to testify on behalf of the 66 members of the Leadership Council of Aging Organizations, and I welcome your questions and comments.

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# Leadership Council of Aging Organizations

## Consensus Recommendations *for the* 2011 Older Americans Act Reauthorization

Adopted April 6, 2011

### Introduction

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The Older Americans Act (OAA) is the major federal discretionary funding source for home and community-based services for older adults. Programs supported through the OAA include home-delivered and congregate nutrition services, in-home supportive services, transportation, caregiver support, community service employment, the long-term care ombudsman program, services to prevent the abuse, neglect, and exploitation of older persons, and other supportive services. These programs provide vital support for those older adults who are at significant risk of losing their ability to remain in their own homes and communities, or who need support and protection in long-term care facilities.

In addition, OAA funds resource centers that support the work of the aging services network, these resource centers address a variety of needs, including access to benefits, elder justice, multigenerational service and volunteering, legal services, financial literacy, long-term care ombudsman training, and targeted services to minority and special populations in need.

To develop and implement the wide array of OAA services, a system of federal, state and local agencies and organizations, known as the Aging Network, was established. The core of the Aging Network is the U.S. Administration on Aging (AoA), 56 State and Territorial Agencies on Aging (SUAs), 629 Area Agencies on Aging (AAAs), 246 Title VI Native American and Native Hawaiian aging programs, and more than 30,000 community-based service provider organizations. This critical aging infrastructure is the backbone of our nation's home and community-based long-term services and supports system offering assistance to older adults. The

Aging Network's activities also benefit other populations such as people with disabilities and caregivers.

Supported by the OAA, the Aging Network has successfully served millions of older adults in the community and in long-term care facilities since 1965, and is positioned to assist the country's growing aging population to remain healthy, active, and in their communities. With each reauthorization, the OAA has been adapted to meet the changing needs of this growing population, the changing role of family supports, and expanding research and technological advances, often with inadequate funding. Further, the Aging Network and its services have the potential to save the Medicare, Medicaid, and Veterans Administration programs billions of dollars each year by enabling older adults to stay in their homes and communities and out of hospitals and long-term care facilities.

This current reauthorization provides an opportunity to reassess the successes and shortcomings of the OAA's ability to serve older Americans, particularly those with the greatest social and economic need. In these times of fiscal restraint, the Leadership Council of Aging Organizations (LCAO) offers in this document recommendations for improving the efficiency and effectiveness of the OAA in its delivery of core services and how it interacts and coordinates with other federal programs that serve older adults.

In order to maximize effectiveness, community-based services provided through the Aging Network must be coordinated and integrated with the various federal health care services that older adults receive. In addition, they must work hand in glove with other programs at the state and federal levels such as the Low-Income Energy Assistance Program (LIHEAP), fraud prevention programs, Senior Corps and other programs promoting community service, transportation programs, the State Health Insurance Assistance Program (SHIP), the Adult Protective Services Program and other elder abuse-related programs.

The goal of the following LCAO recommendations is to authorize the AoA, the Assistant Secretary, and the programs and staff across the nation to fulfill their promise by giving them the tools, direction and flexibility to provide the services that the aging population of our nation demands. Our focus is on person and family-centered care with local flexibility to serve the needs of unique communities and sub-populations. LCAO's recommended improvements do not require major changes to the OAA's core services or eligibility requirements. LCAO strongly believes that increasing the authorized funding for all titles of the OAA is necessary; however, provision of adequate funding is just one of the ways that we propose to improve and expand services. Additionally, any new programs added to OAA should be given specific authorization levels.

With the population of older individuals expected to grow exponentially in the coming years, the aging network faces incredible challenges associated with the influx of older individuals into

OAA programs. The LCAO, which has played a significant leadership role in past reauthorizations, is committed to a reauthorization that will strengthen the OAA for both the older adults currently receiving services and for the boomers who, in 2011, have begun turning 65 years of age.

We urge Congress to update and improve the Older Americans Act, while providing the funding needed for OAA programs to keep older Americans independent and productive, thereby saving federal and state government resources. Therefore, the LCAO makes the following recommendations to strengthen and enhance the OAA.

## General Recommendations

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- ❖ Raise or increase the authorized funding for all titles of the OAA. Additionally, any new programs added to the Act should be given specific authorization levels. With the population of older individuals expected to grow exponentially in the coming years, the Aging Network faces incredible challenges associated with the influx of older individuals into OAA programs. The scope of the OAA is vast and expanding to cover additional populations while the investment in its mission has been severely, and consistently, underfunded.
- ❖ The Aging Network should be considered the focal point for aging related matters at all levels of government. Amend the OAA to explicitly recognize the principal role that State Agencies on Aging have in planning for the social and physical needs of older adults at the state level, and Area Agencies on Aging at the local level.
- ❖ Where possible in the OAA, lesbian, gay, bisexual and transgender older adults should be included as a vulnerable population with greatest social need as a result of a lifetime of bigotry, stigma and discrimination.
- ❖ The underserved, vulnerable communities of all racial and ethnic groups, as well as, lesbian, gay, bisexual and transgender older adults should be explicitly addressed in the OAA in ways that account for their unique family structures and collective experiences. Terms such as “adult care,” “family,” “family caregiver,” “spouse,” “underserved area,” “vulnerable elder,” and “family violence” should be defined to account for the variety of family and care structures of all racial and ethnic communities, and LGBT communities, which include partners and families of choices, as well as spouses and biological families.
- ❖ Where appropriate and practical in the OAA, data collection, project assessments and reporting requirements should ensure that racial groups, as well as lesbian, gay, bisexual and transgender older adults, are studied and appropriately served.

## Title I

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*Title I of the Older Americans Act sets forth the objectives of the statute and the definitions that provide a common understanding of issues, such as how services are targeted and core components of many of the initiatives of the Aging Network. LCAO's recommendations for Title I include those that seek to strengthen and modernize targeting of services to those with greatest economic and social need and modernize language and update definitions to reflect new strategies embraced by the Network.*

- ❖ Establish economic security as a goal of the Older Americans Act. Define economic security as having the income, resources and services and supports necessary to meet all basic needs, including housing, health care, transportation, food, miscellaneous essentials and, when necessary, long-term care.
- ❖ Measure “economic need” as having an income at or below 200% of the federal poverty line, in order to strengthen the Act’s goal of directing services to those with the greatest economic and social need.
- ❖ Instruct the Bureau of Labor Statistics to re-visit the methodology and data collection for the experimental Consumer Price Index for the Elderly (developed in 1987 via reauthorization of the OAA) to account for elders’ true expenses. Also instruct BLS to develop a complementary geographically-based measure of economic security for elders.

### Definitions

- ❖ The definitions of “greatest social need” in the OAA should explicitly name older adults living with HIV—recognizing the growing number of older adults living with HIV and the related health disparities, discrimination and stigma.
- ❖ The definitions of “minority” status and “greatest social need” in the OAA should explicitly name racial minority groups and lesbian, gay, bisexual and transgender older adults.
- ❖ Amend the definition of Aging and Disability Resource Centers (ADRCs) to make explicit the role of AAAs and Title VI programs in this effort, as well as clarify the importance of formal partnerships between aging and disability organizations in order to successfully implement an ADRC network.
- ❖ To reflect the emerging role of the Aging Network in care coordination, the OAA should be amended to include care coordination as a fully restorative service under Sec. 101 (4) and the following definition of care coordination should be added to Sec. 102: “Care coordination” is a person- and family-centered and interdisciplinary approach to meet the needs of the older adult while enhancing the capabilities of the older individuals and family caregivers. Care

coordination integrates health care, long-term services and supports, and social support services in which an individual's needs and preferences are assessed, along with the needs and preferences of family caregivers. A core element of care coordination is the active engagement of the older adult, the family, community-based service professionals, and health care professionals providing care to an individual in the design and implementation of the plan of care. Activities of care coordination aim simultaneously at meeting individual and family needs, building person and family capacity and improving systems of care.

- ❖ Define advocacy with particular attention to the roles and mandates at the federal, state and local levels. A definition will help to eliminate confusion or misunderstanding about what the OAA requires in terms of advocacy, and ensure that there is a consistent degree of advocacy on behalf of and with older Americans across the country.
- ❖ Amend the OAA to incorporate and promote "person-first" language, objectives and goals.
- ❖ Ensure that information and assistance is properly defined and used consistently throughout the OAA. Amend the definition to: include the preference that information and assistance be provided by an entity which is accredited by a program such as the Alliance of Information and Referral Systems (AIRS) and using the *Standards for Professional Information and Referral*, and ensure that information and assistance services links individuals to opportunities for work and volunteer service in the community.

## Title II

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*Title II sets forth the roles and responsibilities of the U.S. Administration on Aging, including coordination of programs serving older adults across federal agencies, support of national aging services projects and resource centers, and evaluation and oversight of initiatives authorized by OAA. LCAO's recommendations for Title II include those that would enhance evaluation to provide better information on the effectiveness and efficiency of OAA programs; strengthen the capacity of the Aging Network to meet the core objectives of OAA; provide improved research and coordination of federal programs serving older adults; and take proven demonstration projects to scale.*

- ❖ The OAA should amend and include provisions that promote cultural and linguistic competence for all racial and ethnic groups, as well as lesbian, gay, bisexual and transgender older adults.

### Systems & Programs

- ❖ Strengthen the role of the Aging Network to integrate medical and human services-based long-term services and supports (LTSS), particularly in order to promote the Aging Network's role in health, wellness (both physical and behavioral health) and care

management. To this end, make permanent and fully fund the Aging and Disability Resource Centers and evidence-based health promotion and disease prevention programs, such as the Chronic Disease Self-Management Program.

- ❖ Strengthen the ability of the Aging Network to improve OAA performance by creating capacity-building initiatives. Specifically:
  - Add to the existing Title II evaluation provisions under Section 206 to enhance the capacity of the Administration on Aging (AoA) to perform program evaluations for current OAA and emerging programs. This enhanced capacity would allow AoA to further develop its involvement in evidence-based programming and evaluate the Aging Network's role and capacity in providing long-term services and supports and related system change efforts. The evaluation activities would be funded through their own authorization under Title II.
  - Add a new section under Title II creating a technology development program to assist the Aging Network to invest in and utilize new and innovative technologies to improve service delivery and more effectively track and report on OAA programs and services.
  
- ❖ Reinforce the role of the Assistant Secretary to provide training and technical assistance, conduct oversight, and disseminate best practices related to the OAA's advocacy provisions. Require the Administration to develop ways to capture and evaluate advocacy activities at the federal, state and local levels which detail their impact on the lives of older adults and on existing policies and systems to improve the lives of older Americans. Such mechanisms shall be developed in collaboration with stakeholders nationwide and focus on process and outcomes elements that can easily be used by the Aging Network.
  
- ❖ Amend Title II to authorize the Assistant Secretary to:
  - Develop evaluation methodologies that seek uniform qualitative as well as quantitative data to measure the impact of legal services on older Americans.
  - Create a national legal advisory committee to:
    - develop uniform reporting and delivery standards for legal services providers who receive funding and entities who distribute legal services funds;
    - make recommendations to the Assistant Secretary for improving and reforming legal services funding and delivery models; and
    - streamline qualification and authority standards for Legal Assistance Developers nationwide.
  - Make changes based on the evaluation and legal advisory committee input.
  
- ❖ Amend Section 202(a) 21, which authorizes the Assistant Secretary to establish information and assistance services as priority services for older individuals, to ensure that quality information and assistance services are consistently provided to older individuals, encourage OAA programs to seek accreditation using programs such as the Alliance of Information and

Referral Systems' (AIRS) Standards for Professional Information and Referral, and ensure that there is full collaboration between all governmental information and assistance systems that serve older individuals, whether specialized, crisis intervention, disaster assistance or others.

- ❖ Authorize the Assistant Secretary to provide training and technical assistance as well as funding to support the local adoption of person-centered approaches to economic casework.
- ❖ Strengthen the work and effectiveness of the Interagency Coordinating Committee on Aging to integrate and coordinate federal programs serving older Americans by:
  - Authorizing specific funding for the Coordinating Committee;
  - Requiring that the committee meet quarterly;
  - Requiring the participation of representatives from the Centers for Medicare and Medicaid Services, the HHS Office on Disability, and Federal Transit Administration in addition to those already required in the Act;
  - Charging the Committee with unifying and coordinating activities of multiple agencies and recommending and drafting necessary regulatory and legislative changes to stabilize, expand and strengthen the direct-care workforce, and
  - Charging the Committee with creating an inventory of all federal programs aimed at reducing poverty and increasing the economic security of older adults; unifying and coordinating the activities of agencies administering such programs; analyzing federal program effectiveness against a goal of economic security that draws on a concrete measure, using a methodology such as WOW's Elder Economic Security Standard Index; and recommending and drafting the necessary regulatory and legislative changes to increase economic security of vulnerable and economically disadvantaged older adults.

### **Resource Centers**

- ❖ Establish a technical assistance and resource center for core programs, peer to peer assistance, and SCSEP programs to identify, develop and promote best practices. The Aging Network needs to promote best practices to develop and expand models of long-term services and supports programs that build upon the core programs of Titles III, V, VI and VII.
- ❖ Aging resource centers delineated in the OAA should explicitly address all racial and ethnic groups as well as lesbian, gay, bisexual and transgender older adults.
- ❖ In provisions that refer to other minority resource centers, the OAA should include and list the National Resource Center on LGBT Aging.



- ❖ Effective engagement of older volunteers, particularly the baby boomers, can dramatically increase the capacity of the Aging Network. Therefore, we recommend that the OAA:
  - transition the Multi-Generational Civic Engagement pilot to a permanent program under Title II and invest in the nationwide adoption of the models and best practices evaluated in recent years;
  - develop new roles and opportunities for older volunteers to expand nonprofit services to vulnerable seniors, children and their families;
  - authorize AoA to create a national strategy—in collaboration with the Corporation for National and Community Service—to tap older volunteers as a source of social capital to meet critical community needs; and
  - fund research on how older volunteers (a) increase capacity for the Aging Network and other nonprofits (b) enhance health and independence for the volunteers, and (c) foster improved outcomes for individuals, families and communities, including ways for older volunteers to provide support and information to older adults and their families or caretakers who have experienced or are at risk of elder abuse.
- ❖ Secure appropriate placement for the National Resource Center for Women and Retirement within Title II of the OAA and make it permanent.

### Title III

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*Title III authorizes the state and community programs of the Aging Network and establishes the leadership roles of State Units (SUs) and Area Agencies on Aging (AAAs). LCAO's recommendations for Title III include innovations and new strategies, but also proposals to retain and strengthen current programs: Supportive Services and Senior Centers, Senior Nutrition, Disease Prevention and Health Promotion, and National Family Caregiver Support.*

#### **State and Area Plans**

- ❖ Clarify the importance of the AAA's responsibility to seek information, input and expertise from community-based organizations serving older adults, other service providers under the Act, independent experts and other advocates in the planning and service area when developing the area plan, particularly as it pertains to determining community needs, identifying pressing issues and proposing solutions. The process by which this input is solicited and considered should be as transparent as possible.
- ❖ Support civic engagement initiatives that promote the placement of older adults in work and community service roles. Specifically (but not limited to):
  - Create a volunteer management grant program available to senior centers, AAAs or other nonprofit organizations. The grants should be awarded to organizations to support volunteer management positions and staff training focused specifically on recruitment,

- placement, and retention of volunteers age 50+. The grant program should be administered under the civic engagement authority of the Administration on Aging.
- Amend the area plan language to include a provision that adds to the plan strategies to tap the resources of adults age 50+ in volunteer and paid work, including multigenerational work and senior-to-senior service activities.
  - Direct the Assistant Secretary to work with state units on aging and area agencies on aging to ensure that older adults requesting information about service, learning, and employment opportunities are provided with appropriate referrals, information, or resources.
- ❖ Allow SUAs, and AAAs in consultation with the SUA, to use a locally determined measure of economic security to measure economic need and target services in the state and area plans.
  - ❖ Strengthen state and area plans by including the option to monitor direct care workforce supply and standards in the State and area's assessment of how prepared the State/area is for any anticipated change in the number of older individuals during the 10-year period following the fiscal year for which the plan is submitted.
  - ❖ Support the development of innovative, community-based service delivery methods by:
    - Incorporating, to the extent feasible, reporting on state funding and/or sponsorship of matching service referral registries into state and area plans for the purposes of assisting participants in identifying and employing qualified service providers. Relevant reporting information includes contact information for the registry; its service area; and the number of consumers and workers participating.
    - Allowing states to develop and run matching service registries as an Information and Assistance service (Sec. 321); and
    - Authorizing funds for creation of and improvements in state matching service registries (Sec. 373(b) and the new Title IV grant program).
  - ❖ When Congress updates the authorization levels in the OAA, it should assess the adequacy of the state minimum funding level established in Section 308 for coordination of statewide long term services and supports, planning, monitoring and evaluation. Section 308 allows states to keep 5% or \$500,000, whichever is greater, for these purposes. This authorization was last updated in 1984. Many states, as a result, have relied on this stagnant amount for almost thirty years. Additionally, the reauthorization should grant states the ability to request additional administrative funding from AoA when the funding they receive is not sufficient to carry out their planning, monitoring and evaluation duties as outlined throughout the Act, including in Sections 305 and 307.

- ❖ Acknowledging the work in some areas to make health care entities aware of community-based supports and services, direct AAAs to include in their area plans their strategies such as a community care coordination task force to ensure that health care entities are made aware of community based supports and services available through the Aging Network and to direct the Assistant Secretary to gather and publish regularly a summary of best practices toward meeting this goal.

### **III B: Supportive Services**

- ❖ Retain the mandate of OAA legal services.
- ❖ Expand the description of transportation services in OAA III B to include mobility management activities. Providing a broad enough definition of mobility management to include the different facets of this burgeoning approach to providing transportation resources promises to improve both program effectiveness and the responsiveness of services they offer to consumers' needs.
- ❖ Formalize the role of the Aging Network in the coordinated public transit–human services transportation planning process and authorize funding support and technical assistance to support these efforts. Include complementary provisions that reinforce and build upon this role under the pending surface transportation reauthorization.

### **III C: Nutrition**

- ❖ Improve data collection in the Title III C nutrition programs, particularly measures of unmet need, such as waiting lists.
- ❖ Enhance the current flexibility in the allocation of Senior Nutrition Program funding in local communities while preserving the integrity of the separate congregate and home-delivered meal programs.
- ❖ Invest in the opportunity to use Title III C funds not only to serve the current population in need but also to transform congregate home-delivered nutrition services to meet the nutrition needs of the burgeoning numbers of older individuals seeking to remain healthy in their communities.
- ❖ Look for and provide support for best practices in nutrition programs that have succeeded in recruiting and retaining first wave boomer participation in addition to existing clientele.
- ❖ Encourage nutrition programs to offer participants full access to fresh fruits and vegetables and where appropriate and financially feasible offer meal options based on cultural and ethnic either requirements or preferences.

- ❖ Add language to the OAA nutrition section to highlight the need for the provision and funding of special meals stemming from a religious requirement, ethnic consideration, or health condition when there is sufficient demand in a community to warrant such special meals. Additionally, have AoA analyze whether service providers are able to obtain viable contracts for these special meals, and ensure that nutrition projects encourage those who distribute meals to homebound individuals are aware of warning signs for medical emergencies, injury and abuse.

### **III D: Disease Prevention & Health Promotion**

- ❖ Key principles, standards and lessons learned from AoA's *Evidence-Based Disease and Disability Prevention Program* should be permanently imbedded in the core services of the OAA. Title III D should be strengthened to integrate evidence-based health promotion and disease prevention programs. Funding levels must be authorized and sufficient to meet the need for these cost-saving and health-boosting programs.
- ❖ Better recognize the importance of nutrition programs that actively support evidence-based disease prevention and health promotion programs.

### **III E: National Family Caregiver Support Program**

- ❖ Strengthen the National Family Caregiver Support Program (NFCSP) by increasing its authorization to \$250 million per year.
- ❖ Clarify that older caregivers of adult children with disabilities are eligible for NFCSP services. Conflicting definitions in the Act have prevented the implementation of congressional intent in the last reauthorization, so all relevant sections must be amended.
- ❖ As part of a person and family-centered care approach, specifically allow for family caregiver assessments to be provided to family caregivers under the NFCSP.
- ❖ Make support of family councils in long-term care facilities an allowable activity under NFCSP.

### **Housing with Services**

- ❖ Add a new housing with services subsection (Part F) under Title III that would target resources for the development and implementation of comprehensive housing with services models to better serve older adults in federally-assisted rental housing and Low-Income Housing Tax Credit Rental Housing. This new subsection would include its own authorized funding amounts for a range of services, including all service categories currently outlined under Title III B and planned for under the Section 305 and 306 planning provisions of the OAA. Specifically, the section would include an area "Housing with Services Plan;" in-home care (including personal care and chore services); coordinated case management services (in collaboration with a service coordinator, if applicable); mental health and wellness referral

services and screenings; congregate meal services; access to personal emergency response systems and medication reminders/management systems; mobility management; chore services; adult day services; aging services technology; and non-emergency transportation services. The new subsection would include provisions focusing on how the programs would coordinate with other Title III programs; interact with HUD Section 202 housing service coordinators; grant allocation; technical assistance; quality assurance; and oversight.

#### **New Ideas, Requirements**

- ❖ Build on existing Title III provisions to encourage greater collaboration between AoA and the DOT and FTA-funded programs that will help break down funding silos. By developing effective partnerships, AAAs will be able to serve more individuals with additional funding available through the FTA's specialized transportation programs.
- ❖ Transfer the current State Health Insurance Assistance Program (SHIP) to AoA and, if necessary, authorize AoA to administer the program under the Act. This transfer of the SHIP from Centers for Medicare and Medicaid Services (CMS) to AoA acknowledges the extensive role of AAAs and Title VI Native Americans aging programs in providing Medicare assistance and counseling to beneficiaries.

## **Title IV**

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*Title IV supports testing of innovative programs and strategies and evaluation of their effectiveness. However, resources have never been sufficient to support a vibrant research and development function for the Administration on Aging, to provide not only rigorous evaluation of new initiatives, but also a strong evidence base for current Aging Network efforts. In particular, there is a need for measuring how these home and community-based services are a cost-effective means to improve the health and economic security of older adults, and thus help bend the cost curve of spending on Medicare and Medicaid. LCAO's recommendations for Title IV include strengthening existing demonstration projects and resource centers. Any new demonstration programs and research on innovations should continue to support and build capacity for the core functions of the Aging Network, and invest in building an evidence base before taking the initiative to scale.*

*In addition, LCAO supports more emphasis on effective models of integrated community service delivery (especially, HCBS delivery), long-term care institutional accountability, health promotion and disease prevention, transportation, successful models of elder abuse and neglect prevention, and training for career preparation and continuing education for personnel in the field of aging.*

### **Building the Capacity of the Aging Network**

*Strengthen the ability of the Aging Network to improve OAA performance by creating capacity-building initiatives, such as the following proposals.*

- ❖ The research and development capacity at AoA should be strengthened by specifying in the Act that a fully qualified Chief Science Officer be appointed with authority to direct Aging Network–related research, demonstration and evaluation projects based on rigorous scientific standards. Rigorous standards, including peer review by leading scientists for the award and execution of evaluations, research, and program demonstrations are needed for the results to be credible, and thus of benefit to the Aging Network and older adults. Research, evaluations, and demonstrations are needed that show cost savings (such as to Medicare and Medicaid) that would be useful for budget scoring to demonstrate the ability to bend the entitlement cost curve.
- ❖ Important service innovations occur at the community level, but there is insufficient funding and research expertise at that level to translate/validate best practices into evidence-based interventions. An investment in such research can be made through appropriately designed grant programs that relate to the priorities of the OAA and the Aging Network.
- ❖ Funding should be made available through grant competitions directed to the community level (to AAAs, senior centers and other CBOs) for evidence-based research, evaluations and demonstrations. The grants should be based on partnerships with local universities and community-level Aging Network organizations, and focus on priority areas where innovation is needed. Research/demo agendas should be consistent with state and area plans.
- ❖ Create a senior center modernization fund to foster senior center innovation, leadership, and capacity-building. Tap into the vast expertise of multipurpose senior centers by expanding their role in state and local needs assessment and planning.
- ❖ Create a new training and professional development program to boost employment efforts in the field of aging services that we as a nation have a strategic interest in growing: jobs in the provision of aging services and long-term services and supports. This new program would have its own funding authorization so it would not be dependent on other OAA funds or take away from services.
- ❖ Direct the Assistant Secretary to work with HHS and CMS to create demonstration projects to assist AAAs and ADRCs to extend their expertise in supportive services planning and delivery to health/medical care entities that are involved in developing new models of care coordination and disseminate best practices and resource tools in these areas.

### **Current Resource Centers and Demonstrations**

- ❖ Reauthorize Community Innovations in Aging in Place to 1) promote aging in place through the identification of innovative strategies to link older individuals to programs and services that sustain quality of life and independence and 2) ensure that the National Technical Assistance Center remains a resource to demonstration grantees and a central repository of the tools, assessments, data, lessons learned, and best practices that arise from the demonstrations, for the benefit of the nation's Aging Network.
- ❖ Authorize dedicated funding to implement the Technical Assistance and Innovation to Improve Transportation for Older Americans program under Section 416 of the OAA.

### **New Ideas for Resource Centers and Demonstrations**

- ❖ Authorize and provide funding for the Assistant Secretary to establish an economic security resource center to test innovative practices in planning, evaluation and service delivery using a locally-determined measure of economic security. Funding will build on existing practices by SUAs, AAAs and other community-based service providers to incorporate an economic security framework and measure in OAA programs through a national clearinghouse of best practices and targeted technical assistance. The resource center will:
  - create an economic security evidence-base;
  - pilot test uses of a locally determined measure of economic need in OAA programs; and
  - build the capacity of the network to target services to economically vulnerable populations.
- ❖ Establish grant programs to fund:
  - state initiatives on coordination and improvement of long-term care workforce training, including standardization of training principles and practices;
  - state establishment of interagency data collection systems on long-term care workforce-related variables; and
  - testing and implementation of state payment and procurement policies that encourage long-term care providers to adopt human resource practices consistent with high quality service delivery.
- ❖ Establish a demonstration program, including an Advisory Panel for oversight and evaluation, to test an Advanced Aide training curriculum for direct-care workers who, with training, have the ability to assume new responsibilities.
- ❖ Develop and fund a Nutrition Resource Center. The function of this center would be to help the Aging Network improve programmatic operations including implementation of best practices, capacity building, broadening coordinated care linkages, resource and information sharing, problem solving, cost containment and multidisciplinary collaborations interactions.

- ❖ To support the expansion and promulgation of Aging Network person-centered approaches to economic casework, authorize the creation of the National Economic Security Center Demonstration by the Assistant Secretary in cooperation with related Federal agency partners administering relevant economic security programs (DOL, HUD, HHS, SSA, USDA, NeighborWorks, CNS). Funding would be provided to establish local economic security centers, implement new or expand existing economic security casework strategies, provide training and technical assistance, evaluate impact and success, develop and maintain a best practices clearinghouse, and provide web-based decision support and assessment tools.

## Title V

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*Title V authorizes the Senior Community Service Employment Program (SCSEP), the only federal program that provides job training and placement services for low-income older adults. Participants are provided with part-time, subsidized employment while they receive training, job placement assistance and supportive services; often SCSEP participants are with Aging Network or other local organizations to increase the capacity to serve the community. LCAO's recommendations for Title V include those that seek to provide employment opportunities in new sectors and strengthen coordination with the Workforce Investment system.*

- ❖ The Senior Community Service Employment Program (SCSEP) should be reauthorized to improve the program and funding should be expanded to serve a greater number of low-income seniors, while enhancing coordination with the Workforce Investment Act system, which is also up for reauthorization.
- ❖ Community service should be maintained as a strong component of the program. In addition to helping older workers achieve self-sufficiency, the SCSEP also provides an economic boost to communities and much needed assistance to agencies where the older workers provide services.
- ❖ Priority service to older individuals with multiple barriers to employment should continue to be maintained as a strong emphasis and the program should continue to provide the full range of customized services and supports that has been proven successful in serving older workers and helping them transition to the workforce.
- ❖ Allow the use of pilot and demonstration authority in Section 502(e) to:
  - provide new services for participants as well as extend services to older adults who are low-income but do not qualify for SCSEP;
  - expand the scope of SCSEP to provide a broad range of direct and referred services for seniors who need job training and placement services and income supports by adopting a person-centered approach that includes assessment of need, economic casework, coordination of benefits, and engagement of diverse service providers; and



- authorize a pilot to test “Sector Strategies” in SCSEP to create employment opportunities and applicable training to place older workers in jobs where local labor market need is identified. Jobs will be created with an emphasis on addressing older worker issues such as requisite physical conditioning, discrimination, workplace culture, flexibility, and job specific skills and employer issues, including recruiting and retaining older workers and redesigning roles for older workers.
- ❖ Encourage SCSEP to train older workers to become Home Health, Personal Care Aides, and other direct care workers, as has been successfully tested in 502(e) pilots.
- ❖ Eliminate durational limits for SCSEP. Participants in SCSEP should be allowed to remain on the program rather than be subject to the maximum time extension they would be permitted in the current law. Revise performance requirements to better reflect the population served, including evaluating placement rate rather than entered employment; measuring earnings gain rather than average earnings; and adopting a community service measure that retains an appropriate balance with job placement, reinforces the core purpose of community service in the program and reflects the value of community service rather than the number of hours worked by participants. Amend OAA Sec. 503(g) to ensure that durational limit exits do not negatively affect the evaluation of programs.
- ❖ Create a competitive grant making process that ensures efficiency, fairness, and minimal disruption to customers and is based on experience and performance. Grantees that meet performance expectations should not have territories disrupted every four years, which results in a decrease in services to older workers, at least for the first full year after competition. Absent unusual circumstances, current or prospective grantees should not be awarded territories for which they have not applied and do not have expertise to serve.
- ❖ Provide clarification and streamline the law to eliminate the complicated data validation and data collection requirements. Current data collection requirements result in complex procedures, which place an inordinate value on compiling information rather than on customer-focused service delivery. Support the administration of SCSEP through employment and training administrative funds rather than reducing grants to cover the cost of administration.
- ❖ SCSEP projects should be encouraged to enter into memorandums of understanding (MOUs) with their local AAAs (if the project is not administered by the AAA), outlining the steps the agencies will take to effectively coordinate their programs, similar to coordination provisions under Section 511 of the Workforce Investment Act.

- ❖ The requirement to be unemployed is often a barrier to service for the most vulnerable older workers who have sporadic, extremely low wage jobs. Eligibility requirements should be changed to allow severely underemployed individuals who meet the program's income limit the opportunity for enrollment.
- ❖ To emphasize the importance of senior-to-senior service and ensure targeted placement of SCSEP participants in serving older adults and preventing elder abuse, amend the grant authority section to provide that each SCSEP project approved by the Secretary "will contribute to the general welfare of the community, which may include support for children, youth, and families and for the health and safety of older adults."
- ❖ SCSEP should be encouraged to:
  - work with nonprofit organizations that have a record of success in developing and implementing effective technology curriculum designed specifically for older adults; and
  - partner with such nonprofit organizations to provide training, comprehensive student materials, evaluation, and support for a broad range of workforce technology skills, including as appropriate and practicable basic and intermediate computer skills, Internet, email, word processing, spreadsheets, presentations, and other key skills appropriate for assisting older adults to enter or re-enter the workforce.

## Title VI

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*Title VI provides primary authority for funding nutrition and family caregiver support services to Native American (Indian, Alaskan and Hawaiian) elders, who are among the most economically disadvantaged elderly minority in the nation. However, there has long been a lack of proper investment in the Title VI programs, which further exacerbates the challenges Indian elders face. LCAO's recommendations for Title VI, therefore, focus on different ways to build the capacity of Title VI programs to better meet the goals of OAA.*

- ❖ Build the capacity of and funding for Title VI programs to strengthen their ability to serve the complex and urgent needs of elders in Indian country.
- ❖ Create a new training, professional development, and technical assistance program under Title VI to boost employment efforts in the field of aging services for Title VI grantees. Current training and technical assistance support to Title VI programs is less than 1 percent of Title VI funding while other Title II and IV training and technical assistance provisions have been unfunded. This new program would have its own authorized funding to promote a range of capacity-building activities including training, professional development, and technology enhancements.

- ❖ Specify authorization amounts for Part A and B of Title VI at a level that corrects the significant underfunding of the program and reflects the need in Indian country for these vital services. Provide a comparable increase in authorization levels for the Part C Caregiver Support Program over the same period.
- ❖ Establish a new subsection under Title VI to focus on addressing the transportation needs of Native American elders. This new subsection would include its own authorized funding amounts for a range of mobility services including: transportation planning and coordination efforts; collaboration with other transportation programs focused on the Native American population; mobility management services; efforts to address unmet transportation needs; and to develop new and innovative programs to serve elders' transportation needs in rural and frontier communities.

## Title VII

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*Title VII, which authorizes vulnerable elder rights protection activities, plays a unique role in the OAA because it does not fall neatly into the category of community-based services. Protecting the rights and well-being of the most frail and vulnerable older adults living in long-term care facilities is equally important to serving those still living in their own homes, and LCAO's recommendations for Title VII are designed to give the long-term care ombudsman program the necessary tools to protect residents' rights, secure and protect necessary documents, avoid conflicts of interest, and address elder abuse, neglect and exploitation. Also included are proposals intended to strengthen the state legal development program to enable it to realize its full potential.*

- ❖ Strengthen the State Legal Assistance Developer Program by requiring each state to have a full-time legal assistance developer; providing that the Assistant Secretary develop, within 12 months, standards for the work and qualifications of developers; and ensuring that the developers be independent from political and other influence to set priorities and address issues as necessary.
- ❖ The Assistant Secretary shall ensure through regulation (or other communications with OAA programs) and through oversight that all programs funded under the OAA have received the appropriate elder abuse-related training, where staff, including volunteers, come into direct contact with older adults. Further, the Assistant Secretary shall ensure the coordination between Title VII abuse prevention education and awareness programs and Title III and Title VI programs.

### **Long-Term Care Ombudsman**

- ❖ Direct the Assistant Secretary to issue regulations that would clarify: requirements for long-term care ombudsman training; the State Long-Term Care Ombudsman's responsibilities to manage the Ombudsman Office, including fiscal management; and that the Ombudsman program shall be a unified program under the Office of the State Long-Term Care Ombudsman.
- ❖ Support and encourage resident and family councils by strengthening the ombudsman role and by making support of such councils an allowable expense under the National Family Caregiver Support Program.
- ❖ Ensure that the Ombudsman program is effective and that the rights of residents are protected by ensuring private and unimpeded access to the ombudsman and confidentiality ensuring access to all records concerning the resident; allowing all facility residents to receive ombudsman services.
- ❖ Amend the OAA to do more to identify, remove, and remedy organizational and individual conflicts of interest.
- ❖ Strengthen the ombudsman program by providing a separate authorization for funding for ombudsman services provided to assisted living facility residents and a demonstration program for ombudsmen for home and community-based services; and update the maintenance of effort provisions to ensure that funding for Ombudsman programs is not cut during state budget crises.

### **Cross-Title Recommendations**

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#### **Livable Communities** (*Titles III and IV*)

- ❖ Establish new provisions with dedicated funding authorizations to support the Aging Network to assist state, county, city, and tribal governments across the nation to proactively prepare for the aging of their communities and particularly the aging of the Baby Boomers. The provisions would authorize funding and outline the role and activities to be performed by a full-time planner/community organizer position. This new planner/community organizer would take a leading role in working with other agencies and stakeholder organizations, including the business sector, in developing a comprehensive livability plan and implementation strategy that would be fully coordinated with the SUA and AAA planning efforts. Activities would center on planning in such areas as health and wellness, housing, transportation, economic development, civic engagement, and the use of health-related technology. The provision would also establish a National Resource Center on Livable Communities for all Ages to provide the necessary guidance, training and technical

assistance to SUAs, AAAs, Title VI Native American aging programs, and non-profits in their comprehensive planning efforts.

**Transportation** (*Titles III and IV*)

- ❖ Explore ways to strengthen the Aging Network's role in transportation's coordinated planning activities through greater collaborative efforts between transit, planning and aging agencies and enhancing the role of the Aging Network in the growing field of mobility management services. (*See other transportation recommendations under Titles III and IV.*) Include complementary provisions that reinforce and build upon this role under the pending surface transportation reauthorization.

**Emergency Preparedness** (*Titles II and III*)

- ❖ Promote federal, state, and local information sharing by establishing a consistent policy to ensure that FEMA voluntary National Emergency Family Registry System and state Silver Alert information for the age 60 and older population is shared with the SUA and AAAs in federally declared disaster areas. In addition, grant funding should be established through AoA and FEMA to support the SUA and AAAs working with regional and local Emergency Management Authorities to implement a voluntary emergency preparedness registry system for people with functional needs. It is recommended that the system utilize geographic mapping technology.
- ❖ Reinforce existing federal policy to formalize coordination plans. Build on the emergency preparedness provisions added to the OAA in 2006 by requiring that AoA work with FEMA to formalize coordination plans with the SUA and AAAs. Direct HHS, AoA, FEMA Office of Disability Integration and Coordination, and Department of Homeland Security to train the Aging Network on how they can work effectively together during disaster planning, response and recovery efforts.
- ❖ Fulfill the promise of the OAA emergency planning provisions by authorizing dedicated funding to AAAs to support the critical endeavors described under Section 306(a)(17). Reassess the OAA disaster assistance program under Section 310 and consider changes that will allow AoA to provide more substantive and timely aid to the Aging Network in times of disaster. As an example, raise the cap on the amount of total payments during any fiscal year to states, AAAs, and tribal organizations to provide supportive services during disasters, which is currently based on a percentage of total Title IV appropriations.

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**For more information about the Leadership Council of Aging Organizations (LCAO) or this consensus document, please contact the current chairing organization. Contact information available at [www.lcao.org](http://www.lcao.org).**



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**Testimony of  
 Heather A. Bruemmer, Executive Director/State Ombudsman  
 State Of Wisconsin; Board on Aging and Long Term Care  
 Before the U. S. Senate Special Committee on Aging  
 on the  
 Reauthorization of the Older Americans Act  
 May 26, 2011**

Chairman Kohl, Ranking Member Corker and members of the committee, thank you for this opportunity to testify on the reauthorization of the Older Americans Act (OAA). My name is Heather Bruemmer. I am the State Long-Term Care Ombudsman for Wisconsin and I am also representing the National Association of State Long Term Care Ombudsman Programs (NASOP).

It is a privilege and honor to be here on behalf of the Ombudsman advocates who work daily to assure the rights and well-being of hundreds of thousands vulnerable residents living in long term care settings in this nation. The significance of the effort to reauthorize the Older Americans Act cannot be overestimated. It is a primary duty of this nation to protect our most vulnerable individuals and to preserve their pride and dignity.

Everyone has a history, a story, and memories, so it is our responsibility to assure that all members of our rapidly aging population have the proper access to services that will respect their right to be who they are and who they have been. They deserve to have the best quality of life and care in the twilight of their lives.

The OAA provides critically needed home and community based services that forestall institutionalization and allow older adults to remain for as long as possible in the community with needed support. Since 1978, the Ombudsman Program has been a core component of the OAA. It is the only program in the Act that specifically serves consumers of services provided by residential care facilities.

*ADVOCATE FOR THE LONG TERM CARE CONSUMER*

I think that we all appreciate and value the importance of living in our own home and, as a result, there has been a remarkable growth in the amount of home and community based services available for seniors in Wisconsin. However, some elders can no longer live safely in their own homes and must move at some point in their lives to either an assisted living facility or a nursing home. In November of 2008, the number of Wisconsin Assisted Living beds surpassed the number of Skilled Nursing Facility beds, indicating a significant trend that is expected to continue into the future. This trend is not unique to Wisconsin as similar shifts in long term caregiving are occurring from the Atlantic to the mid-Pacific. All of the elders who live in long term care facilities of all sorts need to be able to rely on the advocacy services of the Ombudsman Program.

Wisconsin was one of the original pilot states when the Long Term Care Ombudsman Program was first created by Congress, and our state has continuously relied on and improved the advocacy resources available to aging consumers.

When the Wisconsin Board on Aging and Long Term Care was formed to be a home for the Long Term Care Ombudsman Program in 1981, there were only five Ombudsmen serving nursing home residents in all 72 counties. Today, a complement of 15 regional Ombudsmen and over 100 volunteers are serving 95,000 clients of nursing homes, community-based residential facilities, adult family homes, residential care apartment complexes, and persons who reside in their own homes and receive services through the Medicaid waiver programs.

As the need for and nature of long-term care services and supports have grown in scope and complexity, federal support for the LTC Ombudsman Program has not always grown in proportion to that need. When the mandate to serve residents in assisted living was added to our mission by the 1981 amendments to the OAA, there was no new fiscal authorization for this function.

The addition of responsibility for residents of assisted living has nearly doubled the number of potential consumers of Ombudsman advocacy services, yet there still has been no funding specifically directed toward meeting this objective.

Nationally, ombudsmen visited 79 percent of all nursing homes on a quarterly basis last year, yet only 46 percent of all board and care, assisted living and similar homes received a quarterly visit due to funding inadequacies.<sup>1</sup> Throughout the country, it has become increasingly more difficult for Ombudsman Programs to serve residents in assisted living. The inability of Congress to provide sufficient funding is certainly not the result of a lack of trying by champions of the Long Term Care Ombudsman Program such as yourself, Chairman Kohl, and the members of this committee.

Each year, the LTC Ombudsman Program resolves hundreds of thousands of complaints made by or on behalf of aging consumers nationwide.<sup>2</sup> Nationally, 77 percent of these complaints are resolved or partially resolved to the satisfaction of complainants as a result of Ombudsman activity. The majority of Wisconsin Ombudsmen's time is spent in skilled nursing facilities. If we were able to address the needs of people living in assisted living with the same intensity as we do the concerns of those living in nursing homes, our numbers would be astronomical.

Intuitively, we believe that individuals living in assisted living have complaints and concerns that are going unheard. The Ombudsmen cannot confirm this assumption with any degree of certainty due to their inability to visit and advocate for the persons in these provider facilities with the same frequency that we devote to nursing home residents.

The LTC Ombudsman Program offers significant consumer protections to residents. The complexity and diversity of consumers who live in residential care facilities is growing. Noteworthy concerns such as falls, medical mismanagement, medication errors, pressure ulcers, and abuse situations have been on the rise in Wisconsin. Ombudsmen spend a tremendous amount of time investigating these incidents, and also providing education and guidance to facility managers and staff to help prevent reoccurrence of these problems. Unfortunately, the Wisconsin Long Term Care Ombudsman Program is still confronted with the reality of inadequate resources to provide the additional staff necessary to help reduce the incidence of these potentially very dangerous issues.

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<sup>1</sup> Source; 2008 AoA National Ombudsman Reporting System Data

<sup>2</sup> In excess of 250,000 complaints were lodged in nursing homes and board and care facilities in 2008 – source; AoA National Ombudsman Reporting System Data



Ombudsmen spend much time educating and empowering facility leadership, staff and families in methods of providing care that is consumer-centered, consumer-directed and based upon meaningful relationships with caregivers. In Wisconsin and across the nation, Ombudsmen focus on providing service to individuals, taking into account their life history, the rights they are entitled to, and their preferences for services that will provide the highest quality of life and care.

Resident and family councils are the vehicles by which open communications are fostered and facilitated as a means to ensure a common understanding of the issues and concerns that must be addressed in order to deliver excellent quality care and a high level of perceived quality of life. When considering the reauthorization of the OAA, it is important that this requirement to maintain resident and family involvement with the assistance of the Ombudsman Program be continued.

Access to confidential Ombudsmen services is critically important to the individuals we serve in long term care. We are recommending that this reauthorization ensure that private and unimpeded access by individuals to the Ombudsmen services in a confidential setting is not compromised.

The sections of the Act relating to the process of and limitations on disclosure of client information need clarification and emphasis. The current language needs to be strengthened so that facilities are entirely clear that this right of access to and control of information guaranteed to individuals is of the utmost importance to meeting the goals of the Act. We would also recommend changing all references to "files" relating to residents or clients to "information" by amending §712(d) of the Act. We want to ensure that all information provided by those seeking assistance and maintained by the Ombudsman is subject to the recommended OAA disclosure provision, not only that information which is contained in files or records.

It is important that the text of OAA clarify that the privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA) do not impede the access to resident health records by the Ombudsman and representatives of the program. The Administration on Aging has declared, in a memorandum (AOA-IM-03-01; dated February 4, 2003), that the

Ombudsman Program representatives are performing a health care oversight function and they are not impacted by the HIPAA Privacy rules.

Ombudsmen throughout the country report having contact with more and more individuals who cannot speak for themselves and have no legally authorized representative to speak on their behalf. We ask that provisions in Title VII of the OAA be amended to add language that will encourage states to intensify their efforts to educate the public as to the value and importance of completing the documents necessary to establish a trusted surrogacy relationship with a personal advocate.

Wisconsin's Board on Aging and Long Term Care and the National Association of State Long Term Care Ombudsman Programs support the recommendation which would amend Title II of the Act to provide a base appropriation beginning at \$1 million to the National Ombudsman Resource Center (NORC) with subsequent annual increases. NORC has proven to be a valuable site for Ombudsman Programs to obtain training, resources, and technical assistance despite woefully inadequate funding throughout its history. It would be extremely helpful to expand the Center's training capacity and ability to work with state regulators on improving the investigative processes used to deal with resident complaints.

The OAA gives us a strong foundation – and reauthorization gives us a window of opportunity to build an even more robust demonstration of the nation's concern for the well-being of our elders. It is extremely important that Congress and the aging network come together to strengthen our Long Term Care Ombudsman Programs to provide a safe, homelike environment and to protect those members of our aging society who rely on the providers of long-term residential care services.

On behalf of the Wisconsin Long Term Care Ombudsman Program and NASOP as advocates for the nation's vulnerable facility residents and consumers of long term care, I thank you, Sen. Kohl, Ranking Member Corker and members of the committee, for allowing me to share our thoughts about the reauthorization of the Older Americans Act with you.

I will be happy to answer any questions that you may have.

**STATEMENT OF**

**TIMOTHY A. HOWELL  
CHIEF EXECUTIVE OFFICER  
SENIOR CITIZENS HOME ASSISTANCE SERVICE, INC.**

**BEFORE THE**

**SENATE SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE**

**THE GROWTH PROCESS OF A HOMEMAKER  
AND PERSONAL CARE SERVICE PROVIDER**

**MAY 26, 2011**

## INTRODUCTION AND HISTORY

Chairman Kohl, Ranking Member Corker, and Members of the Committee, I would like to thank you for this opportunity to address the Special Committee On Aging. I am Timothy Howell, the Chief Executive Officer of Senior Citizens Home Assistance Service, Inc. (SCHAS), a non-profit 501c3 agency and service provider to the elderly and persons with disabilities. In the interest of space I will address the agency by its initials "SCHAS" throughout the remainder of this document.

SCHAS began serving the elderly and persons with disabilities in July 1970 in Knox County, Tennessee. The mission of SCHAS is to improve the quality of life of the frail, elderly, and persons with disabilities. The agency was formed through a grant from the Older Americans Act in the amount of about \$50,000, and to date SCHAS still receives funding from the OAA. The grant funded a study to analyze whether or not elderly citizens would be able to remain at home if provided caregivers to perform light housekeeping, laundry, grocery shopping, cooking, and other homemaker services.

As a testament to the success of this grant, SCHAS has grown since 1970. The agency now serves residents in 20 counties of East Tennessee with a service area that reaches from the south in Chattanooga (Georgia border) to the north in LaFollette (Kentucky border) over to the east in Newport (North Carolina border) and as far west as Roane County, Tennessee. In fiscal year 2011, SCHAS is on target to help over 2,550 individuals remain in their homes through providing over 360,500 hours of one-on-one care. The best part of this story is that of these individuals 76% or 1,938 of them will be under the 150% federal poverty level.

Along with growth in the geographic service area and the number of individuals served, SCHAS has experienced increases in budget, employees, and programs. The growth is a result of the agency staying true to its mission while focusing on offering programs that fill in the gaps where other services are not provided in the East Tennessee area, and forming partnerships with many different entities and individuals. This has allowed SCHAS to be financially stable throughout the years.

## PROGRAMS

At the core of SCHAS' services is the homemaker and personal care program. This program screens, trains, and employs people that want to be caregivers to provide homemaker and personal care services to elderly and persons with disabilities. This program is successful because of many reasons. The major ones are:

- Full Fee Private Pay Clients – People that have the ability to pay for services should, and this is consistently a major part of the agency's budget.
- Sliding Scale Fee Private Pay Clients – These clients typically do not qualify for government programs because of financial or physical reasons, but they still need the help. Because of funding from United Ways, local governments, and fundraisers, SCHAS is able to offer a reduced hourly rate that is determined from the person's net income, (gross income less necessary expenses).
- Accreditation – SCHAS is accredited by Home Care University, an affiliate of the National Association for Home Care & Hospice. This vital oversight ensures the agency provides the highest possible quality service.
- Caregiver Training – Caregivers are the heart of the program, and SCHAS places emphasis on treating them as professionals. Before hiring, SCHAS performs background checks, reference checks, drug tests, and TB tests. A registered nurse provides 72 hours of orientation and personal care training. On-going training is required at monthly in-services.
- Government Programs – The Federal Government and the State of Tennessee fund several programs that reimburse the agency by the hour for homemaker and personal care services.
- Governing Board – SCHAS has a diverse governing board compiled of business and financial leaders, social workers, medical personnel, legal advisors, and retired individuals. The board members guide SCHAS with financial and legal oversight, ensure high quality programs, help with fundraisers, and advocate for the agency.
- Partnerships – SCHAS partners with for profit companies, government entities, United Ways, foundations, private individuals, and other not-for-profit agencies.

A few examples of these partnerships are: SCHAS receives cleaning supplies from a local office supply company to give to people that cannot afford to purchase them. Second Harvest, a local non-profit that distributes food, donates non-perishable items so our caregivers can deliver it to those that may be running low on food at the end of the month when their money runs low. Volunteer groups paint homes or perform maintenance tasks for people that cannot afford to get those needed chores done. Care-All, a home health company, puts "Dove Trees" in the malls at Christmas to get poorer clients much needed clothes as presents. Partnerships are invaluable in helping SCHAS achieve its mission.

**SCHAS is unique because the agency is capable of helping the affluent that can pay for services, poorer people that qualify government services, and the middle class that might not be able to pay the full fee but still do not qualify for government help.** Once a person or family member decides to make the call for help, we can usually provide service within a week. A timely response is important because if someone is calling for help then he/she is admitting that a loss of independence has occurred in their life.

Although SCHAS caregivers typically work in the home, they are also able to go into hospitals, nursing homes, or assisted living facilities. Caregivers are able to help people transition from an institution environment back into their homes. This is vitally important because people will often have to re-enter a hospital if they cannot get the support services they need. SCHAS is tracking data about people that leave a hospital setting and return to their home that use our services to help with this transition. These people either had no family members to help them, or the family members had to work. 80% of these clients do not have to re-enter the hospital after the first 30 days. I am not claiming that SCHAS is the only reason they succeed at remaining home, but SCHAS caregivers are able to help them get medicines, remind them to take their medicines, perform grocery shopping and meal preparation, provide transportation to doctors' appointments, keep their homes clean, and help them with bathing. Additionally, some of these people no longer use our services because they are now well enough to live by themselves again.

I am positive that SCHAS saves taxpayers' dollars when we receive the phone call in time to help. In the example above Medicare dollars are saved because the agency is a support system so that the person does not have to re-enter the hospital. SCHAS caregivers are trained to notice if a person has significant fall risks in the home (like rugs that slide easily on the bathroom floor), or if the client's physical condition has deteriorated and the person is now a higher fall risk. Our caregivers check the food in the refrigerator to ensure that it has not spoiled. This prevents food poisoning from occurring. Our caregivers are trained to look at skin color to see if it has changed since the last visit, and talk with the person to ensure the client's mental status is unchanged. **Prevention, intervention, and early detection are keys to successfully keeping a person in the home. Caregiver training allows SCHAS to be successful in all of these areas.**

SCHAS employs caregivers of all ages, but over 50% of the employees are older than 49. The agency's oldest caregiver was born in August 1921. As a part-time caregiver, she is excellent at providing companionship to a client while cleaning the home and her wide smile can brighten up anyone's day. Being a caregiver is a career path that older adults can choose for employment. Upon passing all background checks, SCHAS trains new hires, and the only educational requirement the agency has is that the person be able to read, write, and take verbal instructions. Because of the economic downturn, SCHAS has received some funding to help pay for the costs of training for people that need jobs. However, the agency has not been successful in receiving federal grants. **Since the demand for caregivers is growing, I believe that older Americans can find employment as caregivers, and funding for training would allow agencies like SCHAS to employ this group that faces challenges in finding jobs.**

#### RENAISSANCE TERRACE

Despite the best efforts of trying to keep people in their homes, there may come a time when the cost of one-on-one care becomes too expensive. Realizing that people need affordable

solutions to this challenge, SCHAS held a capital campaign to build the corporate headquarters of the agency, and a 48 unit assisted living facility. The facility was completed in October 2008 and offers all the services of an assisted living facility in the State of Tennessee (except a secured behavioral unit) for one price of \$2,200.00 per month.

Renaissance Terrace is a beautiful assisted living facility located in the Fourth and Gill neighborhood of downtown Knoxville. Funding for the building came from several different places including: Knox County government - \$3,000,000.00, State of Tennessee - \$3,000,000.00, Federal Government - \$196,000.00 grant for furniture, foundations, and individual contributions. In total SCHAS raised over \$8,600,000.00. By raising funds to pay for the cost of the building, the agency is able to keep the monthly fee more affordable for the middle class. This plan has worked, and over 50% of the people that live in the building meet the HUD poverty guidelines. However, they are able to pay for their services by themselves or receive financial support from family members, the Veterans Administration, or other funding sources.

Often people that move into assisted living facilities will sell their home in order to pay the monthly fee. If they outlive the money from the sell of the home, they get into a financial bind and may have to move into a nursing home and then Medicaid will pay the cost. Sometimes family members (such as children) have the ability to help pay for the cost, but this puts a financial strain on them if the person lives in an assisted living facility that charges well over the amount the individual receives in Social Security benefits each month. I have personally talked to the residents and their family members, and I can testify that they are grateful for the facility. You can see the stress disappear from their faces when they realize they have found a place to live that they can afford.

Renaissance Terrace is full and has a waiting list. As a program of SCHAS, it has a balanced budget and is paying 26 employees and all other operational expenses without receiving any other funding. I believe this model could be easily duplicated throughout the State of Tennessee and the United States of America. **Renaissance Terrace is an affordable solution that relieves the financial stress of the residents while providing quality care.**



**A short-term investment by several government entities and private donors is now proven to be a long-term health care solution that will save taxpayer dollars for years to come by allowing people to pay for services themselves.**

#### OTHER PROGRAMS

As mentioned previously, SCHAS programs are needed because we strive to fill in the gaps where there are no services offered. This allows the agency to be successful in fulfilling its mission. Some of our other smaller programs at the agency are:

- Home Hair Care – Cosmetologists travel to the homes of people that can no longer travel to the beauty shop and provide all the services that one could receive at a salon. This service is extremely important to the self-esteem of the individual and family members. The pedicures are vital to diabetics that can no longer safely trim toe nails. This program serves around 130 people each year.
- Live-in Caregiver – Caregivers stay in the home of the client for several days at a time. The caregiver lives in the home, has a bedroom, and is paid a daily rate. The client needs to be able to allow the caregiver to sleep through the night. The client pays a daily rate for this service. This program serves around 8 people each year.
- Volunteer Program – Volunteers perform services that our caregivers cannot do such as yard work, building wheelchair ramps, painting houses, and cleaning gutters. We also have volunteers at Renaissance Terrace such as school children that perform skits, and artists that sing or paint. This program serves around 300 people each year.
- Helping Others Provide Excellent Care – The SCHAS nurse educator offers classes to family caregivers that need help dealing with the stress of being a caregiver. We educate people about whom to call in our community to get help, and we teach them how to safely provide care in the home. Local government and foundation grant funding allows us to provide this training.
- Elder Food Program – This program is a partnership with Second Harvest Food Bank. Second Harvest delivers pallets of non-perishable food to our offices and then SCHAS office staff put the food in recyclable canvas shopping bags. If an employee of the agency sees a client that is struggling with purchasing food a caregiver will take a bag of food to the client when the caregiver visits the home to supply

homemaker services. The amount of food in each bag is around a four day supply. This program serves around 450 people each year.

#### SUMMARY

What is the cost for someone to have dignity and the best possible quality of life during the dying process? I have a limited viewpoint of this because I have not personally seen all the different solutions offered in America. However, I can quickly recognize people that succeed at dying with dignity. One example that comes to mind is the story of a widow whose husband died serving America in World War II. She lived in a small house in a rural community in East Tennessee. Her SCHAS caregiver mailed to our nurse educator a tear stained story about how she helped this lady during her last years. This American Hero never remarried after her husband's death because she loved only him and wanted to honor him. She worked in a factory to pay her bills, and this allowed her to buy a small house. Her finances were limited so she ate peanut butter most of the time. She heated two rooms of her home in the winter, and had box fans in the summer. SCHAS provided about three hours of help to her each week on a sliding scale fee so that her home would be clean, and she consistently paid her bill with "thank you" written on the check. The SCHAS caregiver is the person that found her after she had passed away peacefully in her home.

Most people may think that living on a diet that consists of peanut butter as the main staple, and not being able to heat more than two rooms in their home is undignified, but she was a person filled with dignity and honor. She lived a simple life – her life, in a manner that she chose. She made her own decisions, and was able to live and die on her terms.

SCHAS is blessed to have many different funding sources, volunteers, programs, and caring staff. All these resources allow the agency to offer affordable options to a population that is battling to maintain their dignity and honor. Every person that needs the agency's help is different with their own unique story. Recognizing this fact, the agency develops a personal care plan based on the individual client's needs. I do not believe the question should be, "what is the cost for someone to have dignity during the dying process?" I do believe the

question should be, “what message does a society send if its citizens die in an undignified manner?” I have faith that the Select Committee On Aging will find affordable answers to this question.

#### RECOMMENDATIONS

1. Non-profit service providers have efficient, cost effective programs. SCHAS is training and hiring individuals that are over 50 to be caregivers. Renaissance Terrace is an example of how to help the middle class pay for care so they will not become financially indigent and have to rely on government funds for services. Look for programs that provide a return on investment that do not continually request funding.
2. While Tennessee’s Home & Community Based Services provided through the Long-Term Care Choices Act is improving cost-effectiveness and expanding services to needy, seniors the Single Point of Entry System needs to be easier to navigate, and information obtained should be shared with all the organizations that need it. People trying to enroll into services are repeatedly asked the same questions because answers are not shared. As a service provider, we do not always receive information needed to provide care safely for our caregivers and the client. Service providers need to be included in the development stage of this process.
3. Educating people about services is vital, and service providers can help with this task. We need information to distribute at expos and job fairs, and also to clients that call us needing help.
4. Partnerships result in accountability and efficiency. SCHAS values the relationships we have with the Area Agency on Aging, Office on Aging, Veterans Administration, Managed Care Organizations, United Ways, foundations, hospitals, home health agencies, other non-profits, political officials, volunteers, and many others. Funding applications and grants need to request how partnerships will be utilized to make the program efficient.
5. Transitioning from an institutional environment such as a hospital, back to the home is often a daunting task for people with limited resources. A system needs to be in place to help people facing emergency situations to be successful so they do not have

to reenter the institution. I believe service providers can be the link people need to succeed and save dollars in Medicare expenses. Increased effort is needed to develop transitional case management teams representing acute care entities, managed care organizations, and service providers.

6. Transportation is needed in rural areas to get people to doctor appointments. Service providers can help with this because our caregivers can transport clients. SCHAS has this program in place for private pay clients. We need this service to be authorized for people enrolled in government programs.
7. Programs that receive funding need to be accountable and report how the funds are impacting the community that is being served. SCHAS completes success indicators each year for United Ways that report the impact the agency has in the community. This informs the contributors about the success of the agency. I believe American Taxpayers want to be assured that funded programs are successful.

Additional Questions from Senator Casey to Mrs. Rosalynn Carter for the Record:

1. *What opportunities do you see in the Older Americans Act to improve service coordination between professional and family caregivers?*

The Older Americans Act may provide several opportunities targeting the improvement of service coordination between professional and family caregivers. These opportunities are briefly listed below:

Establishment of a National Quality Caregiving Task Force to develop a work plan to create a caregiver support system and implement nationwide. This plan would include, but not be limited to:

- Establishment of state-wide systems to assess and analyze caregiver status and health. Utilizing the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System's (BRFFS) caregiver module, data could be collected every two years. The data from this caregiving module would enable states to identify sub-populations of caregivers with unmet needs, provide much needed information on tracking trends in caregiver health, and implement caregiver support programs. Programs established would be driven by data analyzed for caregiver benefit outcomes and costs effectiveness.
- Encouragement of professional development for current health care professionals regarding the needs of and evidence-based programs for caregivers. Professional development should encompass education and how to assess the needs of family caregivers in a culturally-sensitive manner, how to effectively partner with them and how to implement referral protocols specific to evidence-based programs.
- Revision of training curriculum in current and future healthcare education for all healthcare professionals (physicians, nurses, therapists and many more). New curriculum should target the health of caregivers and evidence-based programs that support and sustain them.
- Revision of routine patient assessments. Routine assessments already being conducted by healthcare providers (hospital discharge, home care, outpatient rehabilitation) or government funded (Area Agencies on Aging) should be revised to include a caregiver component. In addition, government and other third-party payers should reimburse healthcare providers for conducting a caregiver assessment.

2. *From your experiences, what do you see as the biggest impediment family caregivers face in trying to help their loved ones?*

One of the biggest impediments faced by family caregivers today is the awareness of and connection to community resources appropriate for caregivers. Caregiver resources/programs should be evidence-based and culturally-sensitive. To overcome this barrier, a national

outreach and public education campaign should be launched. Goals of the campaign would be to:

- Inform the public about who caregivers are;
- Help family caregivers recognize, identify, and access available community resources; and
- Identify how individuals, communities, employers, and faith communities can empower and assist caregivers.

“Meals, Rides and Caregivers: What Makes the Older Americans Act  
So Vital to America’s Seniors”  
May 26, 2010  
Questions for the Record for Assistant Secretary for Aging Greenlee  
Senate Special Committee on Aging

Additional Questions from Senator Kohl for the Record

*1. It's our understanding that AoA has not promulgated regulations for the long-term care ombudsman program and perhaps other programs in some years. Why is this, and do you think it would be appropriate to issue more guidance than the agency is doing now?*

Regulations for the Older Americans Act were last promulgated in 1988 and are found at 45 CFR Parts 1321, 1326 and 1328. Part 1321 constitutes the regulations for Title III of the Act, which at that time included the Long-Term Care Ombudsman Program. In the 1992 reauthorization of the Older Americans Act, Congress created Title VII, Allotments for Vulnerable Elder Rights Protection Activities. While regulations for Title VII programs, which includes the Long-Term Care Ombudsman program, were proposed and published in the Federal Register by the Administration on Aging (AoA) in 1994, final regulations were not adopted. It is the intention of AoA to issue regulations for the Long-Term Care Ombudsman Program and other provisions of the Older Americans Act in order to provide clear and consistent guidance.

*2. Recently it came to the Committee's attention that 15 or so Aging Resource Disability Centers (ADRCs) are incorporating counseling on housing into their broader missions of assisting older adults with information and referral about long-term care and other benefits and assistance programs. Some of these housing counselors are being asked to assist thousands of seniors who have taken out reverse mortgages under a program offered by the Dept. of Housing and Urban Development (HUD), and who have fallen behind on property tax payments. Apparently some of these seniors, perhaps through a misunderstanding with regard to the terms of their reverse mortgage loans, may face foreclosure. Are you concerned about this, and if so, can you provide information about what solutions may be at hand?*

The U.S. Department of Housing and Urban Development (HUD) offers the Home Equity Conversion Mortgage (HECM) reverse mortgage to adults age 62 and older. These reverse mortgages have been attractive to older adults for a number of reasons. Older adults with few assets aside from their home can tap into their equity to help them age in place. Borrowers can live in the home as long as they want without making any monthly payments, aside from property costs such as property taxes and insurance. Lenders are required to send prospective borrowers to a HUD approved Housing Counseling agency which is required to explain: how HECM works; costs; calculation of principal limit; financial implications of a HECM; alternatives to a HECM; and the borrower's obligations. Prospective borrowers cannot receive a HECM loan unless they have been certified by a Housing Counseling agency as having completed a counseling session.

A number of aging network entities, including area agencies on aging (AAAs) and Aging and Disability Resource Centers (ADRCs), have become certified Housing Counseling agencies by

working with one of the HUD approved Housing Counseling intermediaries. AoA believes that aging network organizations are in a good position to assist prospective borrowers in understanding whether or not a HUD HECM reverse mortgage is an option that would benefit them.

Under the HECM program property taxes, insurance and other property charges are the responsibility of the homeowner. Lenders have advanced property tax, insurance and other property charges to borrowers who were unable to pay them. HUD is now requiring lenders to try to collect these advances. In some cases, older borrowers who are unable to repay these advances may be in jeopardy of mortgage default or losing their home. Five HUD Housing Counseling agencies have been selected to provide free counseling to HECM clients that receive a delinquency letter. The approved delinquency Housing Counselors are working with borrowers to assist them in resolving their delinquency. AoA is concerned and interested in insuring that HECM borrowers receive the assistance they need. Toward this end, AoA has worked to keep the entire aging network informed so that they are in the best possible position to assist older consumers who come to them seeking assistance.  
[http://www.aoa.gov/AoARoot/AoA\\_Programs/Special\\_Projects/HECM/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/Special_Projects/HECM/index.aspx).

*3. What role do the Senior Corps volunteer programs of the Corporation for National and Community Service (CNCS), specifically the Senior Companion Program (SCP) and RSVP, play in the Administration's initiatives on Family Caregiver support and independent living? Is there an active and continuing relationship between AoA and CNCS to coordinate these efforts and what can be done to improve the integration of this work?*

At the community level, SCP and RSVP volunteers have supported family caregivers by working as volunteer respite providers for in-home settings and in senior center and adult day care settings alongside staff who work directly with participants in such programs. These types of activities pre-dated the NFCSP and continue to be an integral component of many caregiver programs at the State and community levels.

SCP and RSVP volunteers have also been looked to for staffing at meal sites, senior centers and have provided telephone reassurance, friendly visiting, and transportation services for homebound and isolated seniors, ensuring a much needed contact to services and supports available in the community. Such activities have helped to augment the capacities of community-based programs.

AoA has met with CNCS to discuss ways in which our programs can collaborate and coordinate more fully. We are currently updating our Memorandum of Understanding to enhance coordination, expand our activities, and test new ideas. There may be opportunities to improve the integration of SCP/RSVP programs more fully into aging network programs by looking carefully at the services being provided and identifying opportunities for greater inclusion of CNCS programs to augment grant-funded activities.



Additional Questions from Senator Bill Nelson for the Record

*As you're aware, as a condition for funds under the Older Americans Act (OAA), states are required to establish and operate an Office of the State Long Term Care (LTC) Ombudsman. Federal law requires that the functions of the State LTC Ombudsman Program include certain activities, such as identifying, investing and resolving resident complaints.*

*On February 7, 2011, Brian Lee resigned as the program director for Florida's Office of State LTC Ombudsman. Mr. Lee resigned his position after he was told he would be fired if he did not voluntarily leave his position. Mr. Lee reported that his resignation came after growing problems with Governor Rick Scott. While a state can terminate an Ombudsman's employment at any time, without cause, there is growing concern that Gov. Scott willfully interfered with performance of official duties by the Ombudsman's office, which is prohibited under the OAA. On March 8, the Administration on Aging (AOA) announced it would conduct a review of Florida's LTC Ombudsman program, and the circumstances surrounding the resignation of Mr. Lee in terms of compliance with the OAA. According to the AOA, there is no expected timeline for completing the review. The agency reported that it intends to be thorough in its review and therefore "does not want to limit the review by setting an arbitrary time frame" for completion. The HHS Office of Inspector General (OIG) has stated it will not initiate a separate inquiry to determine whether actions by Florida officials or long-term care industry representatives warrants criminal wrongdoing, but may reassess this depending on the AOA's findings.*

*(1) Can you please explain the "willful interference" provision of the Older Americans Act, and why this is an important protection for the ombudsman program?*

The pertinent provision under the Older Americans Act states:

"The State shall ensure that willful interference with representatives of the Office in the performance of the official duties . . . shall be unlawful." [Section 712(j)]

Long-Term Care Ombudsmen need to be able to perform their duties in order to resolve complaints and protect the rights of long-term care facilities. Interference with their duties could compromise their effectiveness in successfully fulfilling their duties to these residents.

*(2) Can you please provide an update on the investigation by the AoA on Florida's ombudsman program?*

The compliance review is currently underway by the Administration on Aging. Not only has AoA been reviewing the relevant actions and policies in the State of Florida, but it has also been researching previous AoA guidance in order to identify areas where additional guidance to States may be helpful to strengthening Long-Term Care Ombudsman Programs.

Additional Questions from Senator Wyden for the Record

1. *The GAO study highlights an issue that I think should be addressed. This issue is the lack of data regarding the unmet need for Older Americans Act services such as home based care, meals and transportation. What efforts are currently underway at the Administration on Aging to better identify who needs Older Americans Act services? As Congress takes up reauthorization is there anything that can be done legislatively to help ensure that Older Americans Act services are going to seniors who need them the most?*

Available data indicate that great need exists for home and community-based services for older adults and their family caregivers. In response to that clear need, State and local agencies across the country actively seek additional funding, more than doubling the funding received through the OAA to provide these needed home and community services.

In response to GAO's request for uniform data collection procedures for obtaining information on older adults with unmet needs, AoA recognizes the great variation between States in how they are structured and administer diverse funding for home and community-based services; States' desire for administrative flexibility to assist them in maximizing their resources; the need to avoid imposing additional data collection burden for State agencies on aging; and the difficulties inherent in trying to define need and unmet need for a varying range of services funded by diverse Federal, State and local funding sources using different service definitions, AoA proposes to develop a measure for need and unmet need that will minimize the burden to States. We are proposing the development of a measure that will evolve over time as we work with States and other Federal agencies to refine it to better meet our needs.

AoA proposes to initially use a relatively new data source, the American Community Survey (ACS), to measure prevalence of disability. The ACS collects information on six types of disability: vision, hearing, cognitive, ambulatory, self care (ADLs), and independent living (IADLs). The six disability questions have been tested and vetted and are being used in surveys throughout government. The first three year data file for this measure covering 2008 – 2010 will be out in the fall of 2011. This data file provides a larger sample size than the one year data file, and therefore, more reliable estimates.

AoA proposes to pull data for each State on residents aged 60 and older that answer yes to one or more of the six disability questions. That number will serve as a proxy for need for home and community-based services like those provided through the Title III of the OAA. To get to an approximation of unmet need, states would calculate the total number of unduplicated adults aged 60 and older receiving services like those provided under Title III of the OAA and subtract that from the number of individuals with one or more disabilities.

We recognize that all service delivery through the OAA Title III is not directly related to disability status. For example, an older person living in a rural area, without a car, may have a need for OAA transportation services even though he or she does not have a disability. Consequently this measure serves as a proxy for need and unmet need for Title III like services. Over time, AoA would refine the measure to more closely approximate a direct measure of need

and unmet need for services like those offered under Title III. In the meantime, this calculation would provide an ongoing, uniform proxy measure of need that States could use to compare themselves to other States as well as to a national estimate.

One promising study that may help us to refine this measure of need and unmet need is the new National Health and Aging Trends Study (NHATS). This study of functioning in later life will gather information on a nationally representative sample of Medicare beneficiaries ages 65 and older. In-person interviews will be used to collect detailed information on activities of daily life, living arrangements, economic status and well-being, aspects of early life, and quality of life. The results of this and other data may assist us in further refining the proposed measures of need and unmet need.

*2. Your agency has worked with CMS over the past few years to develop Aging and Disability Resource Centers as a new way to coordinate public outreach to and referral for both the aging and disability populations. As you look to the future, what is the ADRC role vis a vis the Older Americans Act and how does the ADRC model fit with the OAA's Aging Network infrastructure?*

AoA and CMS have given States significant flexibility in the design of ADRC systems to best meet State and local community needs. Most States have embedded them in full or in part into existing aging network infrastructure. To date, 52 States and Territories have developed 365 ADRC sites, with 19 States achieving statewide coverage of their ADRC program. Nationwide, 53 percent of the population now resides in an ADRC coverage area. The goal of the Aging and Disability Resource Center Program is to empower individuals to make informed choices and to streamline access to long-term services and supports. Long-term services and supports refers to a wide range of in-home, community-based, and institutional services and programs, including OAA programs, that are designed to help individuals with disabilities including the elderly. A single, coordinated system of information and access for all persons seeking long term support will minimize confusion, enhance individual choice and support informed decision-making. The ADRC model therefore supports the larger long-term services and support system, including the OAA aging services network.

Additional Questions from Senator Casey for the Record

*1. Administration on Aging programs provide training opportunities to direct care workers, what role(s) can the Administration on Aging have in improving direct care recruitment and retention through other incentives such as wage increases and certification opportunities?*

A number of AoA funded resource centers have assisted in the development and implementation of professional certification programs. For example, the National Aging and Disability Information and Assistance Support Center developed and implemented, in collaboration with the Alliance of Information and Referral Systems (AIRS), professional certification for aging network information and assistance specialists. Additionally, AoA is in the process of convening the Personal Care Attendant Advisory Panel, a FACA committee authorized by the Affordable Care Act. The Committee will provide advice and guidance on issues related to the adequacy of the number of personal care attendant workers, the salaries, wages, and benefits and access to the services provided by personal care attendant workers. The committee will assist and advise the Department on personal care attendant workforce policy as it pertains to the Department, States, local governments, and the private sector.

*2. A recent report by the Kaiser Family Foundation found that there are two major obstacles facing States in moving older Americans out of nursing homes into the community – the lack of affordable housing and the lack of direct care workers. What do you see as ways that the Older Americans Act can address these problems?*

AoA is an active partner in the HUD HHS Community Living collaborative. One project of that collaborative is funded by HUD, AoA and the HHS Assistant Secretary for Planning and Evaluation (ASPE) and is charged with the design of a demonstration to coordinate housing, health and long-term care services and to support low-income older adults. This project will be looking specifically for ways to combine affordable housing with the appropriate supportive services from direct care workers. A potential future effort of the HUD HHS Community Living collaborative is an expansion of the Live Where You Work demonstration where younger persons in subsidized housing are trained as direct service workers to provide support to individuals with disabilities, including the elderly, living in or near the subsidized housing.

Currently the Senior Community Service Employment Program (SCSEP - Title V of the Older Americans Act) is administered by the Department of Labor (DOL). The President's Budget for FY 2012 proposes to transfer SCSEP to AoA. In the past, pilot programs have been conducted through Title V of the OAA to develop training programs to help SCSEP participants (older workers) become direct care workers. Additionally, several of the current grantees continue this type of training when it meets a participant's employment goals. AoA is working with DOL in preparation for this transfer. AoA will also analyze these past pilot programs and the potential applicability to the lack of direct care workers.

*3. So much is said about the wave of baby boomers and the services they will need...can you please share your thoughts about the role the aging network should play in ensuring that the workforce -direct care workers and aging professionals - is in place to provide those services?*

The HHS Office of the Assistant Secretary for Planning and Evaluation has done a study on this important issue, including projections of the need. AoA has been working to build the capacity of the aging network to meet the future needs of America's older adults for a number of years. Within the confines of limited OAA funding, we have established national resource centers to focus on building the capacity of the network in key areas of concern. For example, one resource center is focused on building capacity within AAAs, another is focused on building capacity in ADRCs, and another within State units on aging. While AoA does not currently fund a resource center focused specifically on issues of direct care workers, many of the centers we do fund provide some focus on this issue.

*4. Medicare and Medicaid fraud is an issue that costs the government billions of dollars every year. What increased role do you see the Senior Medicare Patrol Program having in CMS' efforts to combat this?*

The Senior Medicare Patrol (SMP) program serves a unique role in the effort to identify and prevent health care fraud in the Medicare and Medicaid programs. SMP projects utilize the skills of retired professionals as volunteers to conduct community outreach and education and provide information that empowers beneficiaries and their families to recognize and report suspected cases of Medicare and Medicaid fraud. Activities are carried out in partnership with the Centers for Medicare & Medicaid Services (CMS), the HHS Office of the Inspector General (OIG), healthcare providers, and other aging and elder rights professionals from around the country. In FY 2011, 54 SMP discretionary grants were awarded to fund projects in all 50 States, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands.

In 2010, the Secretary of HHS announced that the Administration would double the funding for SMP activities. Grants awarded October 1, 2010 provided additional funds from CMS for expansion of SMP program capacity, including more volunteer "feet on the ground" to further increase Medicare beneficiaries' awareness of health care fraud prevention, identification, and reporting. Funding was targeted to those States or localities identified by CMS data as having higher rates or incidents of fraud and abuse. AoA has begun collecting data on results of this expanded program funding, including increased numbers of volunteers, inquiries, and outreach provided. A second round of CMS expansion grants was recently announced; SMP applications are due July 18.

AoA continues to work closely with CMS to increase the role of the SMP program in health care fraud control. AoA has enhanced collaboration with the CMS Center for Program Integrity to facilitate referrals of fraud complaints directly from SMP projects to the CMS fraud contractors (Program Safeguard Contractors—PSCs, Medicare Drug Integrity Contractors—MEDICs, and ZPICs--Zone Program Integrity Contractors). In addition, SMP referrals are now being made directly to the HHS OIG to ensure investigators can begin to quickly act on complaints. In addition, AoA is working with CMS to provide SMPs facilitated access to 1-800-MEDICARE so that beneficiary issues can be researched more efficiently. And AoA and CMS have developed a protocol for the operators at 1-800-MEDICARE to refer hotline callers to their State SMP in those instances where face-to-face assistance with issues involving potential fraud would be helpful. These new roles and collaborative efforts help to ensure that the SMP program will

educate and empower greater numbers of Medicare beneficiaries to prevent, identify and report health care fraud at the grass roots level.

*5. What more do you think can be done to better integrate the new initiatives in the Affordable Care Act around prevention and chronic disease management with the disease prevention and health promotion programs in the Older Americans Act. How can the nutrition programs and exercise programs at Senior Centers fit help build on this?*

AoA has for some time encouraged States to use OAA Title III D funding to promote evidence-based health promotion and disease prevention activities including through such venues as nutrition programs and senior centers. These preventive health services grants provide funding to States and Territories, based on their share of the population aged 60 and over, that support activities which educate older adults about the importance of healthy lifestyles and promote healthy behaviors that can help to prevent or delay chronic disease and disability, thereby reducing the need for more costly medical interventions. They include programs related to self-management of chronic disease, exercise, falls management and prevention, medication management, mental health and substance misuse, and nutrition among others. Examples of programs include Chronic Disease Self Management Program; Matter of Balance and Tai Chi for falls management and prevention, respectively; Enhance Fitness; the Medication Management Improvement System (MMIS); and Healthy IDEAS. With funding from the American Recovery and Reinvestment Act, AoA has implemented Chronic Disease Self-Management Programs in 48 States. To date, over 36,000 individuals have completed this six week program enabling them to better manage their complex of chronic disease(s). AoA also partners with the Centers for Disease Control and Prevention (CDC) to help coordinate the expansion of evidence-based prevention programs in communities.

Additional Questions from Senator Casey to Max Richtman for the Record

*1. What more do you think can be done to better integrate the new initiatives in the Affordable Care Act around prevention and chronic disease management with the disease prevention and health promotion programs in the Older Americans Act. How can the nutrition programs and exercise programs at Senior Centers fit help build on this?*

The Older Americans Act (OAA) and American Recovery and Reinvestment Act (ARRA) stimulus funding have enabled a strong Chronic Disease Self-Management Program (CDSMP) infrastructure to be developed that now includes over 4,000 community-based delivery sites, a national technical assistance center on evidence-based prevention programs for the elderly, and a national CDSMP training and certification center at Stanford University. In FY 2010, the Administration on Aging (AoA) funded 47 State and territory grants for CDSMPs, with an average award of \$574,468, using funding provided under the Recovery Act. Over 52,500 individuals have participated in the CDSMP programs offered through this infrastructure. And for the first time, Healthy People 2020 objectives for older adults include targets for building confidence in managing chronic conditions.

We are extremely concerned, however, about the implications of the expiration of ARRA funding next year. It is critical that funding for the successful CDSMP be continued; the current state infrastructure will likely fall apart without an extension of resources.

In its FY12 budget proposal, the Administration is calling for CDSMP to have its own stand-alone funding, at a level of \$10 million. The Prevention and Public Health Fund authorized by the Affordable Care Act also provides an opportunity to maintain and expand this important program. An allocation of \$30 million, or 3% of the amount authorized for the Fund this year, would enable over 85,000 people to participate in CDSMP through the delivery of nearly 11,000 workshops. This is the minimal amount needed to sustain existing infrastructure and expand into the four states not currently funded and into other high risk, high needs populations ensuring that every state have continuously available CDSMP workshops.

Senior nutrition and exercise programs implemented without dissemination of other program offerings is a huge missed opportunity for improving the health older adults. Any gathering of seniors, i.e. through the nutrition and exercise programs, is an opportunity to expose them to resources about and offerings of available evidence-based programs. Senior Centers can implement and promote evidence-based programs, and many of them currently do already through the AoA ARRA funds. These evidence-based programs include chronic disease self management, fall prevention programs, and mental health programs. In regards to home-delivered meal programs, this is an opportunity to outreach to seniors about online programs, such as Better Choices Better Health<sup>®</sup>, the online CDSMP. It's our position that new initiatives within the ACA should include a two-venue approach (community-based and web-based programs) whenever feasible to reach those older adults able to participate in the community and those with mobility limitations.

*2. In recommendations for Title V you suggest training older workers to become direct care workers. The direct care worker is the backbone of the workforce who cares for our older citizens. What role do you think specialized training such as in caring for people with dementia or with cancer could play in*

*expanding the career options for direct careworkers and helping to ensure older citizens get high quality, targeted care?*

Title V of the Older Americans Act provides funds for the Senior Community Service Employment Program (SCSEP). Low income older workers perform community service as a pathway to employment and they receive the minimum wage for the time they spend at their community service assignments. Participants in the SCSEP are matched with community service assignments based on their interests, skills training needs, and employment goals. In choosing an employment goal, participants must also take into consideration the types of jobs that are available in the local economy and the wages and benefits they will need to move toward economic security.

Health care is just one of the sectors older workers have expressed an interest in pursuing – other sectors include transportation, computer technology, retail, hospitality, education, service industries, manufacturing, and green jobs – to mention a few. Certainly, the health care field (and the direct care workforce in particular) is one where there is great need. However, since SCSEP participants are extremely low income often with multiple barriers to employment, it is important to ensure that the individuals who undertake this career pathway have opportunities for a livable wage, pursue jobs where they can receive accommodations to any limitations they might have, and they pursue the kind of work for which they have an aptitude, interest, and chances for advancement. For many years some SCSEP participants have been receiving training that leads to certification as nurses' assistants or home health aides – but these job opportunities are often strenuous, low wage, and offer few benefits.

Funding for the SCSEP is severely limited so the training opportunities for more advanced direct care credentials are often beyond the scope of the SCSEP. With additional federal funding for the SCSEP, more specialized training would be possible and very attractive to some participants who have an interest and aptitude for working with older individuals with dementia, cancer, or other health related issues.



Senator Casey's statement for the record from May 26, 2011 hearing.

I would like to thank Chairman Kohl for holding this important hearing on the Older Americans Act. The Older Americans Act was first passed in 1965. At that time President Johnson said the Act "affirms our Nation's sense of responsibility toward the well-being of all of our older citizens. But even more, the results of this act will help us to expand our opportunities for enriching the lives of all of our citizens in this country, now and in the years to come." As we work to reauthorize this legislation this year we must hold true to that vision while at the same time ensuring the programs meet the needs of older citizens living in current times.

As many here know, Pennsylvania is one of the oldest states in the country. We are consistently in the top five for percentage of older citizens. We have an abiding responsibility to get this right. These are the people who fought our wars, worked in our factories, taught our children and gave us life and love. We have an obligation to make sure that they are protected and helped in the best way possible and the Older Americans Act is a key component of that.

I also want to welcome Elizabeth Marshall, a former mayor from York, Pennsylvania. I want to thank her for her service and for being here to testify today. Ms. Marshall is a former Mayor of York, Pennsylvania and her story is a shining example of how people can use the programs provided under the Older Americans Act to live independently in their homes. I look forward to her testimony.

Some describe the Older Americans Act as the glue that holds all the programs that benefit older citizens together. Through these programs older citizens have access to home delivered meals, senior centers and elder justice programs are funded, and family caregivers are supported. Funding is provided for demonstration programs to ensure this Act is a living document, always improving, always expanding to meet the needs of older citizens today and tomorrow.

I look forward to working with my colleagues on the Aging Committee and my colleagues on the HELP Committee as we work to reauthorize this important legislation and again I thank Chairman Kohl for holding this hearing.



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June 9, 2011

The Honorable Herb Kohl  
Chair, Senate Special Committee on Aging  
United States Senate  
Washington, DC 20510

The Honorable Bob Corker  
Ranking Member, Senate Special Committee on Aging  
United States Senate  
Washington, DC 20510

Re: May 26, 2011 Hearing on Older Americans Act Reauthorization

Dear Chairman Kohl and Ranking Member Corker:

On behalf of the American Bar Association, with nearly 400,000 members nationwide, I commend the Special Committee on Aging for holding a hearing on May 26, 2011, on the reauthorization of the Older Americans Act. The ABA strongly supports reauthorization of the Older Americans Act, and we urge the Committee to amend the Act to improve the delivery of legal services to older Americans.

Legal Services under the Older Americans Act

Essential programs and services made possible by the Older Americans Act empower seniors to live independent, dignified lives by helping them understand and navigate essential income and health care options and to remain free of abuse, exploitation and neglect. Literally all older Americans benefit from Older Americans Act programs and services, but the impact is greatest on at-risk seniors -- those with the greatest economic and social needs. At-risk seniors include the over 5.2 million seniors living at or below the poverty level<sup>1</sup> and 3.3 million seniors who are geographically, socially or culturally isolated.<sup>2</sup> These seniors are at the greatest risk of being institutionalized, abused, exploited or neglected, particularly if they are unable to access income, health care and supportive services. For these seniors, legal assistance assures access to essential income, programs and benefits.

In the most recent year that data is available, Older Americans Act legal assistance helped an estimated 87,000 seniors navigate complex systems that provide income, health care, nutrition and housing, as well as resolve numerous other legal problems from debt collection to advance

<sup>1</sup> Population 60 Years and Over in the United States, U.S. Census Bureau, 2008 American Community Survey.

<sup>2</sup> Crossing New Frontiers: Benefits Access Among Isolated Seniors, National Center for Benefits Outreach and Enrollment, Issue Brief, May 2011, [www.centerforbenefits.org](http://www.centerforbenefits.org).

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care planning.<sup>3</sup> Without help, many at-risk seniors would fail to obtain or retain essential services that make it possible for them to live with independence and dignity. An examination of the need for legal assistance by older Americans living at or below the poverty level and the current service delivery capacity in late 2010 showed that the need for legal assistance by older Americans living at the poverty level is at least four times as great as the ability of the system to meet the need.<sup>4</sup>

#### Nine Governing Principles

In August 2010, the ABA adopted a policy urging reauthorization of the Older Americans Act with increased priority to the delivery of legal services and elder justice in conformance with nine principles. We urge the Committee to consider these principles, which are intended to improve the structure of legal services delivery by simplifying and streamlining the fragmented process that currently characterizes the funding and oversight of legal assistance under the Act. They do not demand greater expenditures.

*Principle 1: Achieve the goal of creating a high quality, coordinated legal services delivery system in each state that prioritizes services for individuals with the greatest social and economic need as well as those at risk of institutional placement.*

The Act currently includes as a priority service the provision of legal assistance to those with the greatest social and economic need. The current system of delivering legal assistance under the Act involves over 1,000 separate provider contracts with no system to assure quality or coordination of legal assistance. This principle urges the creation of a coordinated legal assistance delivery system designed to provide high quality legal assistance to elders at the greatest risk of being institutionalized, abused, exploited or neglected if they are unable to access income, health care and supportive services. For these seniors, legal services assure access to essential income, programs and benefits.

*Principle 2: Fund legal services under the Act directly through a state entity designated by the Administration on Aging, rather than through Area Agencies on Aging.*

The current system delegates funding decisions to the local level, generally through a local or regional Area Agency on Aging. This results in over 1,000 separate provider agreements. Many legal aid programs have multiple contracts with different local agencies within their service area. The agreements lack uniform standards, contracts, and reporting or accounting standards, resulting in an undue administrative and reporting burden for the legal services providers. The aim of this principle is to urge moving the funding decision to the state level. This would allow for application of uniform standards for selection of the best qualified provider, service agreements, and reporting and accounting standards.

<sup>3</sup> In Search of Adequate Funding, David Godfrey, BIFOCAL, Vol. 32 No. 2, October 2010 based on 920,397 number of hours of service reported and 10.6 average number of hours per case from LSC statistics.

<sup>4</sup> In Search of Adequate Funding, David Godfrey, BIFOCAL, Vol. 32 No. 2, October, 2010.

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*Principle 3: Ensure that the state entity is qualified to plan and support a high quality, coordinated, legal services delivery system and has the capacity to allocate, monitor, and evaluate the use of funds.*

Statewide coordination of legal assistance programming under the Act will act to increase the level of oversight and accountability. Under this principle each state will have a statewide expert in the development of a high quality, coordinated, legal services delivery system with the capacity to allocate, monitor, and evaluate the use of funds and coordinate agreements with service providers. This change should result in improved oversight and accountability.

*Principle 4: Ensure adequate funding for legal services in each state, but in an amount not less than the state's Area Agencies on Aging had spent in the aggregate.*

As part of their state plans under the Older Americans Act, states are required to set a minimum percentage of funds for legal assistance programming and to ensure that adequate funding is committed. This principle recognizes that, if there is no maintenance of effort requirement imposed, there is a danger of a net loss in funding if contracting and funding authority for legal services are moved from the local Area Agency on Aging to the state level. This principle reflects the importance of ensuring that states spend at least as much as had been spent in the aggregate by the Area Agencies on Aging. This will provide a more effective and efficient use of resources, since the state entity is in a position to develop a comprehensive and coordinated plan statewide, rather than relying on piecemeal and fragmented local funding decisions.

*Principle 5: Fund national support centers composed of national organizations with expertise in law and aging to provide substantive expertise, materials development and dissemination, technical support, capacity building and training.*

The Administration on Aging supports national support centers that provide technical assistance, develop and promote evidence-based best practices, provide expert resource development, promote capacity building, and provide training and consultation services that tremendously boost the capacity of front line service providers. Through the national support centers, all providers have access to top experts resulting in greater efficiency in program development and service delivery. We urge the continuation of these vital programs.

*Principle 6: Utilize a national legal advisory committee including representatives of legal support centers to assist the Administration on Aging in the development of standards and procedures for both state entities that distribute or utilize funds and legal services providers who seek to be recipients of funding.*

We urge the creation of a national legal advisory committee, which would include representatives of the national legal support centers. The committee would assist the Administration on Aging in the development of standards and procedures for both state

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entities that distribute or utilize funds and legal services providers who seek funding. This advisory committee would complement and supplement the expertise of Administration staff.

*Principle 7: Utilize uniform standards and procedures that build upon the ABA Standards for the Provision of Civil Legal Aid.*

We urge the development of service delivery and reporting standards. In establishing standards for the delivery of high quality legal services, the Administration on Aging is urged to use the ABA Standards for the Provision of Civil Legal Aid as a benchmark. These standards are designed to assure that the quality and ethical standards for civil legal aid programs conform to the highest standards of the profession while taking into account the limited resources of legal aid programming. Legal Services Corporation (LSC) case service reporting standards provide an accepted standard for data reporting. Collection of service data in the same format as LSC grantees will result in data that give us a much greater understanding of the scope of services and measurable outcomes.

*Principle 8: Refrain from imposing Legal Services Corporation Act advocacy restrictions on providers that are not LSC funded.*

In select instances, state and local decision makers intentionally choose to fund non-LSC service providers as Older Americans Act legal assistance providers. This decision may be made in the hope that the non-LSC provider will be able to provide services that LSC providers are prohibited from providing. The restrictions limit the kinds of clients and cases the programs can help and limit their ability to participate in the legislative process. We urge Congress to give states the flexibility to engage providers without imposing LSC restrictions on non-LSC legal services providers.

*Principle 9: Strengthen State Legal Assistance Developers by ensuring that they have the qualifications, authority and resources to exercise leadership in developing and supporting a high quality, coordinated legal services delivery system.*

For decades the Older Americans Act has required states to designate a person as a legal assistance (or services) developer. Effective developers identify key issues, develop service delivery capacity, produce training, and develop local resources. However, many states lack effective developers. Today many developers are only able to devote a part-time effort to the work and may not have authority and resources necessary to be effective in their work. We urge Congress to strengthen the position of legal assistance developer by asking the Administration to create guidelines for the qualifications of a person to serve as developer and best practices outlining the resources and authority that developers should have available to them. We urge Congress to take this opportunity to ask the Administration on Aging to establish standards for legal services developers and to encourage the Administration on Aging to reward states that fulfill the requirement of having an effective developer.

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Reauthorization is critical to the continuing operation of programs and services to our fast growing population of older Americans. Legal services can be a key access service that makes it possible for older Americans, especially the lowest income older Americans and seniors who are geographically, socially or culturally isolated, to attain and retain essential services and supports. These services and supports will allow them to live independently in their communities and remain free from abuse and exploitation. Reauthorization presents an opportunity to utilize the lessons we have learned from more than three decades of experience in supporting legal assistance under the Act and to improve its efficiency, focus, and quality. As the Committee moves forward with this discussion, we urge you to give increased priority to the delivery of legal services and elder justice in conformance with the nine principles outlined above.

Sincerely,

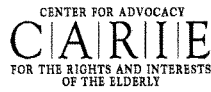


Thomas M. Susman

cc: Members of the U.S. Senate Special Aging Committee

Meeting the Needs of Persons with Alzheimer's or Other Dementia  
When No Informal Support is Available

October 2010



**Center for Advocacy for the Rights and Interests of the Elderly (CARIE)**  
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## Meeting the Needs of Persons with Alzheimer's or Other Dementia When No Informal Support is Available

### Background

The Center for Advocacy for the Rights and Interests of the Elderly (CARIE), coordinates the Dorothy S. Washburn Legislative Committee comprised of legal, health and human services professionals as well as older consumers who monitor legislative and regulatory developments at the local, state and national levels in an effort to promote the well being of frail older adults. The Committee is concerned about the issue of those with Alzheimer's disease and other dementia who do not have a caregiver or responsible party to help them. There have been problems with these older adults being prematurely admitted to nursing facilities or being denied in-home services because of concern about liability. The Committee wants to draw attention to this population to begin to address their needs. There should be a dialogue about how to best strike a balance between preserving autonomy and allowing consumers to take some risks versus ensuring safety through more protective measures. While there is an abundance of information about Alzheimer's disease and related dementia and support for caregivers, there is little, if any, information for those who do not have a caregiver or responsible party. There is enough anecdotal evidence to assume that not all older adults have family or close friends available to help.

It is clear that there is a growing population of individuals with Alzheimer's disease and other dementias that present numerous challenges to our health and long term care systems. The Alzheimer's Association issued a report that estimates that 5.3 million Americans have Alzheimer's disease and the health and long term care costs are almost triple those of other older Americans. The report estimates annual costs of at least \$33,007 for those with the disease compared to \$10,603 for other older adults. This cost does not include the estimated 12.5 billion hours of unpaid care provided by almost 11 million caregivers who are primarily family members.<sup>1</sup> It is imperative that caregivers be valued and supported in their vital role. Unfortunately, there are no statistics readily available about the number of people who have Alzheimer's disease or dementia and who live alone.

"A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group,"<sup>2</sup> describes the devastating impact of Alzheimer's disease on individuals, families, and our nation, and offers strategies and solutions to address the problems. The co-chairs of the independent Alzheimer's Study Group include Former Speaker Newt Gingrich and Former Senator Bob Kerrey. Former Justice

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<sup>1</sup> "2010 Alzheimer's Disease Facts and Figures" at [http://www.alz.org/national/documents/report\\_alzfactsfigures2010.pdf](http://www.alz.org/national/documents/report_alzfactsfigures2010.pdf)

<sup>2</sup> "A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group" at ([http://www.alz.org/documents/national/report\\_ASG\\_alzplan.pdf](http://www.alz.org/documents/national/report_ASG_alzplan.pdf))



Sandra Day O'Connor is among the members of the group. The report highlights that "Over the next 40 years, Alzheimer's disease related costs to Medicare and Medicaid alone are projected to total \$20 trillion in constant dollars, rising to over \$1 trillion per year by 2050." On March 25, 2009, the Senate Special Committee on Aging held a hearing, "The Way Forward: An Update from the Alzheimer's Study Group."<sup>3</sup> At the hearing, Former Senator Bob Kerrey emphasized that the disease creates a tremendous dependency on caregivers whose needs must be addressed by policymakers. There was no discussion about those who do not have a caregiver.

The Council of State Governments has issued a brief, "Cognitive Impairment & Alzheimer's Disease,"<sup>4</sup> that describes why state legislators should be concerned about Alzheimer's disease and what they can do. The brief also identifies several states that have developed Alzheimer's disease plans to help progress with policy solutions. Some states' Alzheimer's Associations have also created a state plan. However, we could not identify any mention of this segment of the Alzheimer's population in any plan.

CARIE's Dorothy S. Washburn Legislative Committee makes the following recommendations:

#### Recommendations

1. Implement an epidemiological study to identify the scope of the problem.
2. Implement research to help identify best practices for ways to ensure early diagnosis for those who live alone. Issues related to stigma and cultural differences should be addressed. Quality assessments should be readily available in all communities for consumers who are becoming concerned about symptoms.
3. Design and fund demonstration projects to identify best practices and practical, cost-effective models for service delivery. There should be a balance between consumers' safety and their need for autonomy. Different needs, preferences and values should be considered. Models should be tested among various cultural groups to identify potential variance with approaches. Identify benchmarks and performance measures that foster good outcomes.
4. Research, design and implement clinical tools to help assess the decision-making capacity of individuals and work to maximize autonomy and

<sup>3</sup> "The Way Forward: An Update from the Alzheimer's Study Group" at [http://aging.senate.gov/hearing\\_detail.cfm?id=310462&](http://aging.senate.gov/hearing_detail.cfm?id=310462&)

<sup>4</sup> "Cognitive Impairment & Alzheimer's Disease" at <http://www.healthystates.csg.org/NR/rdonlyres/265E9FFC-18C4-4757-9254-CB6AC771EA46/0/AlzheimersTPfinal.pdf>

ensure individuals are engaged and involved in making decisions to the greatest extent possible.

5. Identify and utilize an ethical framework for assessment, planning and service delivery to ensure autonomy to the best extent possible as well as cultural considerations.
6. Identify best practices for health care professionals, social workers, and paraprofessionals needed to work with this population including competencies and knowledge needed.
7. Create training programs and help implement best practices for public safety officials such as police and fire fighters, emergency management personnel, and postal workers to help them identify those in need as well as where to turn for further assistance. Information should include but not be limited to what to do for someone who is found wandering.
8. Develop strategies to prevent financial exploitation and premature guardianships for those in the early stages of Alzheimer's disease or other dementia. Ensure access to legal services.
9. Create, test, and implement model community educational programs to increase public awareness and decrease stigma.
10. Encourage a comprehensive national strategic plan as well as the inclusion of the needs of this population in state plans.

Please contact Kathy Cubit at CARIE at [cubit@carie.org](mailto:cubit@carie.org) or 267-546-3438 for more information or to provide feedback.

10/2010

Written Testimony from



for the  
United States Senate Special Committee on Aging Hearing:  
“Meals, Rides, and Caregivers: What Makes the Older Americans Act so  
Vital to America’s Seniors”

Held May 26, 2011

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**Introduction**

Thank you for the opportunity to provide written testimony and for sponsoring the May 26 hearing about the reauthorization of the Older Americans Act (OAA). The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) is a non-profit advocacy organization that works to improve the well being, rights and autonomy of older persons through advocacy, education, and action. CARIE sponsored an Older Americans Act Roundtable on June 9, 2010. Nora Dowd Eisenhower, former Pennsylvania Secretary of Aging, facilitated a discussion among 25 leading professionals in the field of aging and older adults. CARIE coordinates the Dorothy S. Washburn Legislative Committee comprised of legal, health and human services professionals as well as older consumers who monitor legislative and regulatory developments at the local, state and national levels in an effort to promote the well being of older adults. The Committee continued discussions at its meetings to finalize these recommendations. The following recommendations were also submitted to the Administration on Aging (AoA) as part of its process in planning for the reauthorization of the OAA. For more information, please contact Kathy Cubit, Director of Advocacy Initiatives, at [cubit@carie.org](mailto:cubit@carie.org) or 267-546-3438.

**Aging and Disability Resource Centers (ADRCs)****Recommendations:**

With the emerging role of ADRCs, the Older Americans Act (OAA) should clarify relationships among Area Agencies on Aging (AAAs), Centers for Independent Living (CILs) and other agencies and ensure a “no wrong door” policy for accessing services. Secure centralized Internet based models should be developed for individuals to apply for multiple services through one application regardless of location.

**Rationale:**

Even with ADRCs, people still go to AAAs, CILs, and other agencies for assistance. Resources that are already stretched often seem to be spent on something new without examining and strengthening existing programs. Secure centralized Internet based programs can help ensure the “no wrong door” approach while reducing barriers to services and benefits.

**Alzheimer’s Disease****Recommendations:**

Alzheimer’s disease and other dementias should be elevated to its own stand-alone section in the OAA. Key partnerships should be developed such as with the Alzheimer’s Association and National Institute of Health (NIH). There should be a focus on early intervention and reducing the burden of caregiving. It is imperative to identify the extent of those with Alzheimer’s disease or related dementia who live alone with no family or responsible parties to assist them and to create a demonstration project to test models of care to address their needs. Implement an accreditation process for assessment centers that can address what consumers and families need when confronting these illnesses. Accreditation could also apply to providers such as adult day centers so families would know that they were equipped and trained to respond to the needs of consumers with dementia. All AAA staff, particularly assessment staff, should be trained to understand

that people in the early stages of dementia might appear to be highly functional but may actually need and benefit from services.

**Rationale:**

The projected growth of individuals with dementia and the cost to our society points to an epidemic and warrants a special focus. There are multiple challenges in educating the public as well as professionals. There are few “places of excellence” outside major cities to get a comprehensive assessment, pathways to treatment and options for care. Attached is a white paper about those who are “unbefriended” with Alzheimer’s disease or other dementia that provides more background information and specific recommendations.

**Benefits Counseling**

**Recommendations:**

The OAA reauthorization must focus on helping low-income seniors reach and maintain economic security. Application processes must be streamlined and simplified. Benefits access initiatives need to be better coordinated with a focus on a person-centered approach so that all multiple benefits can be obtained at one time. Funding channels need to support innovative methods to promote benefits access and to develop and sustain cost-effective methods to help low-income people gain access to benefits for which they are eligible. The State Health Insurance Program (SHIP) should be enhanced to support the addition of more professionals to the program to work along with volunteers in assisting eligible seniors apply for multiple benefit programs. The SHIP should be more involved in distributing understandable information to consumers, caregivers, and the professionals who serve them.

**Rationale:**

The majority of older adults in America cannot make ends meet without the important support of public benefit programs critical to helping them reach and maintain economic security. Unfortunately, many benefit programs are underutilized due to cumbersome and confusing application processes and the ineffectiveness of dated outreach strategies. SHIP staff and volunteers have the challenging task of staying apprised of complex and changing information related to Medicare and Medicaid. Some SHIP cases are complex and can take hours to resolve. When beneficiaries have questions, they often turn to trusted professionals at Senior Centers and others. The SHIP could broaden its impact by assisting eligible seniors apply for multiple benefits and by training and distributing helpful materials to trusted professionals who encounter seniors each day. These professionals could also benefit by receiving clear updates directly from AoA and CMS via email.

**Capacity Building of the Aging Network**

**Recommendations:**

Standards should be developed for State Units on Aging (SUAs) for the oversight and administration of AAAs to ensure consistency and accountability. However, the standards should allow some flexibility to be able to respond to unique needs of communities or neighborhoods. Standardized evaluations/assessments can provide comparative data for analysis. The Administration on Aging (AoA) should offer

technical support to both SUAs and AAAs to ensure effective state and area planning. Potential conflict of interest issues related to service delivery can impede the AAAs ability to be an effective advocate and should be addressed.

**Rationale:**

AAAs are at the core of the aging network and should be supported in this vital role particularly since resources are limited. As the AAAs have evolved to deliver more services, the potential for conflicts of interest has increased and the function of evaluating and planning for the needs of the community has become a lower priority, even perfunctory.

**Recommendations:**

The AoA should support the aging network in creating a defined role in health care reform implementation and rebalancing efforts. The AoA should strengthen partnerships with the Centers for Medicare & Medicaid Services (CMS), the Veterans Administration (VA), and other federal agencies to help create state and local partnerships to foster a more coordinated streamlined approach for service delivery and possible opportunities for additional funding. The AAA network should help link aging services with health care whenever possible. One example would be to provide support for chronic disease self- management. AAAs could help impact such issues as health literacy. AAAs could also be a vehicle to bring "research to the people," using evidence based models as a start.

**Rationale:**

The aging network has been on the front lines providing services with limited resources for many years. The AAAs should be supported in maximizing opportunities created through health care reform and rebalancing efforts.

**Recommendation:**

The AoA should consider increasing its capacity to work with the states and local communities by maintaining a presence in all regional HHS offices.

**Rationale:**

AoA provides an important leadership role and can provide support to local and state entities. However, in the 1990s, offices were consolidated and some communities lost important connections to the agency. Currently in Region 3, the only AoA official on the ground is based in New York City with responsibility for a region that runs from Massachusetts to West Virginia. The current broad swath of the regional offices creates perceived and actual distance from the programs they administer.

**Caregivers**

**Recommendation:**

When older adults are being assessed for services, the needs of their caregivers should be assessed along with the clients and the care plan should address their needs as well whenever possible.

**Rationale:**

The overwhelming majority of older adults who need long term care assistance do not live in facilities. They live in their own homes in communities in urban, suburban and rural settings. Family members, neighbors and loved ones usually provide the care and services that keep them safe and supported. The importance of supporting caregivers is well documented and care plans should reflect their needs. The well-being and economic needs of caregivers should be addressed to support them in this vital role.

**Consumer Choice and Control****Recommendation:**

The prevention of fraud and abuse should be addressed in the consumer directed model, especially for clients who are reluctant or unable to report their family member or caregiver when there are problems with the provision or lack of care.

**Rationale:**

Consumers in the community are often isolated and dependent upon caregivers for their needs. As the consumer directed model grows, it is important to address the potential for abuse and neglect that may occur.

**Demonstration Programs****Recommendation:**

Create a demonstration program for a neighborhood or community-based program, whether called a village, NORC or something else, particularly in economically challenged areas that do not have the resources or infrastructure to support their aging population. Demonstration programs supporting innovations in sustainable models should be identified for all communities. Outcomes such as hospital readmission rates and overall institutional care referral rates should be analyzed with an eye towards expanding models that improve quality of life for all members of a neighborhood or community.

**Rationale:**

Models should be created by community-based participation in high poverty areas to define the needs from the community's perspective and develop a response or plan on how to utilize limited resources.

**Diverse Populations****Recommendation:**

The OAA should better address diverse populations such as minorities, veterans, LGBT, and people with disabilities who are aging by creating opportunities, recognizing and integrating the needs of special populations throughout the OAA, and helping to create "culturally competent" programs.

**Rationale:**

Currently, Americans are aging into a more diverse and challenging population to serve. It is important to have targeted programs for diverse populations to address their unique

needs and circumstances and support them as they age. In addition, it would be helpful if their needs were more broadly integrated throughout the OAA whenever possible.

### **Elder Rights**

#### **Recommendations:**

The OAA's recognition of legal assistance as a priority service should be reflected in the provision of adequate funding in every state. "Adequate funding" should be defined consistent with the statutory recognition of legal services as a priority service. At the same time, maintenance of effort requirements should be instituted to retain non-AoA funds currently available to fund legal services. States should be required to create a statewide strategic plan that identifies elder rights issues and needs throughout the state, and addresses those needs systematically and in a coordinated fashion. States should be required to develop a coordinated implementation process to most effectively and efficiently deliver legal services that meet the most critical needs. Statewide coordination of technical assistance, training and other supportive functions to legal services providers, as well as to ombudsmen and other elder rights advocates, should be a part of this implementation process. States should be required to collect qualitative and quantitative statewide data to measure the impact of services and to provide consistent information about the efficacy of Title III-B funding in meeting individual and systemic advocacy goals. This data should also be collected, evaluated and reported at the national level.

#### **Rationale:**

Legal assistance is critically important to seniors as they face more complex rules governing crucial public programs, deal with increasingly complicated financial institutions and practices, and are targeted for predatory scams and elder abuse. Title III-B legal services ensure that elders are able to obtain and maintain: Social Security, Medicare, Medicaid, SSI and other benefits and entitlements; housing; financial security; autonomy and protection under the law in the face of diminished capacity, abuse, violence, exploitation, or fraud; planning for health care, independence and financial stability; and, essential services such as in-home care. Now an "adequate proportion" standard is used to designate funds for legal services but the term is not clearly defined.

In addition to resolving the legal problems of individuals, Title III-B legal assistance identifies and remedies systemic problems that harm thousands. Although the OAA makes legal assistance to elders a priority, there are many funding and structural limitations in the current system that prevent the goals of Title III-B legal services from being fully achieved for all. For example in Pennsylvania, the availability of Title III-B legal services is inconsistent from area to area. The proportion of Title III-B funding expended for legal services is very small throughout the state. In some counties, no Title III-B legal services are available at all.

#### **Recommendations:**

Elder rights protection programs such as legal services, protective services and ombudsman programs clearly need more funding. The new national ombudsman position should be added to the OAA. The state legal services developer position also needs to be funded.



**Rationale:**

Funding continues to be an issue for legal services. OAA funds for legal services go to the AAAs where it is often used ineffectively and inefficiently with little or no oversight. Funding also is an issue for the ombudsman, as some areas do not have a full-time ombudsman. Protective services are inconsistent and poorly funded with some AAAs having few substantiated complaints. The potential for abuse with guardianship, particularly since there is little oversight, is also of concern. Unless the new national ombudsman position is formally added to the OAA, it could be eliminated during a future administration. The Act currently provides that the legal services developer is to provide leadership and coordination in the provision of legal assistance; arrange technical assistance and training for AAAs, legal services providers, ombudsmen and others; and ensure the state's capacity to aid elders in understanding and exercising their rights. The role is demanding and requires a great deal of skill and knowledge of legal services and institutions. Yet currently, many state developers have little or no legal training. In Pennsylvania, as in many states, the legal services developer has little authority to promote advocacy initiatives and cannot devote significant time to these critical tasks because of the demands of many other unrelated duties. As a result, there is little state-level coordination of elder rights advocacy and no OAA-supported training for legal services providers, and the availability and quality of Title III-B legal services is extremely uneven in the state. In the absence of dedicated funding, this situation appears unlikely to change.

**Recommendation:**

The OAA should authorize and fund statewide legal hotlines. ABA standards should be used for the collection of quantitative and qualitative data. Statewide Senior Legal Hotlines/Helpines should be supported, as an important part of an integrated, statewide legal assistance delivery system, involving local legal aid providers and state legal assistance developers, among others.

**Rationale:**

Legal Helplines provide free legal advice, information, referrals, advocacy and a variety of additional services cost-effectively to Americans 60 and over, enabling more seniors to maintain healthy, independent lives, free from the threats of poverty, exploitation or abuse. They are also a model of service delivery that addresses the needs of older adults in rural areas, with disabilities and who are socially needy or isolated from friends, neighbors and families. Legal hotlines are necessary to help reduce disparities in accessing legal services especially for those with limited income or living in rural areas.

**Recommendations:**

The OAA should work to reduce and prevent guardianship abuse. Representation of alleged incapacitated persons should be a priority. A public guardianship system should be developed, properly funded and monitored.

**Rationale:**

There should be funding for representation since the older adult is typically not represented by counsel and may not even be at the court hearing. Guardianship abuse is widespread and has been a problem for many years.

**Recommendations:**

The OAA should be expanded to include ombudsman services for consumers of home and community-based care and senior housing particularly given increasing need and the shift from an institutional bias. Due to potential conflict of interest with the AAA providing or coordinating services, there is a need for an independent ombudsman that is not employed by the AAA.

**Rationale:**

Many consumers of home and community-based care are by definition as clinically needy as those in facilities but they are often more isolated. Consumers may transition among the various long term care alternatives and do not always have access to an ombudsman should the need arise. Residents of Continuing Care Retirement Communities (CCRCs) particularly need an advocate as they typically invest their life savings and then have little control over where they receive their services.

**Recommendation:**

Each state ombudsman should be a vocal and independent advocate for all long term care consumers. This position should be located in a separate office that is protected or insulated from political forces of a SUA. State ombudsman should be able to provide testimony or speak freely about issues affecting long term care consumers without the filter or discretion of state government. Regulations should be promulgated about conflicts of interest and require independence in local programs. (Title VII, Subtitle A, Chapter 2, Section 713)

**Rationale:**

Since many state ombudsman programs are now located in the same agency that regulates providers and coordinates adult protective services, there are numerous potential conflict of interest issues that may impede the effectiveness and ability of the ombudsman's resident centered approach. Likewise, in many instances local programs are under the authority of government or service entities that often have real or perceived conflicts.

**Recommendation:**

Improve services to older victims of crime and abuse to ensure their safety, independence and well-being.

**Rationale:**

Services for older victims are very limited and non-existent in many areas. Current victim services and domestic violence agencies are typically not equipped to address many of the unique needs of older victims.

**Home and Community Based Care****Recommendations:**

Develop strategies to engage all governmental agencies and others to help create “livable” communities and the infrastructure needed to help people age in place including such needs as transportation and crosswalks. Community supports and services should be made readily available especially for those transitioning from nursing facilities. Increase Title III funding for neighborhood based supports and develop opportunities to mobilize neighbors to help with activities such as transportation. Strategies should be identified and implemented to prevent and reduce isolation of older adults. Encourage the use of assistive technology to supplement and replace personal care services. Create a demonstration project to study the cost savings of using technology.

**Rationale:**

Older adults almost always prefer to remain in their own homes and communities as they age and yet many communities were created when the population was younger and had different needs. In order to insure that communities age appropriately, there must be a focus on planning with agencies and community groups beyond the aging services network. This may help insure that services and supports will be readily available for those who are homebound. Public policy and planning typically overlook the fact that many older adults do not initially qualify financially for Medicaid but are also not able to finance their long term care needs without eventually needing Medicaid.

**Recommendation:**

The OAA should provide funding for the modernization and upgrade of senior centers to keep pace with the changing needs of older adults, attract people as they age into the service network and respond to the changing needs within a community. The provision of meals also should also be modernized to offer tasty and healthy options that respect the preferences of diverse populations as they age.

**Rationale:**

Senior centers are still a focal point for many older adults. Many important services and activities are offered such as congregate meals, health and wellness programs, and volunteer and educational experiences. Senior centers can serve a key role in NORCs and help all older adults in a neighborhood age in place.

**Home Repair and Modification****Recommendation:**

The OAA should focus on home repair and modification to help older adults remain in their own homes and prevent people from becoming trapped in their homes by creating more accessible and affordable housing and retrofitting existing housing stock to meet the needs of an aging population.

**Rationale:**

Many older adults are on a fixed income and do not have the resources to pay for needed repairs or home modifications. The success of rebalancing efforts of the long term care system will hinge on a more effective response to these problems.

**Housing****Recommendation:**

The OAA should encourage stronger partnerships with HUD to improve coordination of housing and services. Service coordinators in HUD housing should be professionalized and more available. (They are often part-time with low wages.) The housing needs of grandparents raising grandchildren should be addressed and accommodated.

**Rationale:**

Issues related to affordable and accessible housing as well as modifying and repairing existing housing stock has been a problem that continues to exacerbate. The success of balancing the long term care system is directly linked to improving housing. There are increasing numbers of grandparents raising grandchildren and their needs, particularly concerning senior housing should be addressed.

**Mental Health Services****Recommendation:**

The funding of mental health services should be expanded beyond serving those with persistent serious mental illness to address the mental health needs of older adults. Funding should be expanded to include outreach and education, prevention programs, screening and detection, and support groups. Cross-cultural issues should be addressed and programs that provide in-home services should be expanded and more readily available.

**Rationale:**

Pennsylvania is like most states in that a significant number of older adults regardless of whether they are living in their own homes or in facilities are not receiving needed mental health services. It is important to increase the availability of mental health services so that older consumers can access care regardless of where they reside.

**Transportation****Recommendation:**

The role of AAAs should be expanded to provide a greater role in coordinating transportation and mobility management.

**Rationale:**

The availability of reliable, accessible and affordable transportation is imperative to older adults particularly as many lose the ability to drive safely. The AAAs are well positioned to play a key role in mobility management.

**Statement Prepared for the Record  
By Aaron Bradley, Director  
East Tennessee Area Agency on Aging and Disability**

**Hearing of the Senate Special Committee on Aging  
“Meals, Rides, and Caregivers: What Makes the Older Americans Act so  
Vital to America’s Seniors”**

**June 9, 2011**

Thank you Chairman Kohl, Ranking Member Corker and members of the Committee for holding this important hearing. I am pleased to share my thoughts with you as you work toward reauthorization of the Older Americans Act.

The East Tennessee Area Agency on Aging and Disability (ETAAAD) is responsible for developing an advocacy and service delivery system in East Tennessee for persons age 60 and over and people with disabilities. We administer federal and state funds under the Older Americans Act to provide a range of services and supports including group and home-delivered meals, personal care services, legal services, ombudsman services, transportation, information and assistance services, case management, Medicare counseling services, health promotion services, among others. These services are provided directly and through a number of service providers in our region. My agency serves a 16-county area and approximately 25,000 individuals each year.

First of all, let me express my appreciation to your Committee for its leadership in conducting today’s hearing as a way to galvanize your colleagues in the Senate and to listen to older adults, caregivers and advocates, in order to start the reauthorization process in a thoughtful and thorough way. This reauthorization provides an opportunity to bring the entire Aging Network to a newly recognized role in bridging the medical and home systems of services and supports, catalyzing community and economic development to better meet the needs of older adults and people with disabilities, and empowering caregivers and individuals who need assistance in understanding the services and supports available in their community.

**Highlights from East Tennessee and the Rest of the State**

The Area Agencies on Aging and Disability (AAADs) provide the Single Point of Entry services for the new CHOICES Medicaid long-term care program in TN that includes telephone intake, screening, home assessment, and preliminary care plan development.

The State Unit on Aging and AAADs have completed the Veteran Directed Home and Community-Based Services Readiness Review and will soon be in a position to offer this support system to TN veterans.

In East Tennessee, we are using web-based streaming to provide medication management and health promotion educational opportunities in senior centers and other community locations in

cooperation with the University of Tennessee Extension Service and the University of Tennessee College of Pharmacy.

We initiated the East Tennessee ElderWatch Initiative 20 years ago and this effort has led to the development of the Tennessee Vulnerable Adult Coalition, which provides the platform for unprecedented inter-agency coordination efforts and improved public education and response efforts across the state.

The AAADs in TN are all functioning under the Aging and Disability Resource Center (ADRC) standards. We leveraged these activities for the foundation to our work as the Single Point of Entry for CHOICES and Older Americans Act and state-funded home and community-based services.

We also manage and serve as the Single Point of Entry for the state-funded Options for Community Living Program that offers basic home and community-based services for those in need who are not eligible for Medicaid.

**I encourage you to consider the following issues as you work to reauthorize the Older Americans Act in a timely manner. Taking these important steps will assist the Aging Network in meeting the challenge of serving our nation's growing numbers of older adults, particularly the increasing ranks of individuals age 85 and older, who are the most frail, vulnerable and in the greatest need for aging supportive services.**

- Focus on building the capacity of the Aging Network infrastructure to meet the challenges ahead. Creating the infrastructure needed to support the aging of the population requires investment in furthering the Aging Network's capacity. Enhancing capacity requires investments on multiple fronts, including developing core competencies, effectively tracking program outcomes, performing evaluations, and consistently attending to staff/volunteer development, training and retention. There is a tremendous opportunity in the reauthorization of the OAA to attend to this national priority.
- Strengthen the role of the Aging Network to integrate medical and human services-based long-term services and supports, particularly in order to promote the Aging Network's role in health, wellness (both physical and behavioral health) and care management. Consider expanding the role of Area Agencies on Aging (AAAs) as the Single Point of Entry programs for home and community-based services including nursing home care. This will lead to greater coordination and extend our ability to leverage funding from multiple funding sources so AAAs' role as an integral part of the long-term care and health care solutions is reinforced.
- Provide more flexibility within the Older Americans Act to allow staff to utilize funds based on individual needs. Of top importance to AAAs and Title VI Native American aging programs is increasing local flexibility in order to provide more customized support for the consumers that they serve. The reauthorization should provide opportunities to reduce restrictions on local flexibility. If done strategically, the result will be a more

person-centered and successful experience for older adults and caregivers. Congress must be careful not to impose new restrictions that reduce the ability of AAAs/Title VI programs to meet their clients where they are and get them the services and supports they need. For example, the local transfer authority within the Act between all Title III subtitles should be increased.

- Assist the Aging Network to invest in and utilize new and innovative technologies to improve service delivery and more effectively track and report on OAA programs and services. A new program should be developed to assist the network with integrating its information systems with broader health information technology systems for medical and long-term care services. This new infrastructure would promote information sharing and interagency partnerships on such endeavors as healthy aging and wellness programs and chronic disease management programs. Shared data management technology and inter-departmental agreements will help agencies to identify any duplication of administrative and direct services.
- Expand self-directed options for OAA services. These models of service delivery generally cost government less and in most cases are preferred by the consumer and the consumer's family. Continue to support consumer choice and consumer-centered service planning.
- Elder abuse is on the rise in the U.S. and the Aging Network is uniquely positioned to assist with efforts to prevent and properly respond to abuse. Consideration must be given to requiring states to combine elder abuse/adult protection services under one state agency, where feasible, to assure a comprehensive response to this growing problem. We must find a way to ensure stable and sufficiently resourced long-term care ombudsmen programs in every community, to protect older adults at risk for neglect or abuse in institutions. Elder abuse prevention activities under Title VII must also be enhanced to ensure that AAAs can coordinate stable and successful programs, and that Title VII programs build on the national structure of information services inherent through the AAA and Title VI network.
- Reaffirm AAAs/Title VI programs' visibility in the community as the first place to call as needs arise and require states to publicize AAAs so that consumers and family members can find support and information quickly.
- Move the Senior Community Service Employment Program (SCSEP) back under the auspices of the Administration on Aging. The transfer of this program would better integrate it with other aging services provided under the Older Americans Act.
- Transfer the State Health Insurance Assistance Program (SHIP) to Administration on Aging, and if necessary, authorize AoA to administer the program under the OAA. Transferring the SHIP program from CMS to AoA will enhance the program's ability to meet the ever-growing need to provide one-on-one assistance and counseling on Medicare to beneficiaries at the community level. The transfer will also assist the Aging Network as it continues to develop person-centered systems of information and

counseling to make it easier for individuals to learn about and access their health and long-term services and support options.

Thank you for considering these ideas. I look forward to working with the Committee on these issues as the reauthorization process moves forward and proposals are developed for the Older Americans Act reauthorization bill.





**Written Testimony for the Record**  
**William L. Minnix, Jr., President & CEO, LeadingAge**

**Senate Special Committee on Aging May 26, 2011**

**Older Americans Act (OAA) Reauthorization**

As President and CEO of LeadingAge, I thank the Senate Special Committee on Aging for the opportunity to submit written testimony on the re-authorization of the Older Americans Act. This legislation is one of the most important measures ever enacted because it addresses the basic needs of all older individuals.

LeadingAge is an association of 5,500 not-for-profit organizations dedicated to expanding the world of possibilities for aging. We advance policies, promote practices and conduct research that supports, enables and empowers people to live fully as they age.

LeadingAge urges Congress to include a new housing with services section in Title III of this year's reauthorization of the Older Americans Act. We also recommend the addition of funding for technology demonstration programs in Title IV of the OAA as it is reauthorized.

**Why do we need to include housing with services for older adults in the OAA?**

Over two million low- and modest-income older adults live in publicly subsidized housing, including Section 202, public housing, low income housing tax credits and older subsidized housing. The median age of residents in HUD senior housing is 75 years old, and 30% of them are age 80 and older. Studies show that subsidized senior renters experience more chronic health conditions than non-subsidized renters and homeowners. In addition to these chronic health conditions, many of these residents struggle with some form of dementia, and/or mental illness. Low-income older individuals disproportionately live in apartments and have less family support. In the Section 202 program, 69% of the residents have incomes that are below 30% of the area median income.

An OAA housing with services section would help older individuals residing in subsidized housing age in place. Efficiencies and cost savings in service delivery could be obtained when providing services in a congregate housing setting. Housing is always one of the major concerns of older individuals and policy makers involved in improving the ability of older individuals to age in place. For example, the availability of affordable housing for older individuals was a critical issue in the implementation of the Money Follows the Person Demonstration. A specific housing with services program in the Older Americans Act would expand and enhance existing priorities for the Administration on Aging, including its Livable Communities initiative and its Community Initiatives for Aging in Place program.

A housing with services initiative could target the programs available under Title III of the Older Americans Act to affordable housing settings specifically without diminishing the existing

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*Expanding the world of possibilities for aging.*

programs under Title III. We would recommend that a specific, separate authorization of appropriations for housing with services be included in the OAA reauthorization legislation.

**What will a housing with services section in Title III of the Older Americans Act mean for older individuals in each state?**

States would develop an area housing with services plan to identify affordable housing communities and define specific services programs and packages that could be available to older individuals living in those communities. This combination of housing with services could reduce the placement of older individuals in more expensive and restrictive residential settings. A housing with services section within Title III of the OAA would provide in-home services, including personal care and help with chores. Coordinated case management would be provided in collaboration with the service coordinator of federally-assisted rental housing and low income housing tax credit rental housing properties. If there is no service coordinator at the housing site, full case management would be provided to assure the most efficient use of the supportive services.

The housing with services program would provide annual training sessions on available service and support resources, including programs to screen for the prevention of depression, coordination of community mental health services; referral to psychiatric and psychological services; and training on mental health screening for older adults for service coordinators, if applicable. Adults aged 65 and older have the highest suicide rate of all age groups. In fact, the Administration on Aging estimates that only half of all older adults who acknowledge having mental health problems are actually treated. Currently, area agencies on aging are not funded to implement Older Americans Act mental health requirements. In response to the increasing need for mental health services, the Older Americans Act must provide additional resources to the aging network so that the law's requirements for mental health services may be met.

This new section of Title III would assist housing providers with the development and implementation of a congregate meal program and/or homebound meal program at federally-assisted rental housing and low income housing tax credit rental properties. Wellness and preventive care programs that could be provided under the housing with services section could help reduce Medicare and Medicaid costs by keeping residents of assisted housing healthier. This proactive approach reduces the chance of hospital admissions and re-admissions.

Falls and poor medication compliance are a leading cause of hospitalizations among older adults. Adding a housing with services section to Title III of the re-authorized Older Americans Act would provide access to personal emergency response systems and medication reminder and dispensing technology to older adults living in federally-assisted rental housing and low income housing tax credit rental properties.

A housing with services option also would cover other services that enable older individuals to continue living in the community, such as adult day services and non-emergency transportation to

medical appointments, food shopping, etc. Providing these services to elders living in assisted housing would achieve economies of scale that would lower the cost of services per resident.

#### **Technology Demonstration Funding Needed**

Technological innovations continue to improve the way many aging services providers deliver care. Funding for demonstration projects that promote the use of best practices in medication management, preventing falls, and prolonging safety, health and wellness in senior centers and senior housing developments should be made a part of Title IV of the Older Americans Act.

#### Conclusion

There are more than 13 million older Americans who are economically insecure, living on \$22,000 or less each year. Approximately 3.4 million seniors live below the federal poverty line.


Many of these elders have incomes slightly above the Medicaid eligibility level and have no family support. At times they have to choose between paying for food, housing, utilities, or medicine. This situation leads to preventable hospitalizations and re-hospitalizations.

States and communities depend on the Older Americans Act as one of the main resources for delivering social, nutrition, and home and community-based services to seniors and their caregivers. A housing with services section would help target limited resources to older individuals residing in federally-assisted rental housing and low income housing tax credit rental properties who tend to have more chronic diseases and less formal support. Our call for a more proactive use of technology through Older Americans Act funding would also target limited resources without sacrificing quality of care.

Many LeadingAge members have incorporated a variety of housing and home- and community-based services in innovative ways to help older individuals age in place in dignity and in the least restrictive environment. In 1965, when the Older Americans Act, Medicare, and Medicaid were enacted, there were 18 million Americans aged 65 and over. Most of our not-for-profit members that now provide essential home- and community-based services were already doing so in 1965.

But now they have even more of a challenge. There now are 35 million adults aged 65 and over and the number is projected to increase to 88 million by 2050. The re-authorization of the Older Americans Act must contain the innovations that we propose to appropriately serve Americans who are living longer, with more chronic diseases, and who wish to remain at home for as long as possible.

We thank the Senate Special Committee on Aging for your commitment to the re-authorization of the Older Americans Act and we urge your support for expanding the scope and resources that enable older Americans to live their lives independently and with dignity.

 <b>National Association of Senior Legal Hotlines</b>	<p><i>The National Association of Senior Legal Hotlines unites advocates from statewide senior legal hotlines, facilitating the sharing of relevant information to strengthen the role of statewide hotlines in protecting the legal rights of seniors and increasing legal resources available to older Americans.</i></p> <p>P.O. Box 674, Austin, TX 78767 • (512) 791-3455</p>
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June 9, 2011

Hon. Herb Kohl, Chairman  
 Hon. Bob Corker, Ranking Member  
 Members of the Committee  
 Senate Special Committee on Aging  
 United States Senate  
 Washington, DC 20510

Dear Chairman Kohl, Ranking Member Corker, and Members of the Committee:

Please accept this letter and the accompanying proposed amendment to the Older Americans Act for inclusion in the record of the Committee's hearing on May 26, 2011, regarding reauthorization of the Act. Older Americans appreciate the attention which you have brought to the subject.

Legal assistance is a priority service under the Act, as set forth at Section 306 (a)(2) (42 U.S.C. §3026(a)(2)). Together with others from various parts of the senior legal assistance delivery and support systems, we are concerned that this prioritization remain, and we aspire to a more integrated delivery system, one that will make legal assistance more responsive to seniors in need, and more cost-effective.

A crucial component of such a delivery system is the network of senior legal hotlines/helplines that have come into existence in most states over the past two decades and have an exemplary record of service that is *very* cost-effective. They provide seniors, including those who are homebound or isolated, direct access to attorneys skilled in elder law for legal information, advice and additional assistance, in keeping with conditions in each state. When they have the resources to function at their best, SLHs not only excel at problem-solving but also provide preventive services that help seniors -- and therefore society as a whole -- avoid irremediable exploitation and other harm.

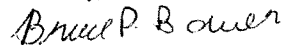
Unfortunately, a lack of stable and sufficient funding has kept most SLHs from achieving their potential. Many have had to reduce services quite severely in recent years, and several have ceased operations altogether.

Our goal in drafting the enclosed amendment was to promote the inclusion of senior legal hotlines as an institution in the OAA, alongside other important elements of the legal assistance delivery system, and to put forth a blueprint of how the proposed national program of SLHs could be overseen and funded through AoA. We realize that inclusion in the Act does not ensure appropriation, but we have learned that especially these days, it is a virtual precondition.

We have communicated our proposal to colleagues in the national aging community, especially but not only those who focus on legal assistance. In doing so, we consistently emphasize that while it focuses on the details of a future national program of senior legal hotlines, we would be glad to see the substance of our suggestions incorporated into a more integrated chapter that will serve to strengthen legal assistance as a whole under the Older Americans Act.

Thank you for your consideration and for your service to our country and its seniors.

Sincerely,



Bruce P. Bower  
Chair, NASLH

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**NASLH**  
**National Association**  
**of**  
**Senior Legal Hotlines**

## Proposed amendments to the **Older Americans Act: 2011 reauthorization**

*NASLH, P.O. Box 674, Austin, TX 78767 • (512) 791-3455*

**Synopsis:**

The following adds a new section (216) authorizing a national network of senior legal hotlines, to operate as part of statewide “integrated legal assistance delivery systems,” which are now being established in many states under the Administration on Aging’s “Model Approaches” program. The proposal adds this term to the definitions in Section 102 of the OAA; and in numerical order by section, it makes several other minor adjustments necessary to incorporate the new Section 216.

**SEC. 102**

*(The following subsection to be numbered among or after the 54 existing definitions in this section of the act)*

(XX) The term “integrated legal assistance delivery system”—

(A) means a collaborative, statewide network established to provide legal assistance, targeted at older individuals with greatest economic and social need, in the most efficient and impactful manner possible; and

(B) includes—

- (i) The Legal Assistance Developer;
- (ii) All legal assistance programs funded under this Act;
- (iii) A statewide senior legal hotline;
- (iv) Law school elder law clinics;
- (v) Programs that recruit private attorneys and other legal professionals to provide pro bono legal assistance to seniors;
- (vi) LSC-funded legal aid programs;
- (vii) Other nonprofit agencies that provide legal assistance to older individuals;
- (viii) Local, regional and statewide mechanisms that coordinate work among the direct legal assistance providers enumerated in subsections (ii) through (vii) and other service providers engaged in helping ensure elder rights, including but not limited to Area Agencies on Aging, Aging and Disability Resource Centers, Long-Term Care Ombudsman programs, pension counseling and assistance programs, benefits counseling programs, Medicare counseling programs (SHIP/HICAP), Senior

- (ix) Medicare Patrol programs, caregiver support programs and elder abuse prevention and victim assistance programs.

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SEC. 202. (a) It shall be the duty and function of the Administration to—

24. establish and carry out senior legal hotline programs described in section 216;

*(existing subsections 24-28 to be renumbered 25-29)*

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*The following Section 216 will be added and cause the current Sec. 216 to become Sec. 217; the reference in existing Section 215(j) will be changed from 216 to 217*

**Statewide Senior Legal Hotlines**

Sec 216.

(a) DEFINITIONS.—In this section:

- (1) ELIGIBLE ENTITY.—The term “eligible entity” means a nonprofit corporation dedicated to providing free legal assistance to indigent or otherwise disadvantaged groups that has—

(A) a proven record of operating an existing senior legal hotline; or

(B) the capacity to provide legal assistance to older individuals through a new statewide senior legal hotline.

- (2) LOCAL SENIOR LEGAL ASSISTANCE PROVIDER.—The term “local senior legal assistance provider” means a program or group that provides legal assistance to older individuals in a geographic area within a State, receiving funds under section 321(a)(6) of the Older Americans Act of 1965 (42 U.S.C. 3030(d)(6)).

- (3) STATEWIDE SENIOR LEGAL HOTLINE.—The term “statewide senior legal hotline” (known in some states as “helplines” or by other names) means a statewide program designed to provide information, counseling, assistance, advocacy and other services as appropriate in each state, by telephone and other means of communication on a broad range of legal issues, at no charge, to older individuals.

- (b) AUTHORIZATION.—The Assistant Secretary shall provide grants to eligible entities to establish and implement statewide senior legal hotlines in each State to provide legal assistance on a broad range of issues by telephone and other means of communication to older individuals, and to supplement such hotlines already provided by eligible entities.

(c) ELIGIBILITY.—

- (1) APPLICATION FOR GRANT.— In order to receive a grant under this section, an eligible entity shall submit to the Assistant Secretary the following:

- (A) PLAN REQUIRED.— A plan to establish or continue operation of a statewide senior legal hotline that —
- (i) provides for a sufficient number of appropriately trained attorneys, paralegals, other staff members, and volunteers to ensure effective delivery of information, counseling, assistance, advocacy and other services as appropriate in each state, regarding all legal matters.
  - (ii) collaborates closely with the state unit on aging, state legal assistance developer, area agencies on aging and local senior legal assistance providers throughout the state, to maximize coordination and cost-effective division of responsibilities in delivery of legal assistance to seniors,
  - (iii) strives to maximize coordination in the delivery of legal assistance with all elements of the state's integrated legal assistance delivery system, as defined in Section 102 of this Act.
  - (iv) builds effective communications with all parts of the state's aging services network, system of long-term care, Medicare, pension, housing and benefits counselors and others to provide mutual assistance and referrals.
  - (v) establishes mechanisms to make referrals for representation and other assistance beyond the hotline's scope to local senior and general legal aid agencies, private attorneys and any other senior advocacy and assistance programs, individuals or entities, as appropriate.
  - (vi) conducts outreach through the state's aging network and by other means to inform eligible clients about the availability of the hotline's service, targeting especially older individuals with greatest economic and social need.
- (B) MATCHING REQUIREMENT.— An assurance that the eligible entity is able to provide, from non-federal funds, an amount equal to not less than 25 percent of the cost of establishing and implementing a statewide senior legal hotline. An eligible entity may use in-kind contributions to meet the matching requirement under this subparagraph.
- (C) OTHER INFORMATION REQUIRED.— Any other information the Assistant Secretary may require, including an assurance that staff members and volunteers have no conflict of interest in providing the services described in the plan submitted under subparagraph (A).
- (2) DETERMINATION OF ELIGIBILITY.—In selecting grant recipients under this Act, the Assistant Secretary shall consider the following:
- (A) EVALUATION OF PLAN.—The extent to which the plan submitted by the applicant meets the requirements of paragraph (c)(1)(A).
  - (B) OTHER CONSIDERATIONS.—
    - (i) POPULATION NEED.—The needs of the population the applicant seeks to serve and its understanding of those needs;



(ii) PROGRAM LITERACY.—A familiarity with the history of senior legal hotlines and published literature on best practices in the operation of such hotlines;

(iii) INSTITUTIONAL KNOWLEDGE.— Knowledge an applicant new to operating legal assistance hotlines has gained from operating other successful hotlines or similar programs.

(d) ALLOCATION OF FUNDS.—

(1) The Assistant Secretary shall allocate, from the amount appropriated under this Act, to each grant recipient in each State—

(A) an amount not less than \$100,000 per grant recipient in any fiscal year;

(B) for states in which the population of older individuals exceeds 2 million, not less than 5 cents per eligible resident, calculated using the most recent census data available;

(2) If the amount appropriated under this Act is insufficient to provide grants to all eligible applicants at the minimum amounts defined in paragraph (1), the Assistant Secretary shall provide grants to those eligible applicants it finds to be the most qualified.

(3) If the amount appropriated under this Act exceeds what is needed to provide grants to all eligible applicants at the minimum amounts defined in paragraph (1), the Assistant Secretary shall increase the grant amounts on a pro rata basis up to 10 cents per eligible resident for states in which the population of older individuals exceeds 1 million.

(4) No more than 5 percent of the amount appropriated for a fiscal year for this section may be used by the Assistant Secretary for administrative expenses, except that such amount shall not exceed \$200,000 in any fiscal year.

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Authorizations Of Appropriations  
(formerly Sec. 216)

SEC 217.

...  
(d) STATEWIDE SENIOR LEGAL HOTLINES.—There are authorized to be appropriated to carry out section 216, such sums as may be necessary for fiscal years 2012, 2013, 2014, 2015, and 2016.

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SEC. 306 Each Area Agency on Aging designated under section 305(a)(2)(A) shall, in order to be approved by the State agency, prepare and develop an area plan for a planning and service area for a two-, three-, or four-year period determined by the State agency, with such annual adjustments as may be necessary. Each such plan shall be based upon a uniform format for area plans within the State prepared in accordance with section 307(a)(1). Each such plan shall—

...  
(2) provide assurances that an adequate proportion, as required under section 307(a)(2), of the amount allotted for part B to the planning and service area will be expended for the delivery of each of the following categories of services—

...

(C) legal assistance provided as part of an integrated legal assistance delivery system.

SEC. 307 (a)(11) The plan shall provide that with respect to legal assistance—

...  
 (C) the State agency, with the leadership of its Legal Assistance Developer, shall promote and maintain an integrated legal assistance delivery system to furnish legal assistance to older individuals within the state, targeting those with greatest economic need and those with greatest social need. This shall include promoting the use of low cost service delivery systems such as senior legal hotlines, law school clinics and pro bono programs. The Legal Assistance Developer shall guide the establishment of case priorities and targeting efforts to ensure that the integrated legal assistance delivery system is maximizing the efficiencies and impact of the available resources. The State shall also provide technical assistance and training for the integrated legal assistance delivery system to enhance the furnishing of legal assistance to older individuals, especially to those with greatest economic need and those with greatest social need.

*The National Association of Senior Legal Hotlines (NASLH) unites advocates from statewide senior legal hotlines, facilitating the sharing of relevant information to strengthen the role of statewide hotlines in protecting the legal rights of seniors and increasing legal resources available to older Americans.*

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## The Importance of Evidence-Based Curriculum for Older Adult Job Training Programs

Testimony from Marcia Kerz, President of OASIS

As the Senate and House work together in the 112<sup>th</sup> Congress to reauthorize the Older Americans Act, I urge the committee to address the importance of technology training for older adults – in particular as it relates to employment and job opportunities. Joblessness among seniors aged 65 and older has nearly doubled since the beginning of the recession in 2007, according to data released by the Bureau of Labor Statistics. Many older workers are unable to retire due to lost retirement savings and the National Council on Aging reports that nearly one-third of Americans aged 60 and older are economically insecure, living at or below 200 percent of the poverty line.

Unfortunately, without the necessary technological skills, older adults are placed at a significant disadvantage in the job market. A survey of employers notes that the biggest disadvantage older workers have in the job market is many individuals lack necessary technology skills. There is a growing need to expand programs that train adults to use new technology and give them the skills they need to look for jobs in the information age.

Studies show that 42 percent of adults over 65 use the internet, compared to 74 percent for the general population. In a world where job openings and applications are only accessible online – for example, WalMart greeter job applications– job seekers now need technology skills just to apply for jobs. There is an obvious need for increased access to technology training programs for older adults, but training must be tailored to their specific learning style, with environments and materials geared towards older adult learners.

As Congress looks for ways to improve the Senior Community Service Employment Program (SCSEP) and other federally-funded workforce training programs, it is important to stress that technology training must be an integral part of the discussion, and I believe this can be done at a cost-savings to the federal government. Encouraging SCSEP providers to partner with organizations and non-profits that already have research based programs with track records of proven success among the older adult population, will save taxpayer dollars through the use of existing programs.

A March 2011 GAO study focusing on the duplication of government programs cited 47 programs that spent close to \$18 billion in fiscal year 2009 to provide job search and job counseling services to participants. GAO suggested consolidating and streamlining services to reduce costs, which could then be used to serve more individuals looking for training. I agree that we should be using our tax dollars toward existing programs that are proven to be effective instead of continuously trying to recreate the wheel and develop new programs.

OASIS has developed such a program called *Connections* and data collected from a 2009-2010 research study by the University of Miami proves that the curriculum is effective for older adults. Pre- and post-

program assessments conducted on 200 individuals revealed significant improvements in computer and internet knowledge among those in the program versus those in the control group.

The *Connections* comprehensive program offers 32 courses – with basic courses translated into Spanish– which are specifically designed with the older adult learner in mind. Individuals can take classes as basic as introduction to computers and the internet, as well as word processing, excel, resume building and how to search and apply for jobs online. These programs are offered through OASIS's 27 training centers and more than 90 partners across the country. Additionally, OASIS is also partnered with five public library systems that are implementing *Connections* in their communities (Pima County, AZ; Broward County, FL; Sacramento, CA; Multnomah County, OR; and Dallas, TX).

OASIS has worked very hard to develop and maintain a curriculum that is proven to be effective. Again, I would encourage the committee to make technology training a priority in the reauthorization of the Older Americans Act. I cannot stress enough how important it is that these individuals are given the opportunity to develop the skills they need to stay in the work force or get back to work. We look forward to working with you and the federal government to ensure that older adults receive the best and most cost effective training possible.

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