



# *Cenla Area Agency on Aging, Inc.*

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**STATEMENT OF KRISTIN DUKE  
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ALEXANDRIA, LOUISIANA  
AND  
MEMBER, BOARD OF DIRECTORS, NATIONAL ASSOCIATION OF  
AREA AGENCIES ON AGING**

**SPECIAL COMMITTEE ON AGING  
UNITED STATES SENATE**

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

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

### **The Mission of N4A and AAAs**

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

The Older Americans Act (OAA) joins together 655 AAAs and 232 Title VI Native American aging grantees across the country, providing a support structure for planning, service coordination, oversight, and advocacy. Since the mid-1970s, AAAs have demonstrated an extraordinary record of achievement in stretching a limited amount of federal money to help hundreds of thousands of older people remain independent in the

community. OAA funds make it possible for AAAs to leverage millions of non-federal dollars, such as local government, foundation, private sector, participant and volunteer contributions. The OAA is a prime example of federal, state, and local partnerships that work.

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

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

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

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

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

### **Cenla AAA Programs and Services**

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

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

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

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

Despite these delays, we continue to mount efforts to identify potential participants. With regard to funding, rather than identifying a new source of funding, Louisiana has chosen to transfer existing state funds that were used for other critical aging services to meet the 25% match requirement for the Family Caregiver Support Program. So,

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

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

### **Implementation in other states**

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

The states that are moving ahead are generally those that have already developed caregiver support programs with state funding. However, because the Family Caregiver Support Program focuses on primarily a new constituency, many states are proceeding cautiously in designing programs. Some state agencies and AAAs are

obtaining input directly from caregivers and community stake-holders, a process that takes time and which reveals a myriad of needs. My peers and I face the difficulty of balancing multiple service needs within our local communities.

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

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

The Family Caregiver Support Program provides an excellent opportunity to increase awareness and visibility of home and community services and the crucial role they play in providing older adults with a good quality of life in their later years. It is vital that we maintain and increase funding for family caregiver support services. As we begin to design local programs, we see how great the needs are. While \$125 million may sound

like a lot of funding to some, it only translates to about \$5 per current caregiver. N4A and local agencies have already established a broad-based advocacy effort to keep caregiver support high on the agenda of the new Administration and Congress.

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