Statement of

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Forum

Until There's A Cure: How to Help Alzheimer's Patients and Families NOW"

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Good afternoon Chairman Kohl, Senator Corker and members of the Senate Special Committee on Aging.

I am Kathy Greenlee, Assistant Secretary for Aging in the Department of Health and Human Services. Thank you for the opportunity to share the current efforts of the Administration on Aging and our national aging network to improve the capability of home and community-based services to support those with dementia, and those who care for them.

Helping older Americans who have Alzheimer's disease and related dementias (ADRD) maintain their dignity and independence is central to our mission at the Administration on Aging (AoA). Access to the appropriate supports is critical in understanding and managing these diseases, especially those services that allow families to plan in the early stages of the disease and those that support family caregivers.

The Administration on Aging strongly supports embedding dementia practice into State long-term services and supports. This effort is designed to improve the responsiveness of home and community-based care systems to persons with dementia and increase availability of support services for persons with ADRD, their families, and their caregivers.

The challenges posed by Alzheimer’s disease and related dementias for persons with the disease and their families are enormous. AoA works with HHS’ research agencies (NIH, AHRQ, CDC) to determine the universe of interventions that are suitable for translation in community-based settings, where about three-quarters of persons with dementia live. The interventions AoA funds are those that have been tested in randomized-controlled trials and found to have positive effects on persons with dementia and their families. For example, AoA has worked closely with the National Institute on Aging (NIA) to understand and disseminate evidence-based interventions, such as Resources for Enhancing Alzheimer's Caregiver Health (REACH) II. This intervention is specifically aimed at enabling caregivers to cope with the daily, often intense, stresses they face providing care to their loved ones. AoA and NIA have also collaborated in the development and dissemination of other consumer education materials to the thousands of seniors who participate in the home-delivered meals program across the nation.

According to recent estimates, between 2.4 million and 5.1 million Americans have Alzheimer’s disease (AD). Unless the disease can be effectively treated or prevented, the number of people with AD will increase significantly if current population trends continue. That’s because the risk of AD increases with age, and the U.S. population is aging. The number of people age 65 and older is expected to grow from 39 million in 2008 to 72 million in 2030, and the number of people with AD doubles for every 5-year interval beyond age 65 (National Institute on Aging). According to the Alzheimer’s Association, at least 10 million baby boomers will develop Alzheimer's disease in their remaining lifetimes – twice as many people as the number estimated to have the disease today. An additional 4 million baby boomers will develop a related dementia, which will pose challenges similar to Alzheimer's for them, their families, and the health and long-term care system.

States and the federal government are currently engaged in major efforts to transform health and long-term services and supports and control the future growth of Medicare and Medicaid expenditures. Those efforts will succeed if they also address the challenge of dementia. While medical research pursues the causes and treatment of the disease, we must also develop better, cost-effective ways to support and sustain family caregivers to meet the social and on-going care needs of people who have the disease.

Leading policy makers are already emphasizing prevention and chronic disease management as strategies for improving quality and controlling costs. The Administration on Aging, through the administration of the Alzheimer's Disease Supportive Services Program is working with States, communities and researchers to translate proven caregiver support programs into practice at the community level. Through this work, we are developing the tools to make available these proven programs and learning how to embed them into the current Long-Term Service and Supports System.

Nearly a decade ago, AoA began exploring support of evidence-based research in community settings. This was through the development and dissemination of evidence-based guidelines for physicians on Alzheimer's disease management. These guidelines were published in a peer-reviewed medical journal and have been adopted nationwide.

Today we are working with 16 States to field test nine evidence-based caregiver interventions, with the goal of embedding successful translations in State programs and funding streams. We are looking at how these interventions can be effectively provided through aging network programs while attempting to ensure fidelity to the original intervention. If these research interventions can be successfully translated to community settings, they will have a significant impact on supporting and sustaining family caregivers.

One intervention currently being translated by six states (California, Florida, Georgia, Minnesota, Utah, and Wisconsin) is the **New York University Caregiver Intervention,** a support program that, in a randomized-controlled trial, significantly delayed institutionalization of persons with dementia by providing education, support, and counseling to spousal caregivers. The average institutional delay for persons with dementia who received this support program was 557 days.[1] According to a 2009 survey[2], the national average nursing home rate was $219 per day; therefore, a 557 day delay in nursing home placement would result in an average savings of $121,983 in institutional costs per person. Although each of the six States is still in the implementation phase, early results indicate that projects are achieving some of the outcomes found in the original study.

Three States (California, Maine and Michigan) are translating **Savvy Caregiver**. This intervention trains families and others for the unfamiliar role they face as caregiver for a relative or friend with ADRD. *Savvy Caregiver* is a 12-hour training program that is usually delivered in two-hour sessions over a six week period; focuses on helping caregivers think about their situation objectively and provides them with the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively. This intervention, also in the implementation phase, provides some caregiver training in a group setting and is also is showing promise.

We have found that successful translation projects should be designed to be embedded in systems that can meet caregiver needs over time. The caregiver interventions that are being translated intervene at one point in a disease that goes on for a long time. If they are to have lasting impact, they must fit into a continuum of services that are available to families through the course of the disease.

The Administration on Aging is advancing State initiatives to create coordinated systems of home and community-based care to develop and deliver supportive services for individuals with ADRD and their family caregivers.

Some examples include:

- Providing information, counseling, skill-building and other activities specifically for individuals in the early stages of ADRD and their caregivers.
- Assisting individuals with ADRD and their family caregivers to develop consumer-directed plans for care.
- Transforming the capacity of existing models of caregiver support and home and community-based care services to provide services to individuals with ADRD and their caregivers.
- Empowering individuals to adopt brain-healthy lifestyle choices.
- Increasing coordination of care of individuals with ADRD and their caregivers across care settings through information, referral and case management services.

There are numerous other examples of success. New Mexico recently enhanced its options for consumer-directed support services by providing dementia-specific training and technical assistance to adult day care organizations and increasing awareness of available respite care services. Minnesota continues to develop the dementia-capability of its Aging and Disability Resource Centers by training its workforce to identify people with memory problems and getting them the information and community services they need. California developed a community network of culturally-competent dementia care services for Latinos that has been sustained for over a decade; it has become a national model that is being replicated in other Latino communities and adapted for other cultural groups.

There are a number of factors that contributed to these successful projects. They have strong leadership at the State level and have created an influential focal point for Alzheimer's disease within State government. They develop strategies for sustainability and succeed in implementing them. They embed program successes in local community and State programs and funding streams. And they have sufficient funding over a period of years to achieve results.

While we have hope that a cure for Alzheimer's disease and related dementias is in our near future, I applaud the Senate Special Committee on Aging for its effort to focus on ways for our health and long-term care systems to help people with dementia and their family caregivers now.

References:

1. Mittleman M, et al. (1996). "A Family Intervention to Delay Nursing Home Placement of Patients with Alzheimer's Disease: a randomized, controlled trial," Journal of the American Medical Association, 276; 1725-1731.

2. Metlife. (October 2009)**, "**MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs", p. 4, Accessed November 29, 2010 from: http://www.metlife.com/assets/cao/mmi/publications/studies/mmi-market-survey-nursing-home-assisted-living.pdf