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TESTIMONY OF

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TESTIMONY BEFORE

the Subcommittee on Aging, Health, Education, Labor & Pensions Committee
United States Senate

Field Hearing on
"Alzheimer's Research & Care: Helping Patients and Families"

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Senator Mikulski and honored guests, I am pleased to have the opportunity to discuss the impact of the Alzheimer's Disease Demonstration Grants to States Program. This program was created in recognition that Alzheimer's disease affects 4 million Americans and that most of their care is provided in the community by family members. The goals of the Alzheimer's Disease Demonstration Grants to States Program are to increase the availability of supportive services for people with Alzheimer's and their caregivers, and to assure that these services are effectively coordinated.

In addition to working as executive director of an Alzheimer's Association chapter, I have experienced this disease first-hand. First, my father's sister, who helped raise me, developed Alzheimer's, then my mother's younger brother. My father was also diagnosed. We cared for him at home for three years until he passed away last June. Now my mom, my hero, is a victim of this disease. Using adult day services and in-home caregivers, my siblings and I are able to keep her in her home, which is very important to her at this point. This is the home where she was born, where she raised eight children, where she lived with my father for 62 years.

As difficult as it has been to lose people I love to this disease, I know my family was fortunate. I knew what questions to ask about our family members' care and I knew where to go for answers to their care needs. Unfortunately, too often this is not the case. Finding the way through a complex system of community services can be frustrating to families already overwhelmed by the challenges of caregiving. As executive director, the saddest thing I have ever heard from a caregiver is "I wish I had known about these services when my family member was alive."

The Alzheimer's Disease Demonstration Grants to States Program helps states assure that community services are accessible and appropriate for the unique needs of people with Alzheimer's and their families. The initial program in 1992 was created to address the needs of underserved populations and gaps in community services for people with Alzheimer's. Twenty-nine states received grants through this program. With this funding, states were able to develop outreach programs and educational materials for under-served rural, urban and diverse ethnic populations. It enabled states to develop respite resources and other supportive services. The program also funded the development of a wealth of training materials for primary and long-term care providers of people with Alzheimer's.

The current phase of the Alzheimer's Disease Demonstration Grants funded nine additional states. The focus is on integrating dementia care services into the mainstream home and community based care system.

The four Maryland chapters of the Alzheimer's Association benefited from this critical funding in the first demonstration program from 1992 to 2000 and it has truly made a difference for families coping with Alzheimer's disease. It enabled the Alzheimer's Association to reach thousands of families who were not using services, because they did not know they were available or because they did not know how to access them.

The Western Maryland, Eastern Shore and Southern Maryland sites targeted families in rural areas. These sites collaborated with other community agencies and developed care coordination programs to help effectively connect families to services. Here in Baltimore city we focused on outreach to African American families. This funding helped our chapter to establish the three support groups targeted to African American caregivers, and it has resulted in increased participation of African American families in all of our services.

The Maryland Alzheimer's Demonstration Grant has had a significant impact on the availability and accessibility of supportive services for caregiving families. It enabled the chapters to offer respite care subsidies, to give family caregivers time off to rest. It increased the number of caregiver education programs, to inform caregivers about the disease and about how to access community resources. It provided for training of assisted living, nursing facility, home health agencies and adult day care staff, to enhance the quality of care for people with Alzheimer's. It helped the chapters to train physicians and health care professionals in community clinics, to encourage early diagnosis and intervention with treatments and services. Finally, it promoted collaboration among the Alzheimer's Association chapters and public agencies to better coordinate care and services throughout Maryland.

The Alzheimer's Association is participating in the current Alzheimer's Demonstration Grant Program through the Maryland State Department of Aging. This program has sites in two areas of the state with limited caregiver services, the eastern shore and southern Maryland. The funding has established a consumer-directed respite program for family caregivers. It also is helping to strengthen the skills of existing and future health care workers through dementia training. It is encouraging the development of new services by offering training to entrepreneurs on how to start and manage a respite services business.

Senator Mikulski, speaking on behalf of the Alzheimer's Association, and the 85,000 Marylanders with Alzheimer's and their families, I applaud your efforts to expand these critical programs through the Alzheimer's Disease Research and Caregiver Act. This bill will help continue to ensure that no one faces this illness alone, by providing essential, accessible services and hope for the future.