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Chairman Michaud, Congressman Brown, distinguished Members of the Committee: Thank you for this opportunity to discuss the needs of family caregivers of veterans. I want to commend you for recognizing the important role caregivers play in the lives of those for whom they care. We honor their heroism by supporting them and their loved ones when they return home.

For more than forty years, the U.S. Administration on Aging (AoA) has served as the effective and visible advocate for older Americans at the Federal level. AoA provides national leadership, funding, oversight and technical support to a national aging network and is charged under the Older Americans Act to develop a comprehensive and coordinated system of home and community-based services for older people and their family caregivers.

The aging network consists of 56 State Units on Aging; 629 Area Agencies on Aging; 246 Tribal organizations; over 20,000 community services provider organizations and thousands of volunteers. The aging network reaches into every community and plays a key role in delivering consumer-centered services and supports to some of the most vulnerable members of society. What is more, funding for State and community-based services is significantly leveraged, with funding from sources other than the Older Americans Act to triple the amounts provided by AoA.

Through strategic partnering with other Federal agencies and national organizations, AoA has positioned the aging network as the leading provider of home and community-based long-term care services to vulnerable Americans and their caregivers.

My testimony today will highlight AoA and the national aging network experiences in addressing the complex needs of caregivers through our National Family Caregiver Support Program (Caregiver Program). This program was the first Federal program to formally recognize the importance of supporting family caregivers on a sustained basis. I will highlight examples of some of the innovative approaches used by our aging network to serve caregivers as well as new opportunities we have to better meet the needs of

caregivers, including AoA's recent collaboration with the Department of Veterans Affairs (VA) to establish a Veteran Directed Home and Community-Based Services Program (VD-HCBS).

Caregivers: Who are they? What do they sacrifice?

Informal caregiving is the foundation of America's long-term care system. Each day, in every State and community, family members, friends and neighbors provide extraordinary levels of assistance to persons of all ages with chronic illnesses and disabilities. Caregivers manage tasks ranging from assisting with basic personal care and homemaking to carrying out more complex health-related interventions like medication administration and wound care.

The needs of family caregivers are complex and ever changing. Whether caring for a child with disabilities, an aging parent with dementia or a veteran returning from active duty with polytrauma or less severe injuries, caregivers face often rapidly changing situations and needs. As a result, caregivers must be able to depend on a system that understands their needs and responds to them with a comprehensive, consumer-centered and flexible array of programs and services.

Caregivers may be found in every community. They come from every walk of life. They are male and female, young and old, and may or may not possess adequate financial resources to meet their own daily needs or the needs of those for whom they care.

It is estimated that 44.4 million Americans provide care for adult family members and friends or other loved ones. The Family Caregiver Alliance in San Francisco, California estimates these caregivers provide in excess of 37 billion hours of care per year.

The economic value of unpaid caregiving in 2007 was estimated to be about \$375 billion, up from \$350 billion in 2006.¹ This is what it would cost if that care had to be replaced with paid services. This amount equals more than the total of medical and long-term care spending in 2006.

We are seeing growing numbers of caregivers “sandwiched” between two generations of individuals needing care: young children and aging family members. They often experience difficulty balancing work schedules with the demands of caring for their loved ones. As a result, many caregivers leave the workforce or struggle with what amounts to two full time jobs: their formal employment – essential for income and health care coverage - and caring for their loved one.

We also are seeing younger individuals caring for parents, grandparents or siblings, and growing numbers of family caregivers working to keep disabled adult family members out of institutions and in their homes and communities. Another growing segment of the caregiver population includes grandparents or other relatives of children, with or without disabilities, taking on full-time parenting responsibilities for the second or third time in their lives because the child’s parents are unable or unwilling to do so, or because they are serving our country in distant lands.

And, not surprisingly, with our military actively engaged in Iraq and Afghanistan, we are seeing an increased emphasis on supporting the families of military personnel who are returning from combat with traumatic brain injuries and other serious, chronic or debilitating conditions.

In recent years, numerous studies have emerged exploring the complexities of caregiving. These studies have examined the health impacts of caregiving, the status and challenges of rural caregivers, cultural differences among caregivers and the challenges faced by those who balance work, family and caregiving responsibilities.ⁱⁱ

Caregivers also fill multiple roles within the context of their caregiving situation. Caregivers are often both nurse and home health aide, paralegal and financial advisor, as well as devoted family member. They often perform highly skilled or specialized medical tasks such as tube feeding, wound care, and medication management and administration.

Caregivers themselves have many needs that often go unaddressed or are ignored altogether. Research has shown the stress associated with caregiving exacts a significant toll on the emotional, physical and financial well being of many caregivers. Caregivers often report declines in their own health and functional ability as a result of the care they provide. Caregivers experience high rates of depression, stress and other mental health issues. Financially, the impact of caregiving can be significant. One study found that caregiving for a parent significantly increases the caregiver's chances of living in poverty in later life.

Despite the negative impacts of caregiving, there is a bright side as well. Many caregivers report deriving great satisfaction from caregiving and from having the opportunity to fulfill what they see as an essential familial obligation to a loved one or friend. In fact, past surveys of recipients of aging network caregiver support services showed that nearly two-thirds of caregivers felt a sense of accomplishment as a result of the care they were providing.

Regardless of their background, living situation, or level of training, family caregivers represent the best society has to offer. And, while caregiving is an experience affecting all races, ethnicities, lifestyles, and income levels, on a deeply personal and individual level, it has become an essential component of the national dialogue surrounding our nation's health and long-term care system.

The National Family Caregiver Support Program

The AoA National Family Caregiver Support Program (Caregiver Program) serves as a platform for the aging network to focus specifically on the needs of family caregivers by integrating those needs with the provision of other home and community-based services, including State-funded caregiver programs. The unprecedented caregiver support infrastructure established by the Caregiver Program created a multifaceted system of services for caregivers, including:

- Information about available services;
- Assistance to caregivers in gaining access to services;
- Individual counseling, organization of support groups and caregiver training;
- Respite care; and
- Other supplemental services.

Amendments to the Caregiver Program in 2006 permitted caregivers of persons with Alzheimer's disease or related dementias of any age to be served and lowered the age of grandparents and relative caregivers raising children from 60 to 55. These two modifications allowed the aging network to expand the scope of its reach to include a broader cross section of service recipients.

The Caregiver Program has allowed AoA and the aging network to acknowledge the central role of caregivers in our health and long-term care delivery systems. National survey data of our service recipients tell us that nearly 73 percent of caregivers assist the care recipients with very basic life activities such as bathing, dressing and eating.

Caregivers must have access to services and supports designed to safeguard their health and emotional well being while offering protections against some of the financial burdens often associated with caregiving. To that end, AoA, through its partnership with the Centers for Medicare and Medicaid Services, has established highly visible Aging and Disability Resource Centers (ADRCs) in 46 States and territories and in more than 200 communities nationwide, with plans to have ADRCs functioning in every State by 2010. For caregivers, ADRCs are a trusted source for reliable information on the range of programs and supports available to them.

The aging network has many examples that highlight its creativity, flexibility and innovation in serving older consumers, persons with disabilities and their caregivers. For example, in Connecticut a pilot consumer-directed cash and counseling option is being developed in the South Central region of the State with funds from our Caregiver Program and the Statewide Respite Care Program. This option helps consumers at risk of

nursing home placement but who are not yet eligible for Medicaid to remain in their own homes.

In Texas, the Area Agency on Aging of Central Texas has partnered with Scott & White Memorial Hospital to establish two innovative programs for caregivers. The first organizes and connects caregivers with volunteer support teams who assist them with practical and emotional support. The second provides the evidence-based Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention. This approach assesses the needs and risk factors of caregivers, matching them with services and supports to reduce their risks and enhance well-being.

The Caregiver Program has allowed AoA and the aging network the opportunity to:

- Infuse the principles of consumer direction into existing service delivery systems;
- Address the unique challenges associated with serving caregivers in both urban and rural settings;
- Provide a broad range of services, including respite, for diverse age groups, including grandparents and other relatives raising grandchildren; and
- Ensure that programs serve consumers in culturally competent ways.

Caregiver Program Accomplishments

The aging network has had a significant impact in the lives of caregivers and in supporting the work they do. Through the Caregiver Program, we annually touch the lives of more than 1 million people – caregivers, families seeking assistance, grandparents and other relatives raising grandchildren.

We know that through the Caregiver Program, the aging network is having a positive impact on the lives of those we serve. More than 81 percent of caregivers interviewed for the most recent National Survey told us that the Caregiver Program enabled them to care for their loved ones longer, thereby avoiding costlier and more restrictive placement in an institutional setting. Seventy-five percent of caregivers indicated that services helped to

reduce some of the stresses they felt and nearly 46 percent of caregivers said respite was the service found to be most helpful, thus underscoring the importance of caregivers taking time away from their situation to rest and recuperate.

The AoA/VA Collaboration

The Department of Veterans Affairs and the Administration on Aging have long recognized the many concerns in serving our respective populations. Addressing the needs of family caregivers is essential for helping individuals remain in their homes and communities; and the knowledge that both younger veterans and older adults want to be in charge of their own lives to direct their own service needs.

AoA and VA recognize the importance of caregivers' service to their loved ones. Together we have a shared commitment to meeting the needs of consumers and their families, on their terms and according to their needs and preferences. The aging network recognizes the importance of partnering with the VA at the local level to meet the needs of veterans. In Maine, for example, Area Agencies on Aging (AAA) coordinate services and benefits for veterans in collaboration with the Veterans Homes throughout the State, the Togus CA Medical Center and the Department of Veterans Affairs. Coordination is done via the ADRCs, the Partners in Caring State-funded respite program, the State Health Insurance Assistance Program, and our Family Caregiver Program.

Additionally, some of the AAAs have veterans' advocates who come to their agency on a scheduled basis to meet with veterans and their caregivers. Community information staff at AAAs obtain and distribute updated information regarding veterans' benefits. Finally, some of the AAAs have adult day programs at which veterans participate.

AoA and VA are jointly funding the Community Living Program and the "Veterans Directed Home and Community-Based Services Program." Through this program, veterans of all ages are being served to direct and purchase their long-term services and supports through the aging network. For its role, the aging network assesses the needs of

veterans and caregivers; develops care plans; supports veterans through the provider selection process; arranges for Financial Management Services; and, most importantly, develops a professional relationship with the veterans to ensure they receive the services as planned to meet their needs, and make changes where necessary.

The program began in February 2009 with funding for 20 States, ten of which provide VD-HCBS. To date 70 veterans are being served in Michigan and New Jersey and we are already beginning to see the results. In Michigan, for example, a 74 year old veteran living in an assisted living facility was referred to the newly established VD-HCBS program at the AAA. Because of that program, the veteran was able to move out of the facility and into his own apartment where he has hired a personal aide who works for him for 40 hours per week, providing the supports he needs to remain independent in the community. Staff report that he is doing well.

By building on the capacities and infrastructure of the aging network, the VA is already helping to ensure a coordinated and consumer-centered approach to serving the needs of veterans and their caregivers.

Conclusion

It has often been said that caring for an older person is a family business. The same can be said for caring for a returning veteran. No one knows better how to care for someone than their loved one and those receiving the care are the better for it. Caring for the caregivers must be a national focus and a top priority as our nation moves ahead.

As AoA and the VA move forward in their collaborative efforts to serve the complex needs of veterans and their caregivers, the aging network stands ready to put its years of experience honoring and serving older persons to work serving those brave men and women who have served our country so honorably.

ⁱ Gibson M.J., & Houser, A.N. *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*. Washington, D.C.: AARP Public Policy Institute: 2008 November, Insight on the Issues #13.

ⁱⁱ For more information on the varied needs of caregivers and to view and download a variety of research reports pertaining to caregivers, please visit the National Alliance for Caregiving's website at: <http://www.caregiving.org/>