

**Statement of
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Before the
Senate Special Committee on Aging
Hearing
Families Helping Families: Tax Relief Strategies for Eldercare
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Good morning Chairman Craig and distinguished members of the Special Committee on Aging. My name is Sandy Markwood, and I am the Chief Executive Officer of the National Association of Area Agencies on Aging (NAA). Thank you Senator Craig for inviting me to testify on the important issue of family caregivers.

Family caregivers truly are the heart of long term care and we strongly believe that any legislation that supports the selfless, dedicated work of our nation's more than 23 million caregivers, whether it provides financial, physical or emotional relief, will make a positive contribution to the lives of both the caregivers and those they love and should be implemented as soon as possible. The SECURE Act legislation you will offer, which provides a targeted caregiver tax credit, will offer much needed help in alleviating some of the tremendous burdens that millions of families face in trying to care for loved ones who are no longer able to fully care for themselves. NAA stands ready to work with you toward the swift implementation of a targeted caregiver tax credit bill that will provide needed relief to the greatest number of our nation's caregivers.

The Mission of NAA and AAAs

As the Administration recognized in its FY 05 Budget Proposal, home and community based services are not only the overwhelmingly preferred choice for individuals with long term care needs, but these services are also the more cost effective means of providing long term services. This compliments the fundamental mission of NAA, AAAs and Title VI Native American Aging Grantees which is to help older Americans stay in their own homes and communities with maximum dignity and independence for as long as possible. The 655 AAAs and 232 Title VI Native American Aging Grantees are dedicated to enhancing the quality of life for older Americans and their families by providing information about and access to a variety of aging supportive and preventative services in communities across the nation. AAAs often serve as a "single point of information" for the complex and fragmented range of home and community-based services for older adults and their caregivers including congregate and home-delivered meals, other in-home services (including personal care and chore services) for the frail elderly, elder abuse prevention and protections, the nursing home ombudsman program, senior centers, transportation, consumer information, education and counseling and senior employment.

For over 35 years, AAAs and Title VI Native American Grantees have effectively and efficiently

served populations across the country that are geographically, racially, culturally and ethnically diverse and found innovative ways to meet the needs of millions of older adults. These agencies offer programs that make a difference in the lives of all older adults ... from the frail older person who can remain at home if they receive the right services to those who are healthy and can benefit from the activities and socialization provided by community-based programs such as senior centers. And, AAAs also play a critical role in supporting our nation's often unsung heroes—family caregivers.

The Toll of Caregiving on Caregivers

Not only are family caregivers the heart of the long term care system in this country, they are also the **back bone** of long term care. 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. Recent estimates have valued the services provided by family caregivers at \$257 billion annually (Arno, "Economic Value of Informal Caregiving"). Caregiving, however, has a cost to the caregiver—though many would never want to admit it. Caregiving has been proven to take a great financial, emotional and physical toll on the caregiver.

Financially many caregivers forego job advancements, reduce their hours on the job, cut back to part-time, or take temporary or extended leaves of absence to stay at home to care for family members. These actions result in direct financial losses in terms of lost compensation and further financial loss due when you take into account the impact of lost salary on other employee benefits. Additionally, caregiver's often deplete their own personal savings as they try to compensate for lost wages and employee benefits.

Reduced wages and job insecurity also negatively affects caregiver's retirement security. This is especially a problem for women who constitute the majority of this nation's caregivers. In a caregiver survey conducted by the MetLife Mature Market Institute Foundation, respondents reported an average lifetime earnings loss of over \$550,000 due to caregiving requirements—and this figure jumps to \$659,000 when pensions and Social Security are taken into account. . Women, in general, already face greater retirement insecurity as a result of their lower wage base than men and the time that many take out of the workforce to raise children.

Caregiving itself has associated costs. Direct expenses incurred by family caregivers themselves often include the cost of prescription drugs, durable medical equipment, home modifications and physical therapy for the care recipient. A 1998 study by the National Alliance for Caregiving found that almost half (49%) of caregivers surveyed suffered "financial hardship" directly related to their caregiving. The Millbank Quarterly reports that families taking care of a relative with a chronic condition spend two and a half times more for out-of-pocket medical expenses.

In addition to the financial toll, caregiving also takes an emotional and physical toll on the caregiver as well. Caregivers cite an increased prevalence of depression, stress, anxiety, frustration and feelings of being overwhelmed than the general public. The American Journal of Public Health reported that a four-year study of middle-aged and older caregivers found that middle-age and older women caring for a relative were almost six times as likely to suffer depression or anxiety. Depression increases the risk of heart disease, cancer, diabetes and other chronic conditions. Other negative health effects experienced by caregivers at a higher than normal prevalence, according to the American Journal of Preventive Medicine last year, include high blood pressure, poorer immune function, sleeplessness and

an increased risk of mortality. All of these health risk factors have a cost associated with them as well.

Caregiving also can cause chronic and acute physical strain on the caregiver—many of whom are aging themselves. A study by the American Society on Aging found that while the average age of a caregiver is 57, over one third of caregivers are 65 years old or older. Caregiving activities such as helping the care recipient out of bed, bathing or changing clothes if done improperly can and often do cause injuries that leave the caregiver no longer able to provide care, and in some cases, in need of care themselves. Reports have indicated that the stress associated with caregiving, especially over a prolonged period of time, negatively affect a caregiver's immune system and make them more susceptible to illness. Often times a caregiver will ignore their own symptoms until an acute condition arises.

To exacerbate the issue even further, population trends forecast a greater need for family caregivers in the near future, as baby boomers begin to reach retirement age. Thanks to advances in health care and medical technology, life expectancies have increased, and many persons can expect to live to be over 77 years old. However, with these longer lives often comes the increased need for long-term care. Currently individuals age 85 and above constitute one of the most rapidly rising populations in the country and it is this population that is in poorer health, has more chronic diseases and functions least independently overall. Studies are showing that baby boomers, who due to lower birth rates, higher divorce rates, and low savings rates, are not planning for their later years and likely face great caregiver challenges.

There is no doubt that caregivers, many who are also raising children, working full or part-time or are facing the challenges of aging themselves, are stressed with multiple responsibilities and need help. It is only right that **those that give help should receive help too.**

The National Family Caregiver Support Program

Congress took the first steps in recognizing not only the tremendous contributions of family caregivers, but also their need for relief, by including the National Family Caregiver Support Program (NFCSP) in the reauthorization of the Older Americans Act in 2000. The program provides critically needed assistance to families as they struggle to provide help to loved ones with such activities as eating, bathing and dressing. It builds upon services provided under the OAA in local communities throughout the country. Over the four years since its establishment, appropriations for the Program increased from \$125 to the current level of \$159 million. While we are appreciative of the yearly increases, given the vast numbers of family caregivers and the extent of their need, I would be remiss in my role as an advocate if I did not mention that this program remains woefully underfunded.

These dollars, though augmented at the state and local level, are stretched thin. AAAs report that the most sought after service provided under the NFCSP is the most expensive, respite care. Respite care, has proven to alleviate, at least temporarily, some of the physical and emotional stresses related to caregiving, reducing the risk of abuse or neglect, reduced strained relationships between caregiver and care recipient, and extending the delay of institutionalization of the care recipient. However, because of its costs, caregivers often need more respite than they can afford privately or that AAAs, who struggle with competing service needs and limited funding, have the capacity to provide. Attached to this testimony is one poignant example of the value of respite care to a caregiver.

Additional services provided by AAAs and Title VI Grantee under the National Family Caregiver Support Program include supportive and supplemental services such as home modifications, transportation, and chore services. Given the flexibility of the NFCSP, AAAs and Title VI Grantees have developed truly novel and very effective programs targeted to meet the individual needs of caregivers. What our members have found is that sometimes caregivers who are stretched to the maximum just need help with shopping, house cleaning or lawn maintenance. Sometimes a small stipend to help caregivers get assistance to cover these chores can enable them to have the extra time and energy they need to provide unstressed care to their loved one.

Through the Eldercare Locator, the national toll free telephone information and referral which n4a along with the National Association of State Units on Aging operate through a grant from the Administration on Aging, we have found that caregivers often reach out when they are in crisis looking to place their loved one in an institutional facility when all they really need was access to one or two supportive services to be able to keep caring for them at home.

Through the NFCSP, AAAs and Title VI agencies are successfully providing services and support to thousands of caregivers nationwide. An n4a survey done in December, 2001 lists almost 300 examples of how this program has begun to provide critical support and relief for caregivers across the country. Some innovative examples of AAA and Title VI NFCSP funded efforts include:

- In Georgia, AAAs pulled a portion of their NFCSP funding to produce a magazine targeted to inform the public about caregiving issues and the resources that exist in each of the AAAs to assist caregivers. Produced quarterly, the magazine has helped caregivers learn critical information about their caregiver roles and the resources available to help them.
- Through the n4a/Administration on Aging NFCSP program *Making the Link*, nearly 200 AAAs are working with physicians, nurses and discharge planners to help identify caregivers and connect them to support services in the community.
- The Hawkeye Valley (IA) AAA offers a Caregiver Helpline and Case Management Services to help caregivers find and manage the services that their care recipient needs.
- The Area II AAA in Lewiston (ID) offers the LINKAGE program in which caregiver peers provide support to one another.
- An AAA in Indiana is coordinating with the local hospice, libraries, parish nurses and community legal services to provide caregiver workshops

What the AAA and Title VI agencies have learned through their experience in implementing the NFCSP is that the needs of caregivers are varied and unique but all caregivers need assistance. And, **ANY** financial assistance that caregivers can get is beneficial and can make a major difference in their lives as well as their ability to care for their loved ones. The Assistant Secretary on Aging reported last September that of the 23 million caregivers nationwide, 85% are receiving no outside help. Many caregivers have limited resources, with approximately half of all caregivers having a household income of less than \$35,000 (Kaiser Family Foundation, 2001), and the majority of older caregivers living on fixed incomes. **The bottom line is that caregivers need financial relief.**

Conclusion

Independence, dignity and choice are strongly held values by all Americans, and individuals with physical or cognitive limitations and impairments are no exception. n4a has determined that a

comprehensive national policy that shifts the focus and funding of long-term care to community-based services is essential to meet the long term care needs and address the desires of America's aging population. Caregivers are truly the heart of the long term care system and we, as a nation, must do more to address the emotional, physical and financial challenges associated with caregiving. The Family Caregiver Support Program was a significant first step in providing some relief and support to caregivers and we look forward to working with you and your committed staff to ensure that the passage of the SECURE Act takes a further step forward toward providing relief to this selfless population.