



DEPARTMENT OF HEALTH & HUMAN SERVICES

Washington, D.C. 20201

Statement of

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Before the

Special Committee on Aging

United States Senate

May 17, 2001

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Mr. Chairman and Members of the Committee:

Thank you for this opportunity to discuss the Administration on Aging's (AoA) efforts to implement the National Family Caregiver Support Program (NFCSP). We appreciate your leadership and look forward to working with you on this and other issues concerning older Americans and their caregivers.

Mr. Chairman, the past several months have been exciting ones for the Administration on Aging. With your support and that of other Members of this Committee, the Older Americans Act (OAA) was reauthorized. That reauthorization included the new National Family Caregiver Support Program. The National Family Caregiver Support Program is the first major new component of the OAA since the establishment of the nutrition program in 1972. For the first time in the history of the Act, there is now a national focus on caregivers as well as care receivers.

AoA was honored that one of Secretary Thompson's first official acts at the Department of Health and Human Services was to authorize the release of \$113 million to States to begin implementation of this program.

Attention to the needs of caregivers could not come at a better time. Families provide 95 percent of the long-term care for frail older Americans. Almost three-quarters of

informal caregivers are women, many are older and vulnerable themselves, or are running households, employed and parenting children. Estimates from the National Long-Term Care Survey (1994) indicate that over 7 million Americans are informal caregivers providing assistance to spouses, parents, other relatives and friends. More than 5 million older adults with disabilities receive significant levels of service from these caregivers. According to the survey, if the work of these caregivers had to be replaced by paid home care staff, the cost to our nation would be between \$45 to \$94 billion per year.

The assistance provided to the elderly or disabled friends or relatives may range from bill payment, transportation for medical appointments, food shopping and/or preparation, to more complex personal care. As our older population continues to grow, especially with the increased numbers expected as a result of the aging of the baby boomers, we can anticipate that the challenges of caregiving will increase as well.

AoA and the national aging network have made good progress in implementing the National Family Caregiver Support Program. This Committee knows the caregiver program is based upon a review of the recent research on caregivers, guidance from professional caregivers and discussions with family caregivers themselves. We looked closely at programs in various States across the country, among them Wisconsin, Pennsylvania, Michigan and Oregon, and engaged Federal, State and local leaders in our discussions. AoA convened a series of roundtables with caregivers in more than 30 cities across the United States, involving hundreds of caregivers, service providers,

policymakers and community leaders. These individuals shared with us their joys in caring for a loved one; their difficulty in accessing services; their unpreparedness for this new, and often scary responsibility; their loneliness and isolation; and the compromises they have had to make in juggling careers, families and finances.

As a result of this invaluable input, the National Family Caregiver Support Program is designed to be as flexible as possible to meet the diverse needs of family caregivers. We have encouraged States to develop a multi-faceted program, as required by the statute, based on their service delivery network and responsiveness to their caregivers. We have offered guidance and technical assistance to States and the network to help them understand and utilize the National Family Caregiver Support Program's flexibility to design their own systems to best meet the needs in their communities.

The National Family Caregiver Support Program is comprised of five service categories:

- ▶ **Information** about health conditions, resources and community-based long-term care services that might best meet a family's needs;
- ▶ **Assistance** in securing appropriate help;
- ▶ **Counseling, support groups and caregiver training** to help families make decisions and solve problems;
- ▶ **Respite care** so that families and other informal caregivers can be temporarily relieved from their caregiving responsibilities; and

- ▶ **Supplemental services** on a limited basis. This could include a wide range of services designed to support the efforts of caregivers. Examples from State-funded programs include such supports as home modifications, incontinence supplies, nutritional supplements and assistive devices.

The legislation targets family caregivers of older adults and grandparents and relative caregivers of children not more than 18 years of age. It also directs the States to give priority to services for older individuals with the greatest social and economic need, with particular attention to low-income older individuals and older individuals providing care and support to persons with mental retardation or who have developmental disabilities.

The \$125 million we received in FY 2001 will enable State, local and tribal programs to provide services to approximately 250,000 of America's caregivers. We distributed \$113 million to States. An additional \$5 million is designated to assist caregivers of Native American elders and will be released shortly in accordance with the guidance AoA received from tribal listening sessions held recently. Very soon AoA will announce the availability of almost \$6 million for competitive innovative grants and projects of national significance (under sections 375 and 376 of the OAA). These projects, once awarded, will demonstrate and test new and diverse approaches to caregiving, providing us with knowledge that will be critical to the future success of the program.

The remaining \$1 million is being used for technical assistance to the aging network to provide State and local programs with the tools to be responsive to family caregivers. These include a national technical assistance conference to be convened in Washington, DC on September 6-7, 2001; a moderated Listserv, on which expert researchers prepare monographs on specific issues related to caregiving and enter into a dialogue with the aging network on how best to implement that issue in our country; an expanded webpage containing the most recent caregiver information and resources; and other educational and public awareness initiatives.

We have recently completed a series of bi-regional video conferences with all the States to discuss and clarify issues related to implementation of the program. In addition, we presented promising approaches from various caregiver programs throughout the country that would be helpful as they design their systems.

In FY 2002, the budget request for the caregiver program is \$127 million, an increase of \$2 million over FY 2001, to help to maintain the current level of services for caregivers as our program takes hold.

Over the next year, AoA is committed to:

- ▶ Develop partnerships with our sister Federal agencies and other national organizations to further the caregiving agenda;

- ▶ Implement a public awareness campaign to inform America of the importance of caregiving and to encourage caregivers to seek assistance and training as they begin their caregiving careers; and
- ▶ Continue to provide the aging network with assistance and support to better serve our caregivers.

Mr. Chairman, we appreciate this opportunity to share our progress on the implementation of the National Family Caregiver Support Program, and we look forward to working with you to meet the challenges and opportunities to support America's families. I would be happy to address any questions you have.