

# Administration on Aging – National Family Caregiver Support Program

**AGINGWELL**  
**LIVINGWELL**

## **Background**

Families and informal caregivers are the backbone of our nation's ability to provide long-term care (LTC) for older persons in the United States. Caregivers provide assistance to family members and friends who experience limitations in activities of daily living (ADLs), such as bathing, dressing, eating, and toileting. They also provide assistance in instrumental activities of daily living (IADLs), such as meal preparation, medication management, and transportation. In many cases, both the caregivers and care recipients are aging adults.

More than 22.4 million US households are serving in family caregiving roles for persons over the age of 50. That number will increase rapidly as the population ages, as medical science continues to extend life, and workforce shortages continue in the long-term care sector.

Currently, 86% of older persons at greatest risk of nursing home placement live with others and receive an average of 60 hours of informal care per week. The contribution of America's caregivers to our health care system is valued at \$257 billion annually. Informal care plays a significant role in preventing or delaying the need of a disabled older person to go to a nursing home.

## **Caregivers Health**

Prolonged caregiving can adversely affect one's physical and psychological health, current and future employment status and earning capability, ability to balance the needs of older parents and younger family members, and the ability to meet personal needs. Caregiving responsibilities impose a heavy emotional strain and can often result in stress and depression. Such emotional strain, accompanied by the physical demands of caregiving, has been shown to be an independent risk factor for mortality among older adults.

Caregivers have, and continue to be the major coordinators and providers of everyday long-term care. During the next few decades, the demand for informal caregivers will rapidly increase even further as the number of older persons needing assistance to remain independent increases dramatically.

## **Recognition of Caregivers**

Recognition and assistance of the role of families in providing long-term care is moving to the forefront of national policy making. The Department of Health and Human Services' Administration on Aging (AoA) has been very active in helping to provide needed services to family caregivers. The enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501) established an important new program: The National Family Caregiver Support Program (NFCSP).

## **What Is the National Family Caregiver Support Program?**

The National Family Caregiver Support Program calls for all states, working in partnership with area agencies on aging and local community service providers, to have five basic services available for family caregivers, including:

1. Information to caregivers about available services;
2. Assistance to caregivers in gaining access to supportive services;
3. Individual counseling, organization of support groups, and caregiving training to assist caregivers in making decisions and solving problems related to their caregiving roles;

4. Respite care to enable caregivers to be temporarily relieved from their caregiver responsibilities; and
5. Supplemental services on a limited basis, to complement the care provided by caregivers.

In FY 2004, the National Family Caregiver Support Program was funded at \$159 million. Of that amount, \$6.3 million is for the Native American Caregiver Support Program, established within the NFCSP to address the special needs of caregivers of Native American elders.

Innovation Grants and Projects of National Significance were awarded to 39 national, state, and local organizations to develop and test model caregiving approaches. These grants focus on systems development, service components, linkages to special populations and communities, testing new approaches, and national projects that enhance the development of caregiver programs.

### **Who Is Eligible to Receive Services?**

Family caregivers of older adults (age 60 and older) and grandparents and relative caregivers (60 and older) of children not more than 18 years of age are eligible for NFCSP services.

### **Older Americans Act Is Vital**

Caregiver support is not provided in a vacuum. Many older people who receive assistance from family members also receive assistance from other OAA-funded home and community-based services such as meals, personal care, and transportation. These services help lessen the burden on family caregivers.

A 2002 survey of caregivers shows that:

- 86% said OAA services allowed them to provide care longer than they would have been able to on their own
- 69% reported that the services helped a lot in their efforts to provide care
- 96% were very or somewhat satisfied with the OAA services

### **NFCSP in Action**

The National Aging Services Network (which includes 56 State Units on Aging, 655 Area Agencies on Aging, 244 tribal organizations, and about 30,000 local service providers) has:

- Reached out to over 3.8 million individuals with information about caregiver programs and services;
- Provided assistance in accessing services to approximately 436,000 caregivers — significantly exceeding the agency target of 250,000 caregivers;
- Served almost 180,000 caregivers with counseling and training services;
- Provided respite to over 70,000 caregivers; and
- Provided supplemental services to over 50,000 caregivers.

Native American and American Indian tribal organizations have seized the opportunity the NFCSP presents to develop systems of support that meet the unique needs of their family caregivers. Most tribes are in the development stages of their programs. A total of 119 tribes received their initial funding in 2002 and:

- At least 4,230 caregivers received one or more caregiver support services;
- All programs are administering public awareness campaigns;
- Respite service is provided by most programs (92%), including respite for grandparents;
- 58% of the programs are providing caregiver training;
- Caregiver conferences have been held by 28% of the programs; and
- 64% of the programs are conducting support groups or individual counseling.

*\*Program accomplishments through December 2002*

*For more information on the NFCSP, please go to the Administration on Aging NFCSP website at <http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>.*

*Where You Can Get Help — If you or someone you care about needs assistance, please contact AoA's Eldercare Locator at 1 (800) 677-1116 or on the web at <http://www.eldercare.gov>.*

