



# supporting caregivers

supporting families in their efforts to care for their loved ones at home and in t

One in three Americans or 22 million people are providing compassionate assistance to a family member, neighbor, or friend. Caregivers include grandparents raising grandchildren as well as those who help older Americans. In many cases, both the caregivers and care recipients are aging adults. The National Family Caregiver Support Program (NFCSP) was established in 2000 to provide supportive services for family caregivers. Since the enactment of the NFCSP, AoA and our National Aging Services Network have demonstrated creativity in implementing family-directed services to caregivers of the elderly and persons with disabilities.

The NFCSP is already producing results. Preliminary data from state agencies indicate that we have exceeded statutory expectations to serve 250,000 caregivers by serving over 325,000 caregivers during the first years of implementation. The same preliminary data reflect that the states and area agencies on aging are providing a solid mix of services to caregivers, including information, assistance, counseling,

respite, and supplemental services. Early data from AoA's first national survey of caregivers indicate that caregivers value the services provided by the Network to older clients. Eighty-eight percent reported that services enabled them to care longer than would otherwise have been possible, and 72% reported that the services "helped a lot."

We have provided leadership, guidance, and technical assistance to the Network in implementing and maintaining the NFCSP. The Network focused on developing support systems and expanding the range of services to meet the diverse needs of caregivers. These efforts have resulted in the formation of new local partnerships, improved access to services, outreach to special populations and caregivers who may not be connected to our service delivery networks, and provision of services to respond to the unique needs of families.

## PROVIDING LEADERSHIP AND TECHNICAL ASSISTANCE

Since the establishment of the NFCSP, AoA has identified and disseminated state-of-the-art knowledge, information, and technical assistance on models and techniques that can be used by states, tribes, and communities to design and implement programs and services that support family caregivers.

In 2002, we developed a *Resource Guide to the National Family Caregiver Support Program*. The guide provides research-based implementation strategies and approaches that network staff may consider in carrying out the NFCSP. AoA also launched a web page, <http://www.aoa.gov/> to provide guid-





## the community

ance in implementing the NFCSP as well as information on the characteristics and needs of family caregivers.

### PROMOTING CONSUMER AWARENESS

Caregivers often are not aware they are caregivers or that services exist which can support them. All too often caregivers seek assistance only when a crisis occurs with their loved ones. To educate family and other informal caregivers about the services available to support them in their caregiving role, we created the following:

- A NFCSP brochure that contains information on eligible populations, services provided through the program, and highlights innovative state caregiving programs;
- A 10-step approach called “Caregiver Survival Tips” for family caregivers to use to identify areas where they may need support and information on how to locate and access this support; and
- A Public Service Announcement entitled “Who Are The Caregivers” which was shown on public television stations reached over 4.6 million people. This five minute segment talked about the NFCSP and was aimed at caregivers who may need support services.



## NFCSP 2002 Funding

\$128 million allocated to states

\$5.5 million distributed to 187  
Indian Tribal and Native Hawaiian  
Organizations

\$7 million was awarded to 39  
innovative projects



“I provide financial, emotional, and hands-on care everyday as the primary caregiver

### SUPPORTING INNOVATION THROUGH THE NFCSP

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Through the NFCSP, AoA is supporting 39 innovative projects to assist families and informal caregivers at a national and community-based level. These competitive grants focus on systems development, service components, linkages to special populations and communities, field-initiated demonstrations to develop and test new approaches to support caregivers, and national projects that enhance the development of caregiver programs. Projects funded in 2002 include the following:

- The Caring Workplace Project is recruiting and establishing ongoing support from eleven major corporations in St. Louis. Individualized action plans for each business were created based on employee and organizational information. Eldercare services and direct services including one-on-one assessments, consultations, home and safety



assessments, and follow-up visits are provided at each company.

- The Elder Caregivers of Adults with Disabilities project is implementing a support system in Pennsylvania for elderly primary caregivers of adult children with mental retardation and developmental disabilities. This consumer-driven project emphasizes supporting the caregiver and family in ways that are specific to his or her needs. The project reimburses these individuals for expenditures related to caregiving and provides resources for all caregiving needs. The strength of the program lies in its flexibility to allow the caregiver to decide how to use the reimbursement.
- The CARE-Pro project uses newer technologies to educate a significant number of health practitioners about how to meet the needs of family caregivers. The Care-Pro project conducted five one-hour Web and teleconference seminars that reached 850–1,000 nurses, occupational therapists, and social workers.
- The Multi-State Family Caregiver Mediation Project, in Michigan, uses mediation to assist frail older persons and their family caregivers to address and resolve problems and disputes which arise when families face the physical, emotional, and financial demands of providing long-term care to an older family member. The goal is to use mediation to protect the autonomy and dignity of older persons while assisting and enabling family caregivers to resolve problems, which if left unresolved, could destroy the family and caregiver support system and could result in institutionalization, financial exploitation, neglect, or abuse.



ver for my mother. I am not an “informal” caregiver.”

— a family caregiver

#### SUPPORTING THE PRESIDENT’S AGENDA

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AoA is active in implementing President Bush’s New Freedom Initiative, a comprehensive plan to remove barriers to community living for people with disabilities by working to ensure that all Americans have the opportunity to learn and develop skills, engage in work, make choices about their daily lives, and participate fully in community life.

We convened the New Freedom Initiative Caregiver Support Workgroup, an interdepartmental workgroup, to identify opportunities for collaboration and coordination in the area of family caregiver support. The Caregiver Support Workgroup developed a *Compendium of HHS Caregiver Support Activities*. To view the Compendium, visit <http://www.aoa.gov/>. The Compendium, a first at HHS, catalogues the existing efforts by HHS agencies to support family and informal caregivers.



## Caregivers Are Receiving Services Through the NFCSP

States and AAAs Reach Out with Well-Rounded Service Programs in 2002

- 1.3 million caregivers reached by states
- 325,000 received access to help
- 150,000 received counseling and training
- 60,000+ received respite help
- 45,000+ received supplemental services



# ensuring elder rights

ensuring the rights of older people and preventing their exploitation, abuse, and

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## ENSURING ELDER RIGHTS

Protecting the rights of older people and preventing their exploitation, abuse, and neglect continues to be one of our most important goals and that of the National Aging Services Network. Predatory lending, home repair scams, and other types of financial exploitation undermine our efforts to promote autonomy and independence. AoA provides critical consumer information, training, technical assistance, and funding for programs that protect the rights of vulnerable, at-risk older persons.

Programs are in place to assist older persons and their families if they are in trouble. If older persons or their family members are having a problem with a nursing home or long-term care facility, the long-term care ombudsman program can help. Long-term care ombudsmen are trained to solve problems and provide information. Similarly, if someone has been the victim of fraud or abuse and needs legal assistance, AoA's legal services may be able to provide support. Additionally, AoA's Senior Medicare Patrol projects train people to detect and stop Medicare and Medicaid fraud and abuse.

Preventing abuse through education is also critical. We have produced consumer education materials and public service announcements to help older persons help protect themselves. We have also provided training to caregivers and elder abuse programs.

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## LONG-TERM CARE OMBUDSMAN PROGRAM

The commitment of AoA and the Network to protect older Americans is reflected in the tireless efforts of the long-term care ombudsman program. Long-term care ombudsman programs in every state and almost 600 regions of the country provide information to residents of long-term care facilities and those in need of long-term care, help residents and their families resolve problems, and advocate for systemic changes to improve care and protect residents' rights.

In 2002, long-term care ombudsmen had the opportunity to use quality data about nursing home programs to assist families in making informed decisions about choosing a nursing home. The quality data is from a pilot project and is based on nine measures of nursing home quality. The six-state pilot project, involving nursing homes serving Medicare and Medicaid beneficiaries in Colorado, Florida, Maryland, Ohio, Rhode Island, and Washington, is part of HHS' Nursing Home Quality Initiative to further improve the quality of care received by the 2.9 million Americans who live in nursing homes.

The success of our nation's ombudsman programs is evident. Ombudsman programs around the country investigate over 260,000 complaints each year, ranging from abuse to inadequate staff to involuntary transfers. They resolve or partially resolve over 70% of the complaints. One thousand paid and 14,000 volunteer staff (8,000 certified) provide information to more than 280,000 people on a myriad of top-



## d neglect

ics including how to select and pay for a long-term care facility, residents' rights, and state and federal rules for facilities. Additionally, the AoA-funded Ombudsman Resource Center provides national and regional training and technical assistance to enhance the skills and knowledge of state and local ombudsmen.

### SENIOR LEGAL SERVICES

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The OAA is one of the top funding sources for low-income senior legal services. There are approximately 1,000 OAA legal services providers nationwide supplying over one million hours of legal assistance per year. The following are two examples of how AoA's legal services help seniors:

- In Michigan, a 73 year-old woman was contacted by a telemarketer and invited to join a discount buyers club. She told the company she wasn't interested. However, when her checks began bouncing, she contacted her bank and found that an electronic transfer to the buyers club had been made. Intervention by senior legal services led to a refund of all her money plus additional expenses.
- In Georgia, an elderly couple was charged nearly \$11,000 for minor home repairs that were never completed. Legal services assisted the couple in canceling the contract.



## Preventing Elder Abuse

"I'm really glad to know you're available for this kind of help. Seems like people start trying to take advantage of you as you get older. Sometimes I just need legal advice or a little help. Thank you for being there for me."

— Comment given to a West Virginia Senior Legal Aid



“For 30 years, the nation’s volunteer ombudsmen have worked to protect nursing h

## PREVENTING ELDER ABUSE

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Financial and material exploitation of older persons continues to be a major problem. To get a better understanding of this phenomenon, AoA is working in partnership with the HHS Office of the Assistant Secretary for Planning and Evaluation to carry out a national study on elder financial exploitation. In an effort to foster information exchange and collaboration, we also co-chair the Elder Justice Interagency Working Group, a group of officials responsible for carrying out elder justice activities in the Federal government.

In 2002, we supported the development of consumer education materials and consumer alerts, including the National Consumer Law Center fact sheet, *Protect Your Investment: Don't Let Predatory Lenders Take Your Home*. The fact sheet can be found at [http://www.consumerlaw.org/initiatives/seniors\\_initiative/protect\\_invest.shtml](http://www.consumerlaw.org/initiatives/seniors_initiative/protect_invest.shtml). Similarly, we are supporting a Pennsylvania Department of Aging project to provide financial literacy training to minority seniors, raise awareness about predatory investment scams, and train adult protective services staff in how to investigate and resolve exploitation cases.

Additionally, AoA's National Center on Elder Abuse worked to carry out the National Elder Abuse Action Agenda 2002. Educating the public, training professionals, and increasing prosecutions are some of the critical areas the agenda addresses.

We are working in partnership with the HHS Office of Women's Health to support an effort by the Wisconsin Coalition Against Domestic Violence/National Clearinghouse on Abuse in Later Life and the AARP Foundation to promote collaboration and information sharing between domestic violence and elder abuse prevention advocates and practitioners.

OAA funding also supports state and local elder abuse prevention public awareness campaigns, training programs, and multidisciplinary teams. Examples of such abuse prevention efforts from 2002 include the following:

- Orange County, California's Fiduciary Abuse Specialist Team met monthly to discuss cases; the program coordinator offered 38 community and law enforcement education sessions to nearly 1,800 people.
- In Broward County, Florida, caregivers were taught how to handle difficult behaviors and defuse stressful situations. Over 400 individuals received in-home training and approximately 700 others attended information sessions about elder abuse.
- Arkansas' Adult Protective Services and the State Long-Term Care Ombudsman programs jointly sponsored regional trainings on elder abuse that included participation by law enforcement and EMT personnel, prosecuting attorneys, hospital and nursing home administrators, social workers, and clergy.



home residents and improve the quality of care.”

— HHS Secretary Tommy G. Thompson

### SENIOR MEDICARE PATROL PROJECTS

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AoA supports 51 Senior Medicare Patrol (SMP) projects in 45 states, the District of Columbia, and Puerto Rico for the purpose of recruiting retired nurses, doctors, accountants, and other professionals to train other older persons and to serve as expert resources to detect and stop Medicare and Medicaid fraud, error, waste, and abuse.

In 2002, AoA launched a website and convened a national conference designed to promote consumer awareness and facilitate the sharing of information and best practices between Medicare and Medicaid beneficiaries; the SMP projects; and federal, state, and local partners. The website also links seniors to information about how to become a volunteer. For more information, please visit the website at <http://www.aoa.gov/smp/index.asp>.

Since their inception in 1998, SMP projects have resulted in the recovery of \$3,008,937 in Medicare funds and \$76,621,601 to the Medicaid program and other payers.



## Making an Impact in 2002

### Senior Medicare Patrols

- 9,000 new volunteers were trained
- 400,000 beneficiaries were directly educated by the retired volunteers