



U.S. Department of Health and Human Services
Administration on Aging



THE OLDER AMERICANS ACT
NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM
(Title III-E and Title VI-C)

Compassion In Action

EXECUTIVE SUMMARY
September 2003

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INTRODUCTION

The aging of the U.S. population has heightened interest in designing efficient and effective systems for delivering health and related services to older people. Developing service networks to provide older people and their caregivers with a continuum of home- and community-based long-term care has become especially important, in order to better meet their support needs and preferences for independence.

Family caregivers provide the vast majority of the assistance that enables older people to live independently in their homes and communities. 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. Many are women. Family caregivers face substantial stresses and burdens as a consequence of caregiving obligations. 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.^{1 2} Because caregivers play such an important role, services that sustain a caregiver's role and maintain their emotional and physical health are an important component of any home and community-based care system.³

The National Family Caregiver Support Program (NFCSP) was authorized by the Older Americans Act of 2000, and is based in large part on successful programs and the needs expressed by family caregivers in discussions held across the country. This report highlights the significant progress made in states, tribes and communities across the country in implementing the NFCSP. The following sections will highlight how the National Aging Services Network has served our nation's family caregivers, under the leadership of the Department of Health and Human Services and the Administration on Aging, and points to future program and policy opportunities to build upon this base of support.

PROGRAM OPERATIONS

The National Family Caregiver Support Program offers grant flexibility to allow states to provide a continuum of caregiver services that best meet caregivers and individual needs. These may include information, assistance and other services. Services support family caregivers of persons age 60 and older and grandparents and relative caregivers of children not more than 18 years of age.

Implemented through the Department of Health and Human Services, Administration on Aging, and the *National Aging Services Network* (which includes the Administration on Aging, 56 state units on aging; 655 area agencies on aging, 244 tribal organizations; and almost 30,000 service providers), the NFCSP is an integral part of our nation's long-term care system.

SNAPSHOT OF THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM IN ACTION

... Communities reached out to over 3.8 million individuals with information...

... Provided access assistance services to approximately 436,000 caregivers, which significantly exceeds the agency targets to serve 250,000 caregivers...

States, tribes and communities across the country are making significant progress in implementing the NFCSP. Early findings show that initial expectations have been greatly exceeded.^a

Communities across the country:

- 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 Administration on Aging's 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.

^a Counts are duplicated across service categories.

States have utilized a variety of approaches to develop multi-faceted systems of support for family caregivers at the local level:

- Designing and financing strategies to help family members through direct services; financial compensation (see family-directed service options); tax incentives; and family leave policies.
- Establishing a new caregiver support program as a result of Title III-E implementation or leveraging existing programs and experience supported with other funds in order to maximize the effect of the NFCSP.
- Developing a single-point-of-entry for caregiver access.
- Establishing family-directed service options, including payment to family caregivers and policies allowing caregivers to hire family members.
- Pooling resources at the Area Agency level for joint information, outreach, and educational activities.
- Informing the community and special populations (rural, grandparents, low-income, minority, deaf, underserved, and limited or non-English-speaking caregivers) about the program through a variety of methods – press releases, fact sheets, newsletters, health fairs, town meetings, informational vans, caregiver handbooks, presentations, support groups, caregiver campaigns, workshops, technology-based resources, senior journals, caregiver resource sections in public libraries, conferences, caregiver Websites, and television and radio announcements.
- Developing new partnerships with employers, faith- and community-based organizations, rural health systems, national aging organizations and universities to expand services.
- Implementing caregiver education curricula; conducting in-depth workshops; developing resource libraries; and conducting a series of caregiver-training events. Statewide public education activities have included coordination with *Thou Shalt Honor*, a national PBS family caregiver documentary.

- Establishing or expanding kinship and grandparent-raising-grandchildren caregiver programs.
- Administering pilot programs to test family-first strategies and new models of service provision.

**SNAPSHOT OF THE
NATIVE AMERICAN
FAMILY CAREGIVER
SUPPORT PROGRAM
IN ACTION**

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 68 tribes received their initial funding in 2002.

*...4,230 Native
American caregivers
received one or more
caregiver support
services...*

- Since few programs for caregiver support are available within the tribe or in nearby communities, the vast majority of programs are building the infrastructure to support such a program.
- 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.
- Nearly two-thirds of the programs are providing support groups or individual counseling (64%).
- Over half the programs are providing caregiver training (58%).
- Caregiver conferences have been held by 28% of the programs.

**OLDER AMERICANS
ACT SERVICES
SUPPORT THE ROLE
OF FAMILY
CAREGIVERS**

Caregiver support is not provided in a vacuum. Many older people who receive assistance from family members also receive assistance from other sources. A typical source of support is provided through Older Americans Act (OAA)-funded home and community-based services such as home delivered meals, personal care, transportation and chore services. These services help lessen the burden on family caregivers and help them maintain their caregiving role in a healthy way. The following findings are from a survey of a random sample of 413 individuals who provide caregiver support to older people who also OAA-funded services in 2002⁴.

...96% were very or somewhat satisfied with the OAA services...

- Caregivers find OAA services to be vital in helping them support the older people they care for.
 - ◇ 86% reported that OAA services helped them provide care longer than they would have been able to without the services.
 - ◇ 69% reported that the services helped a lot in their efforts to provide care.
 - ◇ 96% were very or somewhat satisfied with the OAA services provided to the older person they served.
- Caregiver burden is significant.
 - ◇ 24% report difficulty providing care because of their own physical limitation.
 - ◇ 37% also care for someone else.
 - ◇ 33% are over 65 years old themselves.
 - ◇ 74% of the elders they care for are at least 75 years old.
 - ◇ 32% of the elders they care for are 85 or older.
 - ◇ 46% are working.

- Caregivers provide a variety of services for the elders they care for.
 - ◊ 88% provide transportation assistance.
 - ◊ 79% provide help with meals, laundry and household chores.
 - ◊ 73% provide help with financial matters.

CONTINUED IMPLEMENTATION CHALLENGES AND OPPORTUNITIES

- 86% of States report a need for additional caregiver support. The greatest need is for additional respite and supplemental service support.
- Some elders have family members living near to care for them under Title VI-C, however, a system is not yet in place to support long-distance family caregivers and elderly parents who are taking care of adult children with disabilities.
- Program operators expect these patterns to continue. Most State Units on Aging and Area Agencies on Aging expect further increases in the need for caregiver services and supports. As the program matures, AoA expects the NCFSP to meet caregiver needs to a greater degree. The AoA will continue to measure the degree to which it serves caregivers through the NCFSP and other OAA programs, and will use these data to support programmatic changes and future funding requests.

CAREGIVER SUPPORT: NEXT STEPS

The vast majority of individuals who need long-term care prefer to receive that care in their homes and by family members or friends. As our nation strives to provide more meaningful home and community-based options to these individuals, we must strengthen and maintain our support of the main resource upon which these options rely – family caregivers. This becomes an even more important issue to contend with in light of the aging of the baby boom population. Additional trends that may afford opportunities for progress in this area include states' efforts to balance their

long-term care systems, the shortage in the direct support workforce and the increasing visibility of consumer directed care options.

Promoting a More Balanced System of Long-Term Care

The NFCSP fulfills a key responsibility of the U.S. Department of Health and Human Services (HHS) in its role to implement the President's New Freedom Initiative. The New Freedom Initiative outlines a comprehensive plan to remove barriers to community living and participation for people with disabilities of all ages, including older people. One significant theme of public input received on the New Freedom Initiative was to strengthen support to family caregivers. In response, HHS developed an interagency workgroup to maximize resources dedicated to supporting family caregivers.

Another component of the New Freedom Initiative effort focuses on support to states as they create more balanced systems of long-term care between institutional and community-based options. Through the Real Choice Systems Change Grants, the Centers for Medicare & Medicaid Services has provided \$125 million to states in the past two years to support the development of home and community-based care. Another \$40 million is being provided to states this year. These grants have provided HHS an opportunity to promote attributes of states' long-term care systems that support independent living, of which caregiver support is one.

Addressing the Workforce Shortage

By 2050 our nation will need three times as many paid long-term care workers as are employed now to meet the needs of the aging baby boom generation.⁵ The need to retain existing long-term care workers, attract new workers, support state and local initiatives, and test new models of recruitment and retention of long-term care workers is urgent. Under the auspices of the NFCSP, the AoA can play a prominent role in increasing the number of volunteers providing caregiver support and recruit older workers and individuals with recent experience providing care to family members into the paid workforce

Expanding Consumer and Family Directed Care

Many individuals and families want to manage all or part of the decisions related to their service and support needs.⁶ In response, some states are pioneering consumer-directed service delivery

models. Under the NFCSP, some states allow direct payments to caregivers in the form of cash or vouchers to purchase services and supports to meet their needs.^b Recent studies of consumer-directed programs involving payment to family caregivers show that their satisfaction with consumer-directed services is strong.^{7 8} Moreover, participants' health and safety are not adversely affected.⁹ Beyond the desire to promote greater consumer autonomy and satisfaction, expanding consumer-directed caregiver programs offers one solution to the workforce shortage discussed above.¹⁰ A current thrust in state long-term care reform efforts include expanded opportunities and supports for caregivers to participate in consumer-directed models of service delivery.

BACKGROUND

The NFCSP is authorized under the Older Americans Act and is administered by the AoA. The AoA provides state units on aging (SUAs) Title III-E formula grants to work in partnership with local area agencies on aging (AAA) and faith- and community-service providers and Title VI-C formula grants to tribes. These grants are used to provide direct support services that best meet the range of caregiver needs. These may include, but are not limited to: information; assistance; individual counseling, support groups and training; respite; and supplemental services to family caregivers of persons age 60 and older and grandparents and relative caregivers of children not more than 18 years of age.

In fiscal year (FY) 2002, Title III-E funding for the NFCSP was \$141.5 million. Formula grants were made available to all U.S. states and territories to run programs that provide critical support, including home and community-based services, to help families maintain their caregiving roles. Additionally, competitive caregiver program demonstration grants were awarded to 39 organizations, agencies, research institutions, and faith-based organizations to 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.

Title VI-C funding in 2002 for the NFCSP was \$5.5 million. Formula grants were made available to 177 Indian Tribal Organizations to develop and operate family caregiver support programs. Additionally, competitive model caregiver program

^b Title III-E requirements stipulate that it is a state option to provide families additional assistance in directing services and supports.

demonstration grants were awarded to nine Indian Tribal Organizations, Alaska Native Organizations and Native Hawaiian Organizations to focus on prioritizing caregiver needs and addressing those needs, coordinating and leveraging services and program to support family caregivers, and developing quality standards for supportive services for family caregivers.

TITLE III-E IMPLEMENTATION

Since the enactment of the NFCSP in November of 2000, the AoA and the *Aging Network* has provided information to families that will help sustain them in their caregiving roles; educated the public on the importance of supporting family caregivers; improved access to services; reached out to special populations and caregivers who may not be connected to service delivery networks; and permitted employees to continue to contribute to the workforce. The AoA is also building new partnerships among informal caregivers, business and industry, and government to advance family caregiver support systems. These major technical assistance; consumer education, outreach, and advocacy; research and demonstration; and partnership development accomplishments are highlighted below. They are followed by a brief review of current AoA efforts to support family caregivers.

Technical Assistance

Technical assistance has been provided in the form of direct assistance to the national *Aging Network* (State Units on Aging, Area Agencies on Aging, Indian Tribal Organizations, and community service providers) to develop and expand programs that support informal caregivers. These accomplishments include:

- Creating a web page devoted to the NFCSP. The caregiver web site provides information to service providers, researchers, policymakers and advocates on the prevalence of family caregiving, the characteristics and needs of family caregivers, future trends in family caregiving, and offers program guidance in implementing the NFCSP.
- Commissioning over 20 issue briefs from prominent researchers and leading *Aging Network* professionals on topics and issues related to family caregiving and systems development. The issue briefs are posted on the NFCSP web site.

- Sponsoring the September, 2001 *NFCSP: From Enactment to Action* conference to highlight the new federal program. More than 700 representatives of the *Aging Network*, tribal organizations, service providers and others exchanged information and generated new ideas on family caregiving and systems development.
- Organizing a listserv to disseminate research-based information and to facilitate the exchange of information throughout the *Aging Network*.
- Commissioning a *Resource Guide to the NFCSP*, which brings together information gained from all of the above activities in a practical, user-friendly format. The guide features proven implementation strategies and approaches that the *Aging Network* may consider in carrying out the NFCSP.
- Conducting a *National Caregiving Satisfaction Survey* through the AoA as part of the Performance Outcomes Measure Project. This survey explores service, program and community differences.
- Conducting periodic individual and group technical assistance conference calls with the states and with Indian tribal organizations.
- Conducting periodic grantee meetings to share ideas and create collaborative strategies.
- Issuing program instructions to States on Older American Act State Plan Requirements to help states and tribes document how they are utilizing Title III-E funds and to ensure the effective use of these funds.

The AoA is currently expanding its technical assistance efforts to include identifying and disseminating state-of-the art knowledge and techniques that can be replicated by states, tribes and communities to expand program and service options that support caregivers; and is developing regulations on the NFCSP and updating ongoing reporting requirements.

**Consumer Education
Outreach & Advocacy**

The AoA has increased awareness of the National Family Caregiver Support Program – at the national, state, tribe and local levels – to ensure that all caregivers can take full advantage of available supportive and supplemental services. These accomplishments include:

- Publishing a brochure that provides background information on the program and information on how to locate and access an array of supportive services, in Spanish, Russian and Mandarin Chinese languages; and via national Public Service Announcements on television and radio, in English and Spanish languages.
- Producing fact sheets, a ten-step approach to identifying areas where caregivers may need support, an array of web site resources and related links, and information on how to locate and access an array of supportive services.
- Maintaining the *Eldercare Locator*, a nationwide toll-free and Internet accessible service, to help older adults and their caregivers connect to local services.

The AoA is currently expanding its consumer education and outreach activities to include sponsoring a national caregiver public awareness campaign and a series of public service announcements on the increasing role that caregivers play in the lives of all Americans; and to inform them of services available in their communities. In addition, the NFCSP web site is being redesigned and expanded to provide vital up-to-date information and assistance. Options for expanding technology-based interventions that are responsive to the needs of rural communities and special populations are currently being explored.

The AoA will continue to ensure that all consumer voices are heard, including states, tribal organizations, area agencies on aging, service providers, volunteers, older persons and their caregivers, as well as representatives of federal, state and local policymakers and the media. The Assistant Secretary for Aging is conducting a series of *Town Hall Meetings* and *Tribal Listening Sessions* throughout the year to bring caregivers into the program process and to support future program and policy development.

Research & Demonstrations

In FY 2002, \$7 million was designated to support 39 competitive research and demonstration projects under the NFCSP. These 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. As research findings, program data, and other vital information that informs strategies and approaches to support informal caregivers become available, they will be widely disseminated throughout the *Aging Network* in order to advance the family systems agenda.

The AoA-sponsored *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the NFCSP* summarizes the experiences of 10 states (Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas and Washington) in providing caregiver support services after the passage of the NFCSP. Released in November, 2002, this research report highlights commonalities and differences among the states, crosscutting themes, and integrating NFCSP funds into existing programmatic infrastructures to coordinate systems of care.¹¹

Building on these findings, the AoA is currently sponsoring a 50-state survey to profile the experiences of states in providing family caregiver support services to older people and younger adults with disabilities. Findings are expected to guide future program development and replication efforts at the federal and state levels, and identify crosscutting policy and service delivery issues to support family and informal caregivers.

Building New Partnerships

The AoA has advanced programs and policies that benefit family caregivers by working with other federal agencies and private sector organizations. These accomplishments include:

- Implementing the President'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. Nine federal agencies (including the AoA) have compiled a report for the President with a blueprint for change. This report includes 400 specific

solutions to improve community living for persons with disabilities, with specific goals for caregiver support.¹²

- Convening the *New Freedom Initiative Caregiver Support Workgroup* (a sub-group of the U.S. Department of Health and Human Services New Freedom Initiative workgroup established to respond to the president's Executive Order on Community-Based Alternatives). This interdepartmental workgroup plays a leadership role in identifying opportunities for collaboration and coordination across agencies within the Department of Health and Human Services in the area of family caregiver support. The workgroup is chaired by the AoA.
- Producing a *Compendium of HHS Services Caregiver Support Activities*, the first product of the New Freedom Initiative Caregiver Support Workgroup, and the first such compilation of its kind. The compendium catalogues existing efforts to support family caregivers across agencies within the U.S. Department of Health and Human Services and identifies opportunities for collaboration and coordination. It is a working document that will be updated on a regular basis as additional caregiver support activities are identified or developed.
- Collaborating with the Centers for Disease Control and Prevention to break down the barriers between the aging and public health networks, thereby making services more consumer-oriented and easier to access.
- Collaborating with the Centers for Medicare and Medicaid services, whose eligible beneficiaries can receive support for respite services.
- Assisting other government agencies and private groups in planning and development of conferences and meetings to advance systems of care for family caregivers.

The AoA is currently updating *The Resource Directory for Older People*, a resource tool for family caregivers, professionals, service providers, researchers and others who may be searching for information and resources on matters relevant to older adults. The AoA and the National Institute on Aging jointly sponsor this project.

TITLE VI-C

IMPLEMENTATION

In the short time since the first grants were issued, September 30, 2001, tribes have made significant progress in implementing the NACSP in the areas of technical assistance; consumer education, outreach, and advocacy; demonstration grants; and building new partnerships.

Technical Assistance

Major technical assistance accomplishments for Indian Tribal Organizations include:

- Participating in the September, 2001 *NFCSP: From Enactment to Action* conference to highlight the new federal program and to discuss family caregiving and systems development issues.
- Providing training and assistance at state Indian Council on Aging meetings and national meetings, such as the National Indian Council on Aging conference and the National Association of Area Agencies on Aging conference.
- Providing Technical Assistance Briefs in response to frequently asked questions.
- Conducting periodic conference calls with demonstration grant recipients to share ideas, create collaborative strategies, and ensure effective use of program funds.
- Providing guidance on formula grant application content.
- Conducting individual technical assistance calls in response to specific questions from grantees.

The AoA is currently expanding its technical assistance efforts to include identifying and disseminating state-of-the-art knowledge and techniques that are culturally appropriate and can be replicated by tribes to expand program and service options that support caregivers. In addition, regional staff training, strategies to improve consumer access to resources, and development of additional *Technical Assistance Briefs* are planned.

Consumer Education Outreach & Advocacy

Major consumer education accomplishments include:

- Conducting Tribal Listening Sessions to facilitate a dialogue between Native American caregivers and the Assistant Secretary for Aging regarding program implementation.

- Expanding the Tribal component of the *Eldercare Locator* to additional tribal locations.
- Informing Native American caregivers about the program and teaching Native Americans that caregiving is a public health issue. NFCSP and *Caregiver Survival Tips* brochures and the *Because We Care Caregiver Guide* have been distributed to grantees for use in their programs.

Demonstrations Grants

Tribal leaders from 70 Title VI grantee programs provided input on the design of the NACSP. By consensus, tribal leaders determined that 1) the combination of demonstration and formula funding would be the best approach for the program, and 2) the number of demonstration grants should be limited to eight to ten to provide maximum funding to the formula grants.

Nine tribal organizations each received \$100,000 in demonstration grants to develop and evaluate model caregiver support programs. These grants focus on prioritizing caregiver needs and addressing those needs, coordinating and leveraging services and programs to support family caregivers, and developing quality standards for supportive services for family caregivers. As demonstration findings and other vital information that informs strategies and approaches to support informal caregivers become available, they will be widely disseminated throughout tribal communities in order to advance the family systems agenda.

Building New Partnerships

The AoA Office for American Indian, Alaskan Native and Native Hawaiian Programs has been actively involved in building partnerships to advance the Native American Caregiver Support Program. Major accomplishments include:

- Establishing the AoA, *Indian Health Service, Centers for Medicare and Medicaid Services, and Administration for Native Americans Workgroup on Long-Term Care in Indian Country* to coordinate long-term care efforts throughout the U.S. Department of Health and Human Services.
- Co-sponsoring the *American Indian and Alaska Native Roundtable on Long-Term Care* in April 2002 with Indian Health Service and the National Indian Council on Aging. The Roundtable explored key issues in long-term care.

- Coordinating with the Centers for Medicare and Medicaid Services for the *Long-Term Care Educational Conference for Indian Country* held in December 2002.
- Partnering with the *User Liaison Program* at the Agency for Healthcare Quality and Research, Indian Health Service, and the Centers for Medicare and Medicaid Services to plan a workshop on long-term care policy issues that includes family caregiver issues.
- Partnering with other Tribal programs to develop: a caregiver manual for in-home use; a loan closet for caregivers to get equipment such as wheelchairs or walkers; a comprehensive referral system to other services within the Tribe; and a training resource (the Community Health Representative Program) to provide training to caregivers.
- Coordinating with other Native American Caregiver Programs and Area Agencies on Aging to provide staff and caregiver training, and conferences.
- Coordinating with area hospitals, local respite programs, and other local programs to provide referral services.
- Coordinating with colleges and universities, the Alzheimer's Association, the American Association for Retired Persons, and other organizations to provide training.
- Establishing a Caregiver Advisory Boards and Coordinating Committees to assist some programs in implementing and assessing their program.

MEETING THE NEEDS OF CAREGIVERS PERSONAL STORIES

Selected examples from family experiences illustrate how the NFCSP is making a difference in the American caregiving experience. By extending service options that are essential to strengthening informal caregiving, the NFCSP...

- **Helps families connect to services.**

A daughter who was commuting to college about 100 miles from home contacted the AAA staff about her concern for her family.

Her 83 year-old mother was caring for both a terminally ill, bedfast husband and a 57 year-old son with developmental disabilities. The AAA caregiver staff arranged for respite while the mother had surgery, supplementing what the daughter could provide. The AAA staff also contacted the county board of mental retardation/developmental disabilities to follow-up with the situation with the son with disabilities. Staff then worked with the mother to accept limited services from hospice for her husband. The daughter was able to continue working on her nursing degree during this crisis.

- **Promotes better care-related decisions.**

Mr. D is a 51-year-old male who resides in the District of Columbia and is the sole caregiver for his blind mother. Mr. D is employed outside the home, and consequently, worries about his mother during the day. For Mr. D, the educational seminars provided through the NFCSP are invaluable. He has attended each of the sessions offered, once every other month. At the seminars, Mr. D has learned about community resources, insurance issues and helpful tips from fellow caregivers. The opportunity to learn from other caregivers has helped him plan his mother's care and encouraged him to accept help for others.

- **Helps caregivers take a break.**

An 80-year-old caregiver is caring for her 102-year-old mother. She receives assistance with respite in the evenings so that she can rest prior to rendering care throughout the night. The respite services give her a break when she knows she has reached her limits so that she can continue to meet the day-to-day challenges of caregiving. When talking with this caregiver she will not tell you that this role is a chore or job, but will tell you that it is an honor to be entrusted with the care of her dear mother and a commitment that she is thankful for. She was selected Arkansas' Caregiver of the Year for 2001.

- **Allows caregivers to remain in the workforce.**

A man transferred his 90-year-old mother from the south to northern Minnesota this year. He was able to set her up in a senior high rise but did not realize until she was there that she needed so many support services. He had a new job that required him to be on the road several days a week and wasn't sure how this would impact her adjustment. The Caregiver program allowed for connections to be made to the state services for the blind, meals on wheels, friendly visitor program, and volunteer driver services.

Four months later the care recipient is making new friends in her building, is called and visited weekly, receives daily meals, had her appliances high-marked for ease of use and receives books on tape through the mail. When her son is on the road he is comforted in knowing his mother is receiving food, can manage her daily living and has transportation if needed for outings.

- **Supports long-distance caregiving.**

Long-distance caregiving is a difficult challenge for many adult children. In Minnesota several families use the NFCSP as a connecting point (phone/email/mail) for their loved ones since they (the adult children) live a town away, a state away or even across the country. Through the NFCSP, home visits are arranged for caregivers and distant caregivers are kept informed of the status of the care recipient. When family caregivers do visit, they readily receive information through the program.

- **Prevents unwanted out-of-home placement.**

Mr. and Mrs. B live in a rural Ohio community, and are trying to remain independent in their own home. Mrs. B is 81 years old and has difficulty walking, as well as limited use of her right arm. Her husband provides daily care for his wife despite his own physical problems. The Caregiver Support Program set up services for this couple two times a week. Having a nurse's aide come into the home allows Mr. B time to run errands without worrying about Mrs. B being left home alone. Mr. B states now he cannot imagine how they would cope without the assistance of the Caregiver Support Program.

- **Prevents foster care placement.**

An elderly Kentucky grandmother has taken over caregiving responsibilities for her eleven-year-old grandson. After providing this care for a number of years, the grandmother found herself in need of outpatient surgery that would involve about a week of recovery at home. Knowing that undergoing the procedure would severely limit her ability to provide care to her grandson the week following the operation, this grandmother had already postponed the surgery twice before. Hearing of the NFCSP, the grandmother contacted her local Area Agency asking if she and her grandson would qualify for some temporary assistance under our program. The agency was able to arrange for the help that the two of them needed. A home care worker was able to meet the housekeeping and chore demands of a household with a child present (preparing

snacks and meals, laundry, clean-up, and the like) and at the same time provide personal care assistance to the grandmother until she was better able to manage for herself. She was worried that without such help she might have had to seek out temporary foster care for her grandson, a less than ideal situation, since he had already suffered through a difficult separation from his natural parent, as well as protracted foster care, prior to his grandmother obtaining legal custody.

- **Reaches out to special populations and communities.**

Mrs. I is a 78 year old Japanese care recipient. Mrs. I is legally blind, has diabetes, and arthritis. She is prone to falls and is not able to strictly control her diet on her own, nor prepare her meals. She lives with her 47-year-old son, Jed, who is responsible for running a food shipping business in Alaska. He is the sole family caregiver. The family could only afford a few hours of respite help a week and due to demands of his business, Jed was unable to provide help to his mother during the day. The Alaska Caregiver Program provided the necessary funds and a Senior Companion to provide respite services during the week; the family private-pays for respite help on the weekends. What was a caregiving crisis for Jed is now a stabilized situation.

- **Addresses unmet caregiver needs.**

"I am a caregiver to my elderly mother who is a double amputee. I am a single amputee. We have lived in Rosebud Housing for seven years without a ramp. When the Caregiver Program was implemented on the reservation the staff assisted me by getting the proper forms for the local housing office. Within one week my mother and I had a ramp installed at our home after seven years without one." *White River, SD, Rosebud Sioux Tribe.*

END NOTES

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