



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



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

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Compassion In Action

2004





## FOREWORD

The Older Americans Act Amendments of 2000 authorized the creation of the National Family Caregiver Support Program to help many thousands of family members with the care of their older loved ones.<sup>a</sup> Although caregivers always have been an implicit responsibility of the *national aging services network* under the Older Americans Act, the National Family Caregiver Support Program makes this responsibility explicit and defines it to encompass those family and other caregivers supporting older individuals, as well as grandparents and older relatives caring for children. The National Family Caregiver Support Program bestows significant new authority and resources to reach these target populations with support services and make them a priority under the Older Americans Act.

Responsibility for implementation of the program rests with the *national aging services network* – The Administration on Aging, State Units on Aging, Area Agencies on Aging, Indian Tribal Organizations, and service providers. Intended primarily for this audience, this report highlights the significant progress made by states, tribes, communities, and public and private organizations throughout the country in implementing the program.

Among the report's noteworthy features are:

- National findings on the number of caregivers served;
- *Real-life* examples that illustrate how the program is making a difference in the American caregiving experience;
- Resources and examples to stimulate members of the *national aging services network* to pursue approaches that afford caregivers flexibility and assistance in meeting caregiver service needs.
- A concise narrative with references for further information provided through Web links, footnotes, and appendix materials; and
- Individual State exhibits that highlight examples of implementation approaches and provide program contact information.

The report is being directly disseminated to State Units on Aging, Area Agencies on Aging, Indian Tribal Organizations and selected national organizations and will be posted on the caregiver program website at: <http://www.aoa.gov/caregivers>. State Units on Aging and Area Agencies are encouraged to work together to make copies available to local service providers in their state.

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<sup>a</sup> Public Law 106-501, November 13, 2000.

As our nation strives to provide more meaningful home and community-based options, we must strengthen and maintain our support of the main resource upon which these options rely – family caregivers. As an integral part of our nation’s long-term care system, the National Family Caregiver Support Program fulfills a key responsibility of the U.S. Department of Health and Human Services in its role to implement the President’s New Freedom Initiative.

Early findings show that states, tribes and communities across the U.S. are making significant progress in implementing the National Family Caregiver Support Program and that initial expectations have been greatly exceeded. States and localities have demonstrated a great deal of creativity in forming new local partnerships, improving access to a wide ranges of services, conducting outreach to special populations, and providing flexible services that can respond to the unique needs of consumers.

The best way for us to comprehensively prepare for the aging of the baby boom population is to create incentives for all sectors of our society to actively be involved. The Administration on Aging aims to shape and address our future by building caring communities, and by expanding and providing community-based services.

I believe this report will be a useful tool for all those working to expand home and community services and supports to enable elderly individuals and persons with disabilities to live in the most integrated settings appropriate to their needs.

Josefina G. Carbonell  
Assistant Secretary for Aging

## ACKNOWLEDGEMENTS

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*For more information about home and community-based programs and services that support the well-being, health and independence of older persons and their caregivers, contact AoA's Center for Communication and Consumer Services at 202-619-0724. The Center directs and coordinates AoA's public information, education and outreach activities concerning our nation's large and growing aging population.*

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**THE OLDER AMERICANS ACT  
NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM**

***Compassion in Action***

*To support and train families at all stages of caregiving, the Administration on Aging provides community-based assistance through the National Family Caregiver Support Program. This network of community service providers, faith-based organizations, tribal organizations, State and local agencies on aging, and hundreds of thousands of volunteers informs caregivers that they are not alone, and that help is always available through counseling, support groups, training, respite care, and supplemental services... As we work to build a culture of service, responsibility, and compassion, caregivers continue to bring our families and communities together...*

*-President George W. Bush, National Family Caregivers Month Proclamation, 2002*

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## I. 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 and their caregivers. Developing service networks with a continuum of home- and community-based long-term care has become especially important, in order to better meet individual support needs and preferences for independence.

Although families and friends have traditionally provided the necessary assistance for older persons to remain in their homes and communities, they face ever-increasing demands on their limited time and other resources. Most family caregivers find providing care to their loved ones to be greatly rewarding. However, balancing careers, needs of other family members, and personal needs with the complexities of caring for frail, and sometimes cognitively impaired older persons, can be extremely challenging. Recognizing this, the National Family Caregiver Support Program (NFCSP) was created by Congress in the 2000 amendments to the Older Americans Act.

This report highlights the significant progress made by states, tribes, communities, and public and private organizations throughout the country in implementing the National Family Caregiver Support Program. Although this report was prepared primarily for the *national aging services network* to underscore the vital work they do everyday in support of older persons and their families, it can also be used to provide information to aging services long-term care policy makers. Ultimately, beneficiaries of improved home- and community-based long-term care are the American people.

## BACKGROUND

Nearly one out of every four U.S. households (23 percent or 22.4 million households) contain at least one caregiver for a relative or friend at least 50 years old.<sup>1</sup> The current system of long-term care has relied heavily on these informal supports to shoulder the financial, physical and emotional burdens of paying for and providing care to family members, thereby enabling older people to live independently in their homes and communities.<sup>2</sup> There is little debate about the critical role that families and other informal caregivers play in supplying informal support – about 80% of community care is provided by family caregivers, at an approximate economic value of \$257 billion (in 2000 dollars) annually.<sup>b 3</sup>

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<sup>b</sup> Lost productivity due to informal caregiving costs businesses \$11.4 billion annually. Informal caregivers personally lose approximately \$659,139 over a lifetime (\$25,494 in Social Security benefits; \$67,202 in pension benefits; and \$566,433 in forgone wages) (<http://www.aoa.gov/caregivers>).

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.<sup>4 5</sup> Because caregivers play such an important role in long-term care, 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.<sup>6</sup>

Supportive caregiver services can diminish caregiver burden,<sup>7</sup> permit caregivers to remain in the workforce<sup>8</sup> and prevent or delay more costly unwanted out-of-home placement for care recipients.<sup>9</sup> Families thrust into caregiving situations need accurate, timely information about services and options. Home and community-based services that are essential to strengthening informal caregiving include, but are not limited to, personal assistance; respite; home and vehicle modifications; assistive devices; caregiver training, education and support; day care; and consumer-directed services.<sup>10</sup>

Caregiving relationships are as varied as the faces of those receiving support – a child being raised by a grandmother; a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS.<sup>11</sup> Just as the types and intensity of caregiving tasks vary from household to household, so do familial roles and obligations.

Long-term care systems offering a continuum of service options allow for services to be better tailored to meet individual needs and preferences and to sustain family caregivers in their caregiving role.<sup>12</sup> The NFCSP, administered by the U.S. Administration on Aging provides an important opportunity to support and strengthen the role of informal caregivers and to bring together community agencies to meet the diverse needs of caregivers.

## **THE U.S. ADMINISTRATION ON AGING & THE NATIONAL AGING SERVICE NETWORK**

The Administration on Aging, an agency in the U.S. Department of Health and Human Services, is one of the nation's largest providers of home- and community-based care for older persons and their caregivers. The mission of the Administration on Aging is to ensure that older Americans have the opportunity to age with dignity, have choices in managing their own lives, and remain active and productive members of their families and communities. Created in 1965 with the passage of the Older Americans Act, the Administration on Aging is part of a federal, state, tribal and local partnership called the *national aging services network*. This network, serving about seven million older persons and their caregivers, consist of 56 State Units on Aging, 655 Area Agencies on Aging, 243 Indian Tribal and Native Hawaiian Organizations, at least 29,000 service providers, and thousands of volunteers. These organizations provide assistance and services to older individuals and their families in urban, suburban, and rural areas throughout the United States.

For nearly 40 years, the Administration on Aging and the *national aging services network* has played a leadership role in services innovation and in developing citizen-centered systems of health and long-term care at the state and local level, as evidenced by state units on aging having lead responsibility for managing at least one Medicaid home and community-based waiver in 31 states. The AoA understands the vital role informal caregivers play in home and community-based service systems and is developing effective and timely solutions to support America's families and to ensure that our nation's health and long term care system meets individual needs and preferences. The NFCSP embodies this compassionate spirit.<sup>c</sup> Assistant Secretary Josefina Carbonell has challenged the *national aging services network* to develop a NFCSP that:

- 1) Creates optimum flexibility and choices for consumers.
- 2) Partners with and improves access to faith-based and other community-based service providers to enhance support for older Americans and their families.
- 3) Renews the focus on intergenerational care, and
- 4) Increases access so every American will know about the NFCSP, particularly disadvantaged and hard-to-reach families.

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<sup>c</sup> See Appendix A for a list of *National Family Caregiver Support Program & Related Terms*.

## II. THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

The National Family Caregiver Support program (NFCSP) calls for the states, working in partnership with area agencies on aging and local community-service providers, and tribes to provide a continuum of caregiver services, including information, assistance, individual counseling, support groups, training, respite, and supplemental services. These caregiver support services are available to adult family members, or other individuals who are informal providers of in-home and community care to older persons. Caregiver support services are also available to grandparents or older individuals who are relative caregivers for a child, age 18 and under. Priority consideration for services is to be given to persons in greatest social and economic need, with particular attention to low-income older individuals, and older individuals providing care and support to persons 18 and under with mental retardation and related developmental disabilities.

There are three components to the NFCSP, including two direct service programs -- the National Family Caregiver Support Program (Title III, Part E) and the Native American Caregiver Support Program (Title VI, Part C) – and a research and demonstration program -- National Innovation Programs (Title III, Part E, Subpart 2). Funding is provided by population-based formulas to the states under Title III, Part E and to tribes under Title VI, Part C. The National Innovation Programs provides grants on a competitive basis to foster the development and testing of new approaches to supporting caregivers. It also provides funding for activities of national significance to promote quality and continuous improvement in support of caregivers through program evaluation, training, technical assistance, and research. The appropriations for the first three years of the NFCSP are provided in Table 1.

**TABLE 1. National Family Caregiver Support Program Appropriations**

<b>Congressional Appropriations</b>	<b>FY 2001</b>	<b>FY 2002</b>	<b>FY 2003</b>
State Grants, Title III, Part E	\$113,981,000	\$129,192,000	\$141,574,000
Native American Grants, Title VI, Part C	\$5,000,000	\$5,500,000	\$6,209,000
National Innovation Programs *	\$6,200,000	\$6,800,000	\$7,451,000
<b>Total</b>	<b>\$124,981,000</b>	<b>\$141,492,000</b>	<b>\$155,234,000</b>

Source: The U.S. Administration on Aging, Office of Budget & Finance.

\* The National Innovation Programs are effective for three fiscal years after the date of the enactment of the Older Americans Act Amendments of 2000.

## SERVING FAMILY CAREGIVERS

The NFCSP provides a multifaceted system of support services that includes five basic service categories – information; assistance; individual counseling, support groups and training; respite; and supplemental services. While overall leadership and guidance is provided by the Administration on Aging (AoA), the NFCSP offers flexibility to allow states and tribes to provide services that best meet caregiver and individual needs within these service categories:

### **Information**

Information about available services is power to anyone struggling with a long-term care situation. Families thrust into these situations need accurate information about services and options. Through information and outreach efforts at the community level, AoA seeks to educate older people and their caregivers about the benefits and services available to them. The NFCSP offers a broad range of information resources to help caregivers gain access to support services in a targeted and timely manner. Information about caregiver programs are aimed at large groups of people who may benefit from other services directed towards individuals caregivers.

- In fiscal year 2002, states, tribes and communities across the country have provided over 4.0 million individuals with information about caregiver programs and services.

### **Assistance**

Assistance to caregivers in gaining access to supports is vital to helping individuals remain in their homes and communities. The NFCSP offers an opportunity for individual one-to-one contact to assess the problems and capacities of caregivers and to link caregivers to the opportunities and services available. Assistance may be accessed via care coordination in situations where the older individual or their caregiver experiences diminished functional capacity, personal conditions or other characteristics which require the provision of services by formal providers. Activities such as case management include assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services among providers, and follow-up and reassessment as required. Access also includes referral services and other information targeted to individual caregivers.

The NFCSP is reaching out to special populations and caregivers who may not be connected to service delivery networks. The *Eldercare Locator*, for example, is a service that helps people connect to local resources. Sponsored by the AoA, this service is available through a toll free number, 1-800-677-1116, or online at <http://www.eldercare.gov>.

- In fiscal year 2002, states, tribes and communities across the country have provided assistance in accessing services to approximately 440,000 caregivers.

### **Individual Counseling, Support Groups, and Training**

Advice and guidance made available to caregivers through the NFCSP can minimize the negative financial, physical and emotional consequences of caregiving. Caregiving is stressful in its own right, and even more so when combined with other personal demands and competing priorities. In some cases, emotional stress can lead to depression, thereby impairing a caregiver's ability to provide care. Informal caregivers can become so overwhelmed with their caregiving responsibilities that they neglect their personal health and life.<sup>13</sup> The NFCSP provides opportunities for caregivers to talk about these challenges, with counselors and peers in similar situations, so they are able to make better care-related decisions and better cope with problems or unique situations that may arise.

Training and instruction made available to caregivers through the NFCSP can diminish the negative consequences associated with caregiving as well. Performing informal caregiving tasks can be physically demanding, especially for those individuals who require assistance with activities of daily living (bathing, dressing, feeding, toileting, and assistance with walking or transferring). Proper caregiver training, such as appropriate lifting techniques for transferring a loved one from a chair to a bed, protects the care recipient and the caregiver from injury. Moreover, well-trained informal caregivers are less likely to rely on more costly, formal supports.<sup>14</sup> The NFCSP helps caregivers acquire the necessary skills to be able to perform their caregiving duties.

- In fiscal year 2002, states, tribes and communities across the country have served almost 182,000 caregivers with counseling, support group and training services.

### **Respite Care**

Temporary, substitute supports or living arrangements to provide a brief period of relief or rest for caregivers can be provided in the form of in-home respite, adult day care respite, or institutional respite for an overnight stay on an intermittent, occasional or emergency basis. Respite services are most often requested by caregivers when they become ill and cannot perform their normal care-related responsibilities; when caregivers perform intense support activities for persons with intellectual disabilities, developmental disabilities, or dementia; and/or when the caregiver simply needs a night or weekend off to avoid burnout or to take care of their own personal needs and priorities. Older Americans Act Title III-E requirements stipulate that the care recipient must have two or more activities of daily living limitations or a cognitive impairment for the caregiver to be eligible for respite services. The NFCSP helps caregivers who need a break, take a break. These intermittent service options revitalize caregivers and allow care recipients to remain at home.

- In fiscal year 2002, states, tribes and communities across the country have provided respite to over 76,000 caregivers.

## **Supplemental Services**

Supplemental services are caregiver-centered and offered on a limited basis to compliment the care provided by caregivers. They are flexible and responsive to the unique and often diverse needs of families. As defined by the state, these service options may include, but are not limited to, home or vehicle modifications, assistive technologies, emergency response systems, equipment/supplies, transportation services, legal and financial planning and family-directed services. Older Americans Act Title III-E requirements stipulate that the care recipient must have two or more activities of daily living limitations or a cognitive impairment for the caregiver to be eligible for supplemental services. Title III-E requirements also stipulate that it is a state option to provide families additional assistance in directing services and supports. By providing maximum flexibility and opportunities of greater choice for families, the NFCSP allows a caregiver's situation to often dictate the solution.<sup>15</sup>

- In fiscal year 2002, states, tribes and communities across the country have provided supplemental service to over 56,000 caregivers.



## NATIONAL IMPLEMENTATION FINDINGS

### Numbers of Caregivers Served Across the United States

States and tribes are making significant progress in implementing the NFCSP. Initial expectations have been greatly exceeded. In fiscal year 2002, states, tribes and communities across the country have:<sup>d e f</sup>

- Provided over 4.0 million individuals with information about caregiver programs and services;
- Provided assistance in accessing services to approximately 440,000 caregivers, significantly exceeding the Administration on Aging's target of 250,000 caregivers;
- Served almost 182,000 caregivers with counseling and training services;
- Provided respite to over 76,000 caregivers; and
- Provided supplemental services to over 56,000 caregivers.

The AoA Strategic Action Plan specifically calls for an increase in the number of families who are supported in their efforts to care for their loved ones at home and in the community. To accomplish this goal, AoA is strengthening its capacity to provide information to families that will help them in their caregiving roles, educating the public on family caregiving issues and programs; supporting the *national aging services network's* role in helping family caregivers; and partnering with other federal agencies and private sector organizations to promote policies, programs, and activities that support family caregivers. The AoA provides consumer outreach and education, technical assistance to the *national aging services network*, research and demonstration opportunities, leadership, and advocacy in implementing, managing, and evaluating the NFCSP.

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<sup>d</sup> Counts are duplicated across service categories. Forthcoming tabulations include unduplicated counts.

<sup>e</sup> The AoA collects data on "units of service" across service categories. The actual units of service provided under a caregiver category can vary significantly. For example, respite services could include hours of Adult Day Care, meals, rides, etc. Analysis of these data are forthcoming.

<sup>f</sup> The figures presented in this report are final year-end calculations for FY 2002.

## Consumer Outreach and Education

The AoA has increased awareness of the NFCSP 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:

- Listening to older people and our partners who serve them through town hall listening sessions and conferences across the country. The AoA convened six town hall listening sessions in 2003 in Miami, FL; Chicago, IL; Orange County, CA; Tempe, AZ; Baltimore, MD; and Charlotte, NC to hear from older people, their families and caregivers, along with members of the *national aging services network* on critical issues, including how can we build upon the initial success of the NFCSP and expand access to information, make services more consumer-friendly, and allow caregivers more choices. A recurring message heard at all the sessions was the considerable physical demands, emotional distress, and losses caregiver experience. Another message heard in community after community was that the NFCSP is “the best program the government provides because staying at home is what both the caregiver and those who need caregiving overwhelmingly prefer.”
- Conducting national Tribal Listening Sessions to facilitate a dialogue between Native American caregivers, tribal leaders, program directors, and the Assistant Secretary for Aging regarding program implementation.
- Sponsoring two national conferences to promote excellence in the NFCSP. More than 700 representatives from the *national aging services network* participated in the September 2001, NFCSP: From Enactment to Action conference. More than 1,000 participated in the September 2003, National Summit on Creating Health and Caring Communities. Both conferences promoted policy and program changes at the state, tribal and local level that will make the long-term care system more balanced and more responsive to the needs and preference of older people and their family caregivers. These conferences also provided an opportunity for information exchange and highlighting innovative programs throughout the country.
- Providing expert information on evidence-based caregiver support services to increase the knowledge and skills of the *national aging services network* and support their role in helping family caregivers. Select information includes:
  - Creating the NFCSP Web site to provide timely information to service providers, researchers, policymakers and advocates on a wide range of caregiver issues.
  - Commissioning over 20 issue briefs from prominent researchers and leading *national aging services network* professionals on topics and issues

related to family caregiving and systems development. The issue briefs are posted on the NFCSP web site.

- Organizing a listserv to disseminate research-based information and to facilitate the exchange of information throughout the *National aging services network*.
- Commissioning a *Resource Guide on the NFCSP* to provide strategies for program implementation and approaches that the *national aging services network* may consider in carrying out the NFCSP (available on-line at: <http://www.aoa.gov/caregivers>).

### **Technical Assistance for the *National Aging Services Network***

The AoA supports the *national aging services network's* role in helping family caregivers by providing technical assistance that can be used by states, tribes, and communities to design and implement programs and services that support caregivers. Examples include:

- Conducting periodic individual and group technical assistance conference calls and on-site visits with States and Tribes.
- Conducting regional and other 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.
- Developing program materials for use by states and tribes. This has included publishing a NFCSP brochure on how to locate and access an array of supportive services. This brochure has been published in English, Spanish, Russian and Mandarin Chinese languages. Other materials include fact sheets, a ten-step approach to identifying areas where caregivers may need support, an array of Website resources and related links, and information on how to locate and access an array of supportive services.
- 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.
- Providing speakers and other assistance to agencies and private organizations in planning and developing conferences and meetings to advance systems of care for family caregivers.

- Developing and disseminating the *National Family Caregiver Month Promotion Kit*.
- Maintaining the *Eldercare Locator*, a nationwide toll-free and Internet accessible service, to help older adults and their caregivers connect to local services.

### **Research and Demonstration Opportunities**

The NFCSP provides the opportunity for developing innovative approaches and activities of national significance in providing caregiver support and services. These applied research and demonstration projects help to build the evidence base for “what works” and “does not work” in sustaining the efforts of families in their caregiving roles. They also help provide the tools and strategies that support the *National aging services network* in problem solving and decision-making. Of particular interest is the development and testing of new approaches to particular groups of caregivers, including low-income caregivers, minority caregivers, male caregivers, and geographically distant caregivers, as well as linking family support programs with programs for persons with mental retardation or related developmental disabilities and their families. Upon completion of these projects, the AoA will partner with the grantees to disseminate the results of these projects in useful, understandable formats that enhance the application of the results in a variety of situations and settings.

In addition to providing grants for research, the AoA conducted a National Caregiving Satisfaction Survey as part of the AoA Performance Outcomes Measure Project. This survey was a random sample of 413 individuals who provided caregiver support to older persons who also receive OAA funded services in 2002.<sup>16</sup> The results provide insight into the caregiving situation of current AoA program participants. Not surprisingly, the caregivers reported that OAA services were vital in helping them care for their loved ones. Nearly all the participants (96%) were very or somewhat satisfied with the OAA services provided to the older person they cared for and 86% reported that OAA services helped them provide care longer than they would have been able to without the service. The AoA will continue to assess the outcomes of the NFCSP.

### **Leadership and Advocacy**

AoA promotes the dignity and independence of older people, their families and caregivers through interactions with Congress, state, tribe, community leadership, partnerships with agencies and organizations, and consumers. In implementing the NFCSP, the AoA provided leadership and advocacy in various ways, including:

- Partnering with other federal agencies and private sector organizations to promote policies, programs, and activities that support family caregiving as an integral component of home and community-based long-term care.

- 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 solutions to improve community living for persons with disabilities, with specific goals for caregiver support.<sup>17</sup>
- Convening the *New Freedom Initiative Caregiver Support Workgroup* (a subgroup 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 (a copy of the compendium is available at: <http://www.aoa.gov/caregivers>).
- Collaborating with the Centers for Disease Control and Prevention (CDC) to help 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 (CMS), whose eligible beneficiaries can receive support for respite services. With assistance from the National Alliance for Caregiving and the AoA, CMS has produced two on-line resources: 1) *Medicare Basics: A Guide for Caregivers* to guide caregivers through 8 decision points in the health care process; and 2) *When Employees Become Caregivers: A Manager's Workbook* to outline issues that affect employees.
- Partnering with the Indian Health Service (IHS) and CMS to promote policies, programs, and activities that support family caregiving in Native American communities as an integral component of home and community based long-term care. Joint activities included:
  - Establishing the AoA, IHS, and CMS workgroup on long-term care in Indian Country to coordinate long-term care efforts throughout HHS.

- Co-sponsoring the American Indian and Alaska Native Roundtable on Long-Term Care in April 2002.
- Coordinating with CMS 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 Research and Quality, IHS and CMS to convene a workshop on long-term care policy issues that include family caregiver issues in Bismark, ND, in July 2003.
- Testifying before Congress and in other public forums on issues faced by older Americans and their caregivers. In her testimony before the Senate Committee on Aging, Assistant Secretary Carbonell reported that the caregiver program is creating a new way of doing business in the aging network by focusing on caregivers, not only care recipients. It is promoting creativity at the state and local level, while allowing consumers to have choices. The Assistant Secretary charges that we must work together to develop a comprehensive approach to health and long-term care that focuses on the community and truly reflects the needs and preferences of older Americans.

### **SNAPSHOT OF THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM IN ACTION**

A profile of the NFCSP in each state is provided in Appendix D.<sup>8</sup> A review of these profiles indicate that States have utilized a variety of approaches to develop multi-faceted systems of support for family caregivers at the local level.<sup>18</sup> Early implementation activities include:

- 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.
- Pooling resources at the Area Agency level for joint information, outreach, and educational activities. This includes enabling the NFCSP to have clear recognition throughout the state as a result of outreach efforts and public awareness campaigns.
- 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,

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<sup>8</sup> Data are from new, untested systems. State comparisons should not be made.

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.
- Establishing or expanding kinship and grandparent-raising-grandchildren caregiver programs.
- Identifying NFCSP services as *essential elements* of comprehensive caregiver support.
- Adopting and/or establishing family-directed service options, including payment to family caregivers and policies allowing caregivers to hire family members.
- Designing and financing strategies to help family members through direct services; tax incentives; and family leave policies.<sup>h</sup>
- Administering pilot programs to test “family-first” strategies and new models of service provision.

### CONTINUED IMPLEMENTATION CHALLENGES

The National Association of State Units on Aging (NASUA) in collaboration with the AoA is assisting State Units on Aging in developing statewide caregiver support programs that are integrated with home- and community-based services programs, accessible, flexible, consumer-directed and culturally competent. In their AoA-sponsored innovation grant, NASUA conducted a series of teleconferences with 30 State Unit on Aging representatives in 25 states to learn more about program implementation. The program implementation challenges are identified in the report, *The Aging Network Implements The National Family Caregiver Support Program*.<sup>19</sup> These continuing program implementation challenges include:

- Assisting case managers, program managers, and direct care staff to more readily *accept* the caregiver as the client.

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<sup>h</sup> To access legislative information, see this Federal link: <http://thomas.loc.gov>

- Developing comprehensive programs with limited budgets.
- Reaching and serving caregivers in all areas of the state, especially rural areas.
- Reaching employed caregivers and employers of working caregivers.
- Reaching caregivers at a point when they are most likely to accept help and before they are in crisis.
- Gaining a better understanding of the dynamics at work in caregiver situations and how to handle family conflict.
- Balancing flexibility with the need for structure in the design of the NFCSP.
- Meeting the match requirements associated with the NFCSP at a time when most states are experiencing severe budget challenges.
- Reaching out to and serving grandparents and acknowledging them as legitimate consumers of caregiver services.
- Developing ways to help caregivers self-identify and recognize the need for help.
- Striking the right balance for data collection.
- Responding to differences in Area Agencies on Aging program resources and the impact on family caregiver support program implementation.
- Ensuring that each of the NFCSP services is offered and provided.
- Coordinating state programs with the new NFCSP while avoiding duplication of services and conflicts in program administration.
- Developing culturally sensitive service options for all caregiver populations.

Program operators expect these patterns to continue. Most State Units on Aging, Area Agencies on Aging, and Indian Tribal Organizations expect that reliance on caregivers will continue to grow along with the needs of caregivers for service and support. 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.



### III. INNOVATIVE SOLUTIONS

A three-year National Innovation Program is a critical component of the NFCSP. The Innovation Grants Program provides grants on a competitive basis to foster the development and testing of new approaches to sustaining the efforts of families and other informal caregivers of older individuals. Activities of National Significance, provide grants to carry out activities of national significance to promote quality and continuous improvement in the support provided to family caregivers through program evaluation, training, technical assistance, and research.

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. This section provides examples of discretionary grants in each of these priority areas. Information on all National Innovation Grants and Activities of National Significance is reviewed in the publication, *Promising Practices in the Field of Caregiving*, which is available on the AoA website at: <http://aoa.gov>.<sup>20</sup>

#### SYSTEMS DEVELOPMENT

##### Adapting Existing Service Systems

The New Jersey Department of Health and Senior Services is expanding the *NJ EASE* (Easy Access Singly Entry) system for senior services by adding a caregiver service component that includes a caregiver assessment and care planning tools; a staff caregiver training curriculum; policies, critical pathways and service protocols to guide consumer decision making and worker actions; and a caregiver resource website. This project is being demonstrated in three New Jersey counties and includes a controlled experimental design evaluation.

##### Care Management

Mid-County Senior Services of Pennsylvania is adding caregiver care management to its adult day services to create *Adult Day Services Plus*, a program responding to the needs of both the impaired older participant and the family caregiver. The *Adult Day Services Plus* model is testing care management tools that facilitate targeting where caregiver support is needed; designing plans of care for the caregiver that are integrated with the care plan of the care receiver; and delivering support in ways to which the caregiver is receptive. This model builds on the care management practice of the Area Agency on Aging's Family Caregiver Support Program. An impact evaluation will compare *Adult Day Services Plus* caregivers to those who receive traditional Adult Day Services. A program replication manual is planned.

## SERVICE COMPONENTS

### **Assistance/Support/Education**

Contra Costa County Aging & Adult Services Bureau in California is testing a model to support, educate and empower family caregivers of older persons (60+) whose care recipient chooses to transition back to the community or remain in a skilled nursing facility. A team of professionals (social worker, public health nurse, ombudsman, advocacy and support specialists, and independent living specialist) provides varying levels of care coordination to maximize the family caregivers' ability to keep their family members in the most integrated and appropriate setting possible. The working relationship between the professional team and the family caregiver continues until a caregiving situation stabilizes, or until other support systems are in place.

### **Counseling**

The Pennsylvania State University Gerontology Center and The Benjamin Rose Institute of Ohio are demonstrating a program of counseling to family caregivers and their care recipients in the early stages of dementia. Through positive communications and active program participation, care recipients and their family caregivers are gaining a better understanding of available services and preferences for care.

### **Training**

The Mather Institute on Aging in Illinois is implementing a regional family caregiver education project to deliver a cadre of experienced trainers to work with local aging service providers to improve caregiver outreach, service referrals and follow-up. As of this writing, 100 individuals have been trained and another 30 are on a waiting list to participate in the next "train-the-trainer" program. These trained class leaders have conducted 37 *Powerful Tools for Caregivers* classes for 360 caregivers. Early findings suggest the classes have made a positive difference in caregivers' lives. Upon completion of the classes, caregivers are better able to care for themselves and avoid or minimize the ill effects of caregiving. The *Powerful Tools for Caregivers* model is being tested among faith-based communities.

### **Respite**

The Alliance for Aging in Florida is demonstrating a 24-hour crisis respite and referral system for caregivers of elders and adults with disabilities. Early findings indicate this demonstration is increasing flexibility and convenience of current services, providing crisis respite for elder caregivers of children and adults with disabilities, recommending ways to reduce caregiver stress, and minimizing or preventing future crisis events. As of this writing, over 1,400 caregivers have received services. A state-supported media campaign included 17 billboards, 2000 radio ads, and a series of public service announcements.

## LINKAGES TO SPECIAL POPULATIONS AND COMMUNITIES

### **Ethnically and Culturally Diverse Populations**

Investigators at the Pima Council on Aging in Tucson Arizona are developing a model caregiver assistance program, *Cuidando con Confianza* (Caring with Confidence), that is culturally and linguistically appropriate for its predominantly Mexican American population. Twenty-one focus groups have explored: cultural practices and attitudes pertaining to caregiving; outcomes of the caregiving experience; methods for reaching the caregiving community; community workshop interests; and the types of formal services that are used and potentially could be used by caregivers. Support groups and informational workshops focus on home and personal safety issues for elders and caregivers. A bilingual resource manual offers a comprehensive listing of resources to assist elders and caregivers to access services, including a listing of agencies with bilingual staff available to assist Spanish-speaking clients.

### **Caregivers of Deaf, Late Deafened, and Hard of Hearing Elders**

The Massachusetts Department of Elder Affairs and the Commission for the Deaf and Hard of Hearing are demonstrating the benefits of a social day care program tailored to the needs of culturally deaf elders' and their caregivers. Training centers have made available assistive technology information, videos, manuals and resource lists to assist elders with a hearing loss and their family caregivers gain access to necessary services and supports. For a population that has traditionally been *underserved*, early findings reveal that the program is meeting the needs of families caring for an elder who is hearing impaired. Families are receiving information and referral assistance, transportation assistance, and interpreting assistance.

### **Grandparent and Relative Caregivers**

The United Cerebral Palsy of Southern Arizona is increasing service to grandparents and older caregivers who are raising children with mental retardation or developmental disabilities. The *Aging Caregivers and the Exceptional Child* project is identifying barriers to access and implementing a voucher system to improve access to services. A *Special Needs and Behavioral Health Resource Guide* has been developed to provide information and service access resources. The *Guide* will be included in a *Handbook for Grandparents Raising Grandchildren* and will be widely disseminated. In addition, videos addressing legal custody issues, options and case studies; and a documentary about a grandmother raising grandchildren with special needs will be widely disseminated. Educational and resource materials will be condensed for use in public service announcements.

The Catholic Family Center *Kinship Care Resource Network* of New York and area service partners have joined forces to create an accessible, comprehensive continuum of services for kinship care families in the Rochester area that are accessible from a single entry point – case coordination and management; legal consultations and direct services; support groups; educational workshops and presentations; counseling; and emergency services. As of this writing, *Kinship Care* has worked with over 100 caregivers (grandparents raising their grandchildren) and over 250 professionals to improve services and supports to families.

### **Caregivers of Adult Children with Mental Retardation/Developmental Disabilities**

The Pennsylvania Department on Aging is piloting a consumer-driven support system in two counties for elderly primary caregivers of adult children (age 19-59) with mental retardation and/or developmental disabilities who reside in the same household. This project supports the primary related caregiver and family in ways that are specific to his or her needs, reimbursing them for legitimate caregiving-related expenditures (supplies, goods, and/or services). The strength of this program lies in its flexibility to allow the caregiver to decide how to use the reimbursement (subject to family household income and program benefits ceiling). Local Area Agencies on Aging provide core services, but services are not restricted to those provided by these agencies. An intake form will be used to evaluate caregiver required service information, demographic data and needs assessment. This project is modeled after the Pennsylvania State Family Caregiver Support Program, operating statewide since 1990.

The Illinois Department on Aging is providing supportive services to frail older caregivers who are the parent, legal guardian or family member caring for an adult child with developmental disabilities. This project maximizes independence by using a holistic family approach to service support and the use of joint waivers and shared resources with the potential of cost cutting.

### **Rural Caregivers**

Caregivers are more likely to use information, support and training services when a need is validated by a trusted healthcare provider and the assistance is personally tailored to their needs. The Eastern Area Agency on Aging, in Bangor, Maine is demonstrating that primary health care is an effective and efficient point of caregiver intervention in a rural setting. As of this writing, nearly 6,000 adults have been screened during routine visits to their primary care practitioner office to determine whether they are providing care for an older adult, whether they felt stressed or burdened by their responsibility, and whether they wanted to be contacted by a caregiver specialist for assistance. Early findings suggest that approximately 7% of these adults were referred for services.

## **FIELD-INITIATED DEMONSTRATIONS TO DEVELOP & TEST NEW APPROACHES TO SUPPORT CAREGIVERS**

### **Programs to Provide Maximum Flexibility**

The Georgia Division of Aging Services is increasing service options for Georgia's elderly population by developing and implementing five self-directed care voucher programs in non-Medicaid home and community-based service settings that can be replicated in other states. Caregivers and care recipients are equally involved in program-related decision making. Consumers have the option of choosing to receive services through the traditional service delivery system, or may elect to participate in the self-directed voucher program. Participants in the self-directed program, submit vouchers to a third party for payment, either a designated Area Agency on Aging or its subcontractor. The *Caregiver Support and Satisfaction Survey*, currently in use by states participating in the AoA's Performance Outcome Measurement Project (POMP), will be administered to evaluate the effects of self-directed care.

### **Programs to Provide Health Care to Caregivers in Their Home**

The Philadelphia Corporation for Aging is developing a model health care and training intervention that targets African American daughters serving as caregivers. Nurse Practitioners and Social Workers collaborate to identify health issues of concern and caregiver challenges in order to improve the caregivers' quality of life, health status and caregiving skills. Preliminary findings indicate that African American caregivers are empowered to take charge of their own health and well-being. In instances where caregivers had no medical coverage or primary care physician, they received assistance in accessing resources and services. A protocol is being developed to guide other organizations in replicating this intervention for African Americans or other minority caregivers. Outcomes will be measured using the *Zarit Burden Scale* and the *Comprehensive Options Assessment Form*.

### **Employed Caregivers**

St. Andrews At Home Services in Missouri is developing a model cost-effective eldercare management services program, *The Caring Workplace*, to allow employed caregivers to provide quality care and continue working. The project has established a pilot project to evaluate alternative eldercare approaches and provide assessments and services to caregivers. As of this writing, 11 major corporations have been recruited in the St. Louis area representing varied disciplines (health, education, technology, biotechnology, manufacturing, retail, financial services and government). These businesses range in size from 300 to 3,000 employees with a total of nearly 15,000 employees currently served. Eldercare management services include one-on-one caregiver assessments, home and safety assessments, consultation, and follow-up visits. Each site offers educational programs on aging issues and how to access community resources, referral resources, and emotional and peer supports. Over 75 presentations on

working-caregivers have been made in the St. Louis area. This project will produce a comprehensive workplace model in which employed caregivers can balance family and work life more effectively, due to the collaboration of employers and community agencies. The model will be replicated and disseminated nationally through professional and business associations, and via the project website.

## **NATIONAL PROJECTS THAT ENHANCE THE DEVELOPMENT OF CAREGIVER PROGRAMS**

### **Technical Assistance**

The National Association of State Units on Aging in the District of Columbia is providing technical assistance to State Units on Aging to develop state family caregiver support programs that are integrated with home and community-based services programs, accessible, flexible, consumer-directed and culturally competent. Experts representing policy, research, administration and advocacy perspectives are generating new approaches for improving the operation of family caregiver support programs.

The National Association of Area Agencies on Aging is bringing together the *Aging Network* and health care providers to raise awareness of caregiving issues and local services available to caregivers among physicians. As of this writing, 120 Area Agencies on Aging have provided information about caregivers and caregiver services to their local physicians. A national awareness campaign is planned to further *Making the Link*.

### **Resource Materials for the *National Aging Services Network***

*Transportation Solutions for Caregivers*, administered by Easter Seals, has produced a caregiver transportation toolkit that includes a video, informational booklet and list of helpful products and resources for family caregivers and volunteer drivers. Toolkits are available in English and Spanish, and in closed and open-captioned formats. A facilitator's manual may be used to guide group instruction. Information and referral roundtables provide a forum for collaboration among several national organizations to improve service to caregivers, older adults, and communities.

### **Training for the *National Aging Services Network***

Generations United has established the *National Center on Grandparents and Other Relatives Raising Children* to provide technical assistance and training to the *Aging Network*. As of this writing, the national network of expert trainers have conducted eight trainings around the country and delivered 34 presentations at local, state, and national conferences on issues affecting grandparent and relative caregivers of children. A series of fact sheets, including service-related information, have been made available for distribution.

The American Society on Aging is collaborating with the American Nurses Association, the National Association of Social Workers, and the American Occupational Therapy Association to increase the skill and knowledge of their members who provide professional services to family caregivers and to link these groups to the *Aging Network*. As of this writing, five web-based and teleconference seminars on *Meeting the Needs of Family Caregivers* have reached audiences up to 1000 individuals per seminar. Outreach efforts to provide information to 500,000 nurses, social workers and occupational therapists are expected to be obtained at the end of this three-year grant.

## **Research**

The AoA is currently sponsoring a 50-state survey to profile the experiences of states in providing family caregiver support services to the elderly and younger adults with disabilities.<sup>21</sup> The San Francisco-based National Center on Caregiving at the Family Caregiver Alliance is surveying state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid waivers, state-funded home and community-based services with a family caregiver component and state general fund programs that have a caregiver-specific focus to advance family caregiver systems development in the United States. Findings from this research will expand the experiences of states, beyond those identified in this report.

#### **IV. THE NATIVE AMERICAN CAREGIVER SUPPORT PROGRAM**

The Native American Caregiver Support Program (NACSP), established under Title VI, Part C, assists American Indian, Alaska Native and Native Hawaiian families caring for older relatives with chronic illness or disability and grandparents caring for grandchildren. The NACSP is similar to the NFCSP in that tribes offer direct services that best meet the range of caregivers' needs including, information; assistance; individual counseling, support groups and training; respite; and supplemental services. The NACSP differs from the NFCSP in that there is no requirement for matching funds and no limit on funds for support services to grandparents caring for grandchildren. In addition, Tribes are able to decide the age at which a member of the Tribe is considered an elder and thus, eligible for services under the program. A core value for the NACSP, expressed by Tribal leaders, is that the program should not replace the tradition of families caring for their elders. Rather, it provides support that strengthens the families' caregiver role.

In FY 2003, formula grants were made available to 177 Indian Tribal Organizations to develop and operate family caregiver support programs. Additionally, competitive model caregiver program 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 programs to support family caregivers, and developing quality standards for supportive services for family caregivers.

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

American Indian, Alaska Native and Native Hawaiian organizations have seized the opportunity the NFCSP presents to develop systems of support that meet the unique needs of their family caregivers.

- 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.
- Reported barriers to program implementation include staffing, recruiting participants, geographic isolation, and meeting unmet needs.

### **EMERGING AMERICAN INDIAN, ALASKA NATIVE & NATIVE HAWAIIAN MODELS**

A three-year demonstration grant component is included as a part of the Native American Caregiver Support Program. These competitively awarded grants are allowing Tribes to develop model caregiver support programs in Alaska, Hawaii, Montana, South Dakota, Washington and Wisconsin.

*Alu Like, Inc., Hawaii* is developing a multifaceted Native American Caregiver Support Pilot Program consisting of a workshop, user friendly/culturally appropriate manuals, direct services, satisfaction survey and utilization surveys. They are developing a “Caregiver Kit” that includes end-of-life issues, a caregiver resource guide, and other topics as they are identified through needs assessments and group meetings. Preliminary results from a needs assessment conducted at the Caregiver Conference indicate that the vast majority of Native Hawaiian caregivers are female (90%), over half have been caregivers for more than two years, and nearly a third care for more than one individual.

*Blackfeet Eagle Shield Senior Centers, Montana*, is focusing on developing a network system for referrals under the “Caregivers Taking Care of Each Other” project. Network members include community programs and traditional medicine people. A state-wide directory of resources, a training manual, health and wellness information, and a video library is currently under development.

*Central Council Tlingit and Haida Indians Tribes, Alaska*, are collaborating with the Cornerstone Home Health Services to develop a training program that reflects the unique needs and cultural values of the Native community. A *Caregiver Support Assessment* on the services, barriers to services and belief and attitudes that utilization of support services by Native Elderly caregivers.

*Confederated Salish and Kootenai Tribes, Montana* are developing a comprehensive service delivery program through a teamwork and consumer-centered approach. This will be accomplished by bringing all existing service providers together who provide in-home services to elders to brainstorm ideas and determine needs. A plan is being developed among the various agencies and programs for providing the available services in a coordinated fashion. A *Home Care Services Program Policy and Procedures* and *Home Care Attendant Handbook Manual* will be developed.

*Hana Community Health Center, Hawaii* is developing a caregiver-training program for family caregivers and potential family caregivers through coordination with several organizations including Hale Makua, Maui Community College and Kula Hospital. They have provided 40 hours of training over a six week period and are following the training with monthly support groups. They plan to have a curriculum and training materials that can be shared with others.

*Jamestown S'Klallam Tribes, Washington* are using the Family Group Conferencing Model for providing caregiver support, including counseling services, support groups, and other support services. A manual is being redesigned based on empowering the family itself, including a section on how the rest of the family can support the primary caregiver.

*Oneida Tribe of Indians of Wisconsin* is coordinating a pilot statewide American Indian elderly caregiver system for caregivers caring for elders both on and off the eleven reservations throughout Wisconsin. Based on workgroup and other meetings with families of seven of the eleven Tribes, six goals for the project were identified: 1) develop a resource manual and video targeted to the tribal populations; 2) develop a website and ListServ for caregivers; 3) develop/adapt a curriculum for caregiving in the home; 4) determine the future needs of family caregivers for further revisions of the resource manual; 5) create and implement a Family Caregiver Board to ensure future needs are met after the demonstration grant is over; and 6) ensure all Wisconsin tribal caregivers and elders have access to the resource manual through tribal, county, and state agencies. Multiple partners are involved in this project, including the Area Agencies on Aging, Senior Centers, and local tribal colleges and universities.

*Rosebud Sioux Tribe, South Dakota*, is expanding the availability of education and training in a multi-faceted manner that will address the psychological and physical needs of American Indian caregivers. Through collaborating efforts with the University of Colorado, Project Hope, Gatorade, Indian Housing, Catholic Family Services, Native American Advocacy and the Indian Health Service, access to counseling services, support groups, caregiver training, information, transportation and respite care is being provided. Assistance is being provided to the caregiver in making decisions and problem solving relative to their caregiver roles. The *Rosebud Sioux Tribe* is developing an effective and efficient data collections system to measure outcomes. A uniform reservation-wide assessment and information system to ensure quality of care and policy to support and strengthen family caregiving is planned.

*South Puget Intertribal Planning Agency, Washington* is coordinating with the *Confederated Tribes of the Chehalis Reservation* and the *Nisqually Indian Tribe* to increase the level of coordination and leveraging of resources for caregiver support services for the Tribal elderly population within the Tribal service areas of Thurston, Pierce, and Grays Harbor Counties in southwest Washington State. The project is assessing the current status of caregiver support within the area, both through Tribal and non-Tribal programs. *South Puget* is identifying barriers to accessing these resources, including cultural, financial, and geographical barriers. Additional plans to develop and demonstrate a program model for maximizing the coordination and leveraging caregiver support resources that reflects the unique needs, circumstances and cultural values of the Tribal elders are forthcoming.

## **V. 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 is...

### **HELPING 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.

### **PROMOTING 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 from others.

### **HELPING 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.

### **ALLOWING 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.

### **SUPPORTING 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.

### **PREVENTING 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.

### **PREVENTING 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.

### **REACHING OUT TO SPECIAL POPULATIONS AND COMMUNITIES**

Mrs. I is a 78 year old 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.

### **ADDRESSING 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.*

## **VI. PRESSING LONG-TERM CARE ISSUES**

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 promote services at home, in the community; addressing the workforce shortage; and expanding consumer/family directed care options.<sup>22</sup>

### **PROMOTING SERVICES AT HOME, IN THE COMMUNITY**

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 to 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.

The Aging and Disability Resource Center Program, a collaborative effort of the Administration on Aging and the Centers for Medicare and Medicaid Services, provides states with an opportunity to effectively integrate their long-term support resources for persons with disabilities of all ages and their caregivers into a single coordinated system. As part of the New Freedom Initiative, 12 state grants of up to \$800,000 were issued as cooperative agreements in 2003 for a three-year period under this program.<sup>i</sup> An additional 12 new Aging and Disability Resource Center grants totaling nearly \$9 million were awarded in 2004.<sup>j</sup> States can use these funds to better coordinate and/or redesign their existing systems of information, assistance and access, which currently involve

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<sup>i</sup> LA, MA, MD, ME, MN, MO, NH, NJ, PA, RI, SC, and WV.

<sup>j</sup> AK, AR, CA, FL, GA, IL, IN, IO, NM, NC, NMI AND WI.

multiple federal, state and local programs. A single, coordinated system of access for persons with disabilities, including seniors, seeking long-term care support will minimize confusion, enhance individual choice and support informed decision-making. For more information on the Aging and Disability Resource Centers Grant program, including descriptions of grantee projects, go to the following websites: <http://aoa.gov> and <http://www.cms.hhs.gov/newfreedom>.

## **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.<sup>23</sup> 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. Moreover, given that many states are finding that implementing consumer-directed caregiver programs can significantly expand the potential pool of workers, AoA will continue to encourage states to adopt consumer-directed options.

## **EXPANDING CONSUMER /FAMILY DIRECTED CARE**

Many individuals and families want to manage all or part of the decisions related to their service and support needs.<sup>24 25</sup> In response, several states are pioneering consumer-directed service delivery models.<sup>26</sup> Under the NFCSP, some states allow direct payments to caregivers in the form of vouchers or cash to purchase services and supports to meet their needs.<sup>k</sup> Recent studies of consumer-directed programs involving payment to family caregivers show that their satisfaction with consumer-directed services is strong<sup>27 28</sup> and that states can develop consumer-directed services at no greater cost than traditional agency care.<sup>29</sup> Moreover, participants' health and safety are not adversely affected.<sup>30</sup> Beyond the desire to promote greater consumer autonomy and satisfaction, expanding consumer-directed caregiver programs offers one solution to the workforce shortage discussed above.<sup>31 32</sup>

Many states are finding that implementing consumer-directed caregiver programs can significantly expand the potential pool of workers by adding workers who, although may be willing to work for a friend or relative, would not join the staff of a provider agency. This is especially true for individuals living in rural areas who find it difficult to access traditional agency-based workers.<sup>33</sup> A current thrust in state long-term care reform efforts

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<sup>k</sup> Title III-E requirements stipulate that it is a state option to provide families additional assistance in directing services and supports.



include expanded opportunities and supports for caregivers to participate in consumer-directed models of service delivery.<sup>34 35<sup>1</sup></sup>

Consumer direction is not new to the aging network – the Older Americans Act is based on the philosophy of consumer direction, choice and control. What is new is the emergence of a wide variety of options that the aging network has and can continue to employ to provide varying levels of choice and control to older adults and their family members in the Medicaid program, state and local revenue programs, and the Older Americans Act.

The AoA has recently joined forces with the Robert Wood Johnson Foundation and the Assistant Secretary for Planning and Evaluation at HHS to replicate the successful Cash and Counseling program in 10 states. Under the new Cash & Counseling program states must utilize Medicaid funding, but have the option of expanding the model to Older Americans Act and other federal and state-funded long-term care support programs. For additional information on this program, see: <http://cashandcounseling.org>.

## CONCLUSION

The issue of informal caregiving touches us all, as many of us will likely have family members or friends who will someday require assistance with everyday activities, and may ourselves require assistance in our aging lifetime. The NFCSP embodies this compassionate spirit and stands as a significant legislative accomplishment on behalf of caregivers in the United States. Direct services for caregivers provides an important opportunity to support and strengthen the role of informal caregivers and to bring together community agencies to meet the diverse needs of caregivers.

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<sup>1</sup> The Administration on Aging is a new funding partner in the second phase of the successful Cash and Counseling program – a consumer-directed care model that focuses on person-centered planning for personal assistance services, consumer-directed individual budgets, client supports including financial management and counseling services, and quality assurance and improvement systems. The expanded program will provide grants and comprehensive technical assistance for up to 10 states to replicate, and in some cases, expand on this model of maximum consumer choice. Under the new Cash and Counseling program states must utilize Medicaid funding, but have the option of expanding the model to Older Americans Act and other federal- and state-funded long-term support programs. For more information on this program go to: <http://www.cashandcounseling.org>.

The NFCSP has succeeded in accomplishing its mission of improving the availability of caregiver services and supports. The program is evolving to meet the changing needs of older people brought on by shifting demographics and changes in the health care system and public policy environment. There are indications of greater needs for the program's services, as well as signs that there may be new roles for the program in the future. This report highlights 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.

## **APPENDIX A**

### **NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM & RELATED TERMS**

## NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM & RELATED TERMS

**Activities of Daily Living (ADLs):** Basic personal care tasks to be performed daily such as dressing, bathing, eating, toileting, transferring in and out of chair, and walking.

**Administration on Aging (AoA):** The AoA, an agency in the U.S. Department of Health and Human Services, was established by the Older Americans Act in 1965 and serves as the federal focal point and advocacy agency for older persons and their concerns. The AoA heightens awareness among other federal agencies, organizations, groups, and the public about the valuable contributions that older Americans make to the nation and alerts them to the needs of vulnerable older people. The AoA also administers various grant programs in conjunction with state and local efforts that include a comprehensive and coordinated system of care for older people and their family caregivers. Grant programs and advocacy are carried out in collaboration with the National aging services network. The AoA administers The National Family Caregiver Support Program.

**Adult Day Care:** Organized program, outside of the home. Services are supervised and include social and/or health care for elders who require skilled services or physical assistance with activities of daily living.

**Assistance to Caregivers:** One-to-one contact made available to caregivers in their communities through the NFCSP to assess the problems and capacities of caregivers and to link caregivers to the opportunities and services available.

**Care Recipient (or) Consumer:** The person receiving care who typically has a condition such as Parkinson's disease, cancer, Alzheimer's disease, traumatic brain injury, AIDS, muscular dystrophy, paralysis, multiple sclerosis, frailty attributed to old age, or other chronic illness.

**Caregiver Support:** Opportunities made available to caregivers through the NFCSP to talk about the day-to-day challenges associated with caregiving with counselors and peers in similar situations and to help caregivers make better care-related decisions and better cope with problems or unique situations that may arise.

**Caregiver Training:** Instruction made available to caregivers through the NFCSP to diminish the negative consequences associated with caregiving and the reliance on more costly, formal supports.

**Child:** An individual who is not more than 18 years of age.<sup>m</sup>

**Companion Services:** In-home services that provide supervision and socialization to a functionally impaired adult who might live alone. This may include meal preparation or shopping.

**Consumer Direction<sup>n</sup>:** Many phrases have been created to refer to service delivery models where elderly persons or persons with disabilities have more control over their health care decisions. Among these are consumer direction, self-direction, person-centered, self-determination, empowerment, self-help, and family and individual directed. Consumer directed supports and services refers to a service delivery system whereby elderly persons, families of persons with disabilities or persons with chronic conditions have more involvement, control and choice in identifying, accessing and managing the services they obtain to meet their personal assistance needs.

**Counseling to Caregivers:** Advice and guidance made available to caregivers in their communities through the NFCSP. This may include assisting caregivers in making decisions and solving problems relating to their caregiver roles.

**Eldercare Locator:** A service that helps people connect to local resources. Sponsored by the AoA, this service is available through a toll free number, 1-800-677-1116, or online at <http://www.eldercare.gov>.

**Family Caregiver:** An adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.<sup>o</sup> (Used interchangeably with informal caregiver).

**Grandparent (or) Older Individual who is a Relative Caregiver:** A grandparent or step grandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and a) lives with the child; b) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and c) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.<sup>p</sup>

**Home Health Care:** In-home assistance to address medical needs, such as administering medications or physical therapy.

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<sup>m</sup> Older Americans Act of 1965, Amendments of 2000, Part E-National Family Caregiver Support Program, the U.S. Administration on Aging.

<sup>n</sup> *Consumer direction* may be referred to as the *independent living model* among working age adults with physical disabilities, *self-determination* among persons with mental retardation/developmental disabilities and their families, and *self-help* and *empowerment* among persons with severe and persistent mental illness.

<sup>o</sup> Older Americans Act of 1965, Amendments of 2000. Ibid.

<sup>p</sup> Ibid.

**Homemaker:** In-home assistance with daily IADL activities.

**Informal Caregiver:** An adult family member or another individual who provides care without pay and who usually has personal ties to the care recipient. Examples include family, friends and neighbors. The caregiver can be a “primary” or “secondary” caregiver, can provide full- or part-time help, and may live with the care recipient or separately.

**Informal Supports:** Commonly referred to as “informal caregiving” in the service system for elderly persons and “family supports” in the service system for persons with disabilities.

**Information to Caregivers:** Resources made available to caregivers within their communities through the NFCSP to help caregivers gain access to support services in a targeted and timely manner. Service units for information and assistance refer to individual, one-to-one contact between an information and assistance provider and a caregiver.

**In-Home Respite:** Services provided on a short-term basis due to the absence or need for relief of the regular caregiver.

**Institutional Respite:** Services provided on a short or long-term basis in a residential or assisted living facility, nursing home, or other institution due to the absence or need for relief of the regular caregiver.

**Instrumental Activities Of Daily Living (IADLs):** Personal tasks such as meal preparation, shopping for personal items, medication management, making telephone calls, money management, performing light housework, and transportation assistance.

**Long-Term Care and Support:** Long-term care and support refers to a broad and highly variable range of rehabilitative, restorative and health maintenance services that assist people with ADLs, IADLs, and the emotional aspects of coping with illness or disability.

**National aging services network:** Includes 56 State Units on Aging, 655 Area Agencies on Aging, 243 tribal organizations, over 29,000 local community service organizations, 500,000 volunteers, and a wide variety of national organizations.

**Older Americans Act of 1965:** An act to provide assistance in the development of new or improved programs to help older persons through grants to the States for community planning, services, and training, through research, development, or training project grants, and to establish within the [former] Department of Health, Education, and Welfare an operating agency to be designated as the Administration on Aging.

**Outreach:** Intervention with individuals initiated by an agency or organization for the purpose of identifying potential clients (caregivers).

**Personal Care:** In-home assistance with daily ADL activities.

**Respite:** Services which offer temporary, substitute supports or living arrangements for older persons made available through the NFCSP to provide a brief period of relief or rest for caregivers. This may be provided in the form of in-home respite, adult day care respite or institutional respite for an overnight stay on an intermittent, occasional or emergency basis.

**Supplemental Services:** Services provided on a limited basis to compliment the care provided by caregivers.

**Title III:** Grants for State and Community Programs on Aging. The largest program under the OAA, this title lays out responsibilities and requirements for State and Area Agencies on Aging. It is through the programs and structures established by this title that appropriated monies are authorized and most of the legislative detail is found.

The legislative intent of the Community-Based Services Program is to make community-based services available to elders who are at risk of losing their independence. It is intended further that States and communities participate actively in funding community-based services and develop the capacity in communities across the States to support the home and community-based service needs of elderly individuals, particularly the poor, minorities and those who live in rural areas where access to services may be limited. Under Title III, SUAs are allocated funds for state and community programs based on formulas that reflect the number of older residents in their state. The AoA, other Federal, state, local and private source funds are used by SUAs, AAAs and service providers to coordinate and to provide services for elderly individuals.

The Community-Based Services Program provides *access services*, such as information and assistance, outreach, and transportation; *community services*, which include nutrition services, meals, senior-center activities, adult day care, pension counseling, and health promotion and physical activity programs; *in-home services*, including home-delivered meals, chore, home maintenance assistance, home-health, and personal care; and *caregiver support*, such as respite services and information and assistance to caregivers for the coordination of health and social services.

### **Part E - National Family Caregiver Support Program**

The enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501) established the NFCSP. Under Title III-E, the AoA provides State Units on Aging formula grants to work in partnership with local Area Agencies on Aging and faith- and community-service providers. These grants are used to provide direct support services that best meet the range of caregiver needs to family caregivers of persons age 60 and older and grandparents and relative caregivers of children not more than 18 years of age.

**Title VI:** Grants for Native Americans. This program serves as the focal point for advocacy on behalf of older individuals who are Indians, Alaskan Natives and Native Hawaiians. Supportive and nutrition services that are comparable to services provided under Title III are provided to 241 Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians. Services are provided in a manner that preserves and restores their dignity, self-respect, and cultural identities. Grants may be awarded to tribal organizations representing at least 50 individuals age 60 or older.

**Part C – Native American Caregiver Support Program**

The Older Americans Act Amendments of 2000 established the NACSP. Under Title VI-C the AoA provides formula grants to tribes to provide direct support services that best meet the range of caregiver needs. The program requirements for the NACSP are similar to the Title III-E program.



**APPENDIX B**

**TITLE III-E**

**NFCSP 2001-2003 FORMULA GRANT AWARDS**

**TITLE III-E 2001-2003 FORMULA GRANT AWARDS**

State	FY 2001 Grant Amount (\$)	FY 2002 Grant Amount (\$)	FY 2003 Grant Amount (\$)
Alaska	564,300.	644,212.	700,790.
Alabama	1,739,242.	1,996,374.	2,171,708.
Arkansas	1,125,177.	1,303,240.	1,417,698.
American Samoa	70,538.	80,526.	87,599.
Arizona	1,956,318.	2,337,035.	2,542,287.
California	11,359,851.	12,657,601.	13,769,261.
Colorado	1,245,978.	1,429,311.	1,554,841.
Connecticut	1,509,874.	1,709,384.	1,859,512.
District of Columbia	564,300.	644,212.	700,790.
Delaware	564,300.	644,212.	700,790.
Florida	8,721,584.	10,083,438.	10,969,024.
Georgia	2,305,333.	2,659,575.	2,893,154.
Guam	282,150.	322,106.	350,395.
Hawaii	564,300.	644,212.	700,790.
Iowa	1,391,731.	1,594,075.	1,734,075.
Idaho	564,300.	644,212.	700,790.
Illinois	4,732,281.	5,344,843.	5,814,257.
Indiana	2,331,599.	2,661,771.	2,895,543.
Kansas	1,139,251.	1,290,151.	1,403,460.
Kentucky	1,516,043.	1,745,716.	1,899,035.
Louisiana	1,535,025.	1,788,389.	1,945,456.
Massachusetts	2,766,510.	3,120,206.	3,394,240.
Maryland	1,843,229.	2,089,617.	2,273,140.
Maine	564,300.	646,191.	702,943.
Michigan	3,848,418.	4,315,224.	4,694,212.
Minnesota	1,875,522.	2,138,248.	2,326,042.
Missouri	2,337,876.	2,666,197.	2,900,358.
Northern Mariana Islands	70,538.	80,526.	87,599.
Mississippi	1,031,878.	1,189,322.	1,293,775.
Montana	564,300.	644,212.	700,790.
North Carolina	2,916,628.	3,326,460.	3,618,609.
North Dakota	564,300.	644,212.	700,790.
Nebraska	732,458.	837,679.	911,249.
New Hampshire	564,300.	644,212.	700,790.
New Jersey	3,496,629.	3,974,716.	4,323,798.
New Mexico	594,433.	709,061.	771,334.
Nevada	603,803.	715,220.	778,035.
New York	7,612,334.	8,680,794.	9,443,192.
Ohio	4,739,721.	5,356,995.	5,827,478.
Oklahoma	1,388,901.	1,586,096.	1,725,396.
Oregon	1,396,517.	1,578,189.	1,716,795.
Pennsylvania	6,097,763.	6,973,272.	7,585,705.
Puerto Rico	1,203,867.	1,409,945.	1,533,774.
Rhode Island	564,300.	644,212.	700,790.
South Carolina	1,421,896.	1,646,884.	1,791,523.
South Dakota	564,300.	644,212.	700,790.
Tennessee	2,083,754.	2,417,677.	2,630,011.
Texas	6,147,379.	7,087,631.	7,710,108.
Utah	573,563.	658,988.	716,866.

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Virginia	2,354,500.	2,728,115.	2,967,714.
Virgin Islands	282,150.	322,106.	350,395.
Vermont	564,300.	644,212.	700,790.
Washington	2,083,944.	2,355,545.	2,562,423.
Wisconsin	2,203,655.	2,522,840.	2,744,410.
West Virginia	854,259.	974,517.	1,060,104.
Wyoming	564,300.	644,212.	700,790.
Total	112,860,000.	128,842,340.	140,158,013.

Note: The Administration on Aging, Office of Budget & Finance withholds 1% of gross NFCSP appropriated funds for contingencies and other administrative related expenses. Unused funds are returned at the end of the year. The above figures represent actual appropriated NFCSP funds.

**APPENDIX C**

**TITLE VI-C**

**NACSP 2001-2003 FORMULA GRANT AWARDS**

**TITLE VI-C 2001-2003 FORMULA GRANT AWARDS**

State	Tribe Name	FY 2001 Grant Amount (\$)	FY 2002 Grant Amount (\$)	FY 2003 Grant Amount (\$)
AK	Association of Village Council Presidents	63,020	42,810	49,630
AK	Bristol Bay Native Association	na	42,810	49,630
AK	Copper River Native Association	na	12,230	14,180
AK	Hoonah Indian Association	18,010	12,230	14,180
AK	Kodiak Area Native Association (Northern Section)	na	12,230	14,180
AK	Kodiak Area Native Association (Southern Section)	na	12,230	14,180
AK	Metlakatla Indian Community	27,010	18,350	21,270
AK	Native Village of Barrow	na	24,460	28,360
AK	Tanana Chiefs Conference / Kuskokwim Subregion	na	12,230	14,180
AK	Tanana Chiefs Conference / Lower Yukon Subregion	na	12,230	14,180
AK	Tanana Chiefs Conference / Yukon Flats Subregion	na	12,230	14,180
AK	Tanana Chiefs Conference / Yukon Koyukuk Subregion	na	18,350	21,270
AK	Tanana Chiefs Conference / Yukon Tanana Subregion	na	12,230	14,180
AK	Fairbanks Native Association	45,020	42,810	49,630
AK	Maniilag Association	63,020	36,700	42,550
AK	Chugachmiut	18,010	12,230	14,180
AK	Denakkanaaga, Inc.	na	18,350	21,270
AK	Klawock, I.R.A.	18,010	12,230	14,180
AK	Kootznoowoo Inc.	18,010	12,230	14,180
AK	Native Village of Fort Yukon	18,010	12,230	14,180
AK	Native Village of Point Hope	na	12,230	14,180
AK	Sitka Tribes of Alaska	36,010	24,460	28,360
AK	Yakutat Native Assocociation (Includes Craig)	18,010	12,230	14,180
AK	Ketchikan Indian Corporation	36,010	24,460	28,360
AK	Kuskokwim Native Association	na	18,350	21,270
AK	Southcentral Foundation	63,020	42,810	49,630
AK	Kenaitze Indian Tribe	na	18,350	21,270
AK	Wrangell Coop.Assoc	na	12,230	14,180
AK	Native Village of Gambell	na	12,230	14,180
AL	Poarch Band of Creek Indians	na	24,260	28,360
AZ	Colorado River Indian Tribes	na	30,580	35,450
AZ	Gila River Indian Community	72,030	42,810	49,630
AZ	Hopi Tribal Council	63,020	42,810	49,630
AZ	Hualapai Tribal Council	18,010	12,230	14,180
AZ	Navajo Nation	63,020	42,810	49,630
AZ	Pascua Yaqui Association	36,010	24,460	28,360
AZ	Salt River Pima-Maricopa Community	36,010	30,580	35,450
AZ	San Carlos Apache Tribe	na	24,460	28,360
AZ	Tohono o'Odham Nation	na	42,810	49,630
AZ	White Mountain Apache Tribe	45,020	30,580	35,450
AZ	Ak-Chin Indian Community	18,010	12,230	14,180
AZ	Havasupai Tribal Council	18,010	12,230	14,180
AZ	Inter-Tribal Council of Arizona	18,010	12,230	14,180

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AZ	Quechan Indian Tribe	na	18,350	21,270
CA	Bishop Indian Tribal Council	27,010	18,350	21,270
CA	Blue Lake Rancheria	na	24,460	28,360
CA	Karuk Tribe of California	63,020	24,460	28,360
CA	Pit River Health Service	na	12,230	a
CA	Riverside-San Bernardino County Indian Health for Morongo	na	18,350	21,270
CA	Riverside-San Bernardino County Indian Health for Pechanga	na	18,350	21,270
CA	Riverside-San Bernardino County Indian Health for Soboba	na	12,230	14,180
CA	Southern Indian Health Council-Area I	27,010	18,350	21,270
CA	Southern Indian Health Council-Area II	27,010	18,350	21,270
CA	Toiyabe Indian Health Project	na	12,230	14,180
CA	Tule River Indian Health Center	na	12,230	14,180
CA	United Indian Health Service for Resighini	18,010	18,350	21,270
CA	United Indian Health Service for Smith River, etc.	36,010	24,460	28,360
CA	California Indian Manpower Consortium	18,010	12,230	14,180
CA	Indian Senior Center, Inc.	na	18,350	21,270
CA	California Indian Manpower Consortium-LaJolla & Susanville	18,010	12,230	14,180
CA	California Indian Manpower Consortium- Ysabel, Pasual	18,010	18,350	21,270
CA	Pala Band of Mission Indians	na	18,350	21,270
CA	Redding Rancheria	63,020	42,810	49,630
CA	Toiyabe Indian Health Project	na	12,230	14,180
CA	Hoopla Valley Tribe	na	18,350	21,270
CA	Fort Mojave Indian Tribe	na	12,230	14,180
CO	Southern Ute Indian Tribe	na	18,350	21,270
ID	Coeur d'Alene Tribe	na	18,350	21,270
ID	Nez Perce Tribe of Idaho	54,020	30,580	35,450
ID	Shoshone-Bannock Tribes	na	36,700	42,550
KS	Kickapoo Nation in Kansas	18,010	12,230	14,180
KS	Prairie Band of Potawatomi I	na	42,810	49,630
KS	Iowa Tribe of KS &NE	na	12,230	14,180
ME	Aroostook Band of Micmac	18,010	12,230	14,180
MI	Grand Traverse Band of Ottawa and Chippewa Indians	27,010	18,350	21,270
MI	Inter-Tribal Council of Michigan	27,010	24,460	28,360
MI	Keweenaw Bay Indian Community	27,010	18,350	21,270
MN	Fond du Lac Reservation Business Committee	na	30,580	35,450
MN	Leech Lake Reservation Business Committee	45,020	36,700	42,550
MN	Minnesota Chippewa Resource Development	36,010	24,460	28,360
MN	White Earth Reservation Tribal Council	27,010	18,350	21,270
MS	Mississippi Band of Choctaw Indians	na	36,700	42,550
MT	Assiniboine and Sioux Tribes	54,020	36,700	42,550
MT	Chippewa-Cree Tribe	36,010	24,460	28,360
MT	Fort Belknap Community Council	36,010	30,580	35,450
MT	Northern Cheyenne Tribe	36,010	24,460	28,360
MT	Crow Tribal Elders Program	54,020	42,810	49,630
NC	Eastern Band of Cherokee Indians	na	42,810	49,630
ND	Spirit Lake Nation	36,010	18,350	21,270
ND	Standing Rock Sioux Tribe	63,020	42,810	49,630

The National Family Caregiver Support Program: *Compassion In Action*

ND	Trenton Indian Service Area	36,010	42,810	49,630
ND	Turtle Mountain Band of Chippewa Tribe	63,020	42,810	49,630
NE	Omaha Tribe of Nebraska	27,010	18,350	21,270
NE	Winnebago Tribe of Nebraska	na	18,350	21,270
NM	Jicarilla Apache Tribe	na	24,460	28,360
NM	Laguna Rainbow Corporation	54,020	42,810	49,630
NM	Pueblo de Cochiti	27,010	18,350	21,270
NM	Pueblo of Acoma	54,020	30,580	35,450
NM	Pueblo of Isleta	63,020	42,810	49,630
NM	Pueblo of Jemez	na	24,460	28,360
NM	Pueblo of San Felipe	36,010	24,460	28,360
NM	Pueblo of Taos	na	30,580	35,450
NM	Pueblo of Zuni	63,020	42,810	49,630
NM	San Juan Pueblo	63,020	42,810	49,630
NM	Santa Clara Pueblo	na	42,810	49,630
NV	Inter-Tribal Council of Nevada -Duckwater, etc.	18,010	12,230	14,180
NV	Inter-Tribal Council of Nevada -South Fork, etc.	18,010	12,230	14,180
NV	Inter-Tribal Council of Nevada - Moapa, etc.	18,010	12,230	14,180
NV	Shoshone-Paiute Tribes	27,010	24,460	28,360
NV	Washoe Tribe of Nevada and California	na	18,350	21,270
NV	Pyramid Lake Paiute Tribe	27,010	18,350	21,270
NV	Elko Band Council	27,010	12,230	14,180
NY	St. Regis Mohawk	18,010	42,810	49,630
NY	Seneca Nation of Indians	45,020	36,700	42,550
OK	Apache Tribe of Oklahoma	na	36,700	42,550
OK	Caddo Tribe	na	24,460	28,360
OK	Cherokee Nation	72,188	49,870	57,251
OK	Cheyenne-Arapaho	na	42,810	49,630
OK	Chickasaw Nation	72,030	48,930	56,730
OK	Choctaw Nation	72,030	48,930	56,730
OK	Citizen Band Potawatomi	72,030	48,930	56,730
OK	Comanche Indian Tribe	na	42,810	49,630
OK	Delaware Tribe of Western Oklahoma	na	42,810	49,630
OK	Iowa Tribe	63,020	42,810	49,630
OK	Kickapoo Tribe	na	42,810	49,630
OK	Kiowa Tribe	na	42,810	49,630
OK	Muscogee (Creek) Nation	72,030	48,930	56,730
OK	Osage Nation	na	48,930	56,730
OK	Otoe-Missouria Tribe	na	24,460	28,360
OK	Pawnee Tribe	63,020	42,810	49,630
OK	Quapaw Tribe	45,020	30,580	35,450
OK	Sac and Fox Tribe	na	30,580	35,450
OK	Seminole Nation	na	42,810	49,630
OK	Wichita and Affiliated Tribes	na	42,810	49,630
OK	Wyandotte Tribe	63,020	42,810	49,630
OK	Absentee Shawnee Tribe	na	30,580	35,450
OK	Fort Sill Apache Tribe	27,010	24,460	28,360

The National Family Caregiver Support Program: *Compassion In Action*

OK	United Keetowah Band of Cherokee Indians in Oklahoma	na	42,810	49,630
OR	Confederated Tribes of Siletz Indians	27,010	24,460	28,360
OR	Confederated Tribes of the Umatilla Indian Reservation	45,020	30,580	35,450
OR	Confederated Tribes of Warm Springs	36,010	24,460	28,360
OR	Confederated Tribes of Grand Ronde	27,010	18,350	21,270
OR	Klamath Tribe	36,010	30,580	35,450
OR	Confederated Tribes of Coos, Lower Umpqua, and Siuslaw	27,010	12,230	14,180
SC	Catawba Indian Nation	na	12,230	14,180
SD	Crow Creek Sioux Tribe	na	18,350	21,270
SD	Lower Brule Sioux Tribe	18,010	12,230	14,180
SD	Oglala Sioux Tribe	na	48,930	56,730
UT	Uintah and Ouray	27,010	18,350	21,270
WA	Colville Confederated Tribes	na	42,810	49,630
WA	Lower Elwha Klallam Tribe	na	18,350	21,270
WA	Lummi Indian Business Council	45,020	30,580	35,450
WA	Makah Indian Tribal Council	18,010	12,230	14,180
WA	Muckleshoot Indian Tribe	36,010	30,580	35,450
WA	Nooksack Indian Tribe	27,010	18,350	21,270
WA	Puyallup Tribal Health Authority	63,020	42,810	49,630
WA	Quinault Indian Nation	36,010	24,460	28,360
WA	South Puget Intertribal for Skokomish and Squazin Island	45,020	36,700	42,550
WA	Swinomish	18,010	12,230	14,180
WA	Spokane Tribe of Indians	27,010	18,350	21,270
WA	Yakama Indian Nation	18,010	12,230	14,180
WA	Tulalip Tribes	63,020	42,810	49,630
WA	Quileute Tribal Council	18,010	12,230	14,180
WA	South Puget Intertribal for Shoalwater Bay	27,010	18,350	21,270
WA	Stillaguamish Tribe	27,010	18,350	21,270
WA	Upper Skagit Indian Tribe	na	12,230	14,180
WA	The Suquamish Indian Tribe	18,010	18,350	21,270
WA	Port Gamble S'Klallam Tribe	18,010	18,350	21,270
WA	Samish Indian Nation	18,010	12,230	14,180
WA	Cowlitz Indian Tribe	na	18,350	21,270
WI	Bad River Band of Lake Superior Chippewa	36,010	24,460	28,360
WI	Forest County Potawatomi Community	18,010	12,230	14,180
WI	Lac du Flambeau Band of Lake Superior Chippewa Indians	27,010	24,460	28,360
WI	Menominee Indian Tribe of Wisconsin	63,020	36,700	42,550
WI	Red Cliff Band of Lake Superior Chippewa	18,010	18,350	21,270
WI	St. Croix Tribal Council	na	12,230	14,180
WI	Ho-Chunk Nation	45,020	18,350	21,270
	<b>Total</b>	<b>4,015,678</b>	<b>4,538,680</b>	<b>5,247,281</b>
	na - not a grantee in FY 2001      a - Grantee withdrew from the program			

Note: The Administration on Aging, Office of Budget & Finance withholds 1% of gross NFCSP appropriated funds for contingencies and other administrative related expenses. Unused funds are returned at the end of the year. The above figures represent actual appropriated NFCSP funds.



## APPENDIX D

### STATE APPROACHES AND EXPERIENCES IN PROGRAM IMPLEMENTATION<sup>q</sup>

#### -- How to Read The Entry For Each State --

- NFCSP State Contact – The central point of contact for the National Family Caregiver Support Program.
- Administrative Structure – A cursory overview of how the NFCSP was implemented in relation to other related programs, funding streams, and/or legislation.
- Services/Number of Caregivers Served – A graphic representation of the numbers of caregivers served in the state in FY 2002. Percentages represent the numbers of people served in relation to the total number written at the top of the bar chart. These early counts are duplicated across service categories; future counts will be unduplicated. In many cases, states reported that the *Information/Outreach* service category lead directly to the provision of caregiver services (i.e. the reason for including the graphic arrow).
- Public Awareness/Education – Statewide and local public awareness and education activities. Some may be replicated by other states.
- Consumer/Family Direction – The emergence of a wide variety of options that the aging network has and can continue to employ to provide varying levels of choice and control to older adults and their family members. The status of early and well-established ideas for inclusion of consumer-directed options in the NFCSP.
- Assessment Standards - Most state approaches to caregiver assessments and the type of information collected are varied across and within states. Ideally, this intake information might be standardized in order to facilitate an examination of service users and program impacts locally or statewide.<sup>36 37 38</sup> The state approach to assessment standards are reviewed, as known.
- Opportunities – Interesting state facts or innovations that may include, but are not limited to, enacted legislation, innovation grants, assessment and/or evaluation-related instruments under development or currently in use, collaborations, and tools under development.
- Information Links – Helpful resources. May include the State Department/Office on Aging website, program-related links, support group directories, and more.

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<sup>q</sup> Information is Forthcoming = State did not provide this information.

**A L A B A M A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

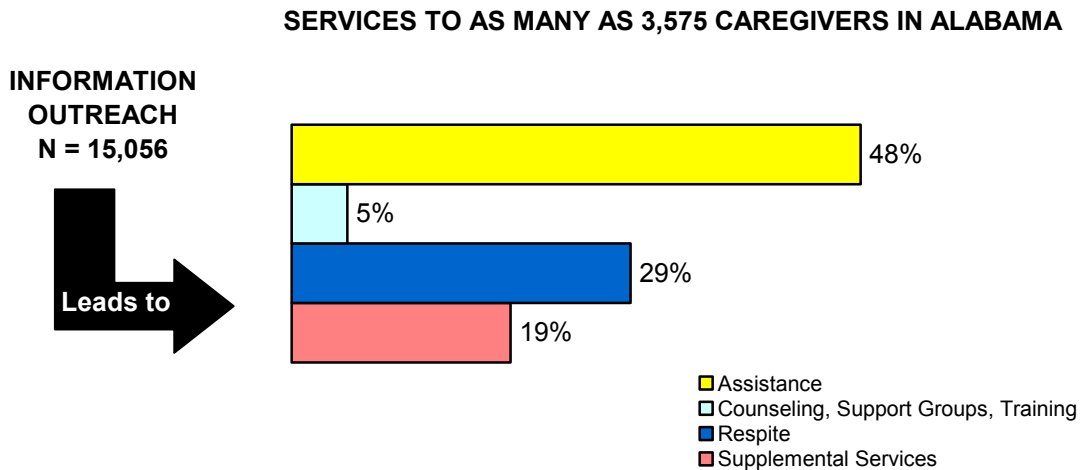
Tara Shaver-Jarmon, State Coordinator  
Alabama Cares  
Alabama Dept. of Senior Services  
770 Washington Avenue, Suite 470  
Montgomery, AL 36130 -1851  
Phone: (334) 353-9636 or (877) 4252243  
Fax: (334) 242-5594  
e-mail: [tshaver-jarmon@adss.state.al.us](mailto:tshaver-jarmon@adss.state.al.us)

**Administrative Structure**

Provides caregiver support for the first time as a result of the passage of Title IIIE and requires each Area Agency make available all 5 NFCSP service components. The State Unit on Aging targets technical assistance to the Area Agencies that have not previously provided caregiver support.

Cost sharing has been implemented for respite and supplemental services. Although caregivers are not explicitly recognized as a central component of the current LTC system, efforts have been made to expand HCBS options to care recipients.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Promoting a consistent statewide identity for the caregiver program, *Alabama Cares* (Caregiver Assistance with Resources, Education and Services), building on existing state infrastructures and model programs.
- Alabama Public Television and local news programs, featured articles in major newspapers, and statewide conferences.
- Uses *Mobile Van Tour* to reach remote, hard-to-access areas.
- Uses *list-serves* to promote dialogue/ information exchange between the State Unit on Aging and the Area Agencies on Aging.

Efforts of specific Area Agencies include sessions at churches, civic group meetings, senior centers, and health fairs.

### **Consumer/Family Direction**

Some Area Agencies provide funding to caregivers in the form of vouchers to purchase respite and supplemental services. Caregivers choose from a menu of services, including choice of respite provider. Although Alabama does not have a policy allowing caregivers to hire family members, a contracting agency can hire family members to provide services.

### **Assessment Standards**

Alabama applies a uniform statewide caregiver assessment that includes caregiver information.

### **Opportunities**

- Developed instrument to collect basic demographic information on caregivers for state reporting system.

### **Information Links**

Alabama Cares – Support for Caregivers (Alabama Department of Senior Services)  
<http://www.adss.state.al.us/AlaCare/index.htm>

For more detailed information on Alabama, see Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

**A L A S K A**  
**NFCSP INFORMATION PROFILE**

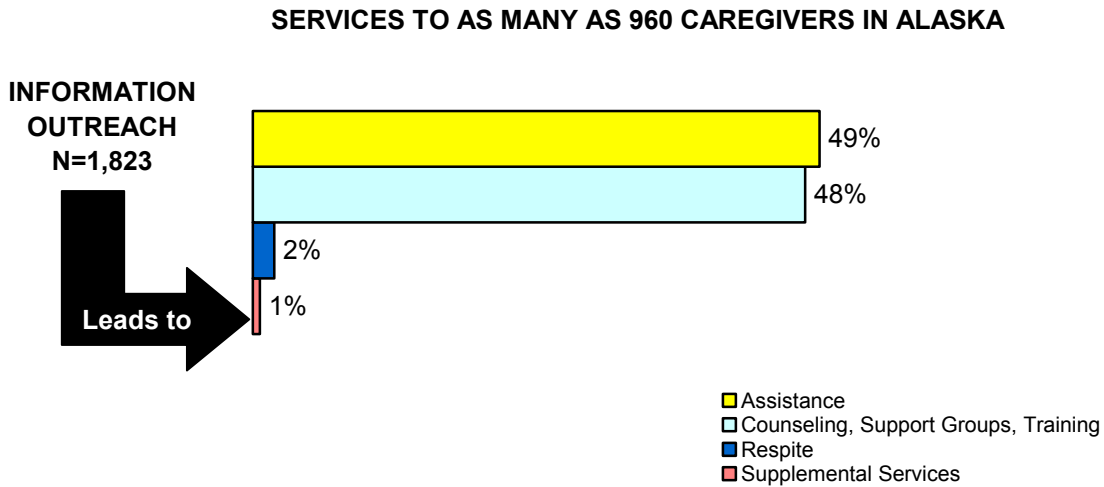
**NFCSP State Contact**

Lisa A. Morley  
 Division Of Senior Services  
 Department of Administration  
 P.O. Box 110209  
 Juneau, AK 99811-0209  
 Phone: (907) 465-4798 Fax: (907) 465-4716  
 e-mail: [lisa\\_morley@admin.state.ak.us](mailto:lisa_morley@admin.state.ak.us)

**Administrative Structure**

Alaska has recognized the importance of family caregiving and has offered services to benefit caregivers for a number of years. However, until recently there was no comprehensive program for family caregivers. The enactment of the NFCSP has allowed for the growth of a more comprehensive program. The Alaska Commission on Aging (ACoA) releases requests for proposals independently of other state and federal grants. Some grantees may combine the NFCSP with other grants from the ACoA but it is not required by the state. Under the NFCSP, cost sharing has been implemented for state-funded Adult Day Programs, care coordination and respite services based on a sliding fee scale.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Efforts of specific Area Agencies include television media spots, radio ads, and newspaper ads; caregiver workshops; public presentations about service options and caregiving issues; and outreach via boat to reach isolated communities connected only by the Yukon River. Adopts innovative caregiving-related training materials created by other states. Provides statewide training materials that explain legal issues that caregiver's might face.

### **Consumer/Family Direction**

Alaska offers a consumer-directed program – separate from the NFCSP - whereby caregivers can hire family members to provide respite for a care recipient as long as they do not live in the same residence. Providers are hired and paid by the host agency.

### **Assessment Standards**

At this time, employs no uniform assessment of caregiver needs.

### **Opportunities**

The ACoA has adopted a two-tiered approach to target seniors in economic need under Title III services. First, primary targeting to the highest concentration of seniors at or below 100% of poverty. Second, targeting Alaska's elderly with the most economic need by making use of the census data (for seniors who are 65+ living at or below 200% of poverty) and weighting the poverty factor at 25%.

### **Information Links**

The Alaska Commission on Aging  
<http://www.alaskaaging.org/>

Alaska Family Caregiver Support & Outreach Projects  
<http://www.hss.state.ak.us/dsds/hcbsforms/FY02FC4web.pdf>

Alaska – Grandparents & Other Relatives Raising Grandchildren  
[http://research.aarp.org/general/kinship\\_care\\_ak.pdf](http://research.aarp.org/general/kinship_care_ak.pdf)

## A R K A N S A S NFCSP INFORMATION PROFILE

### NFCSP State Contact

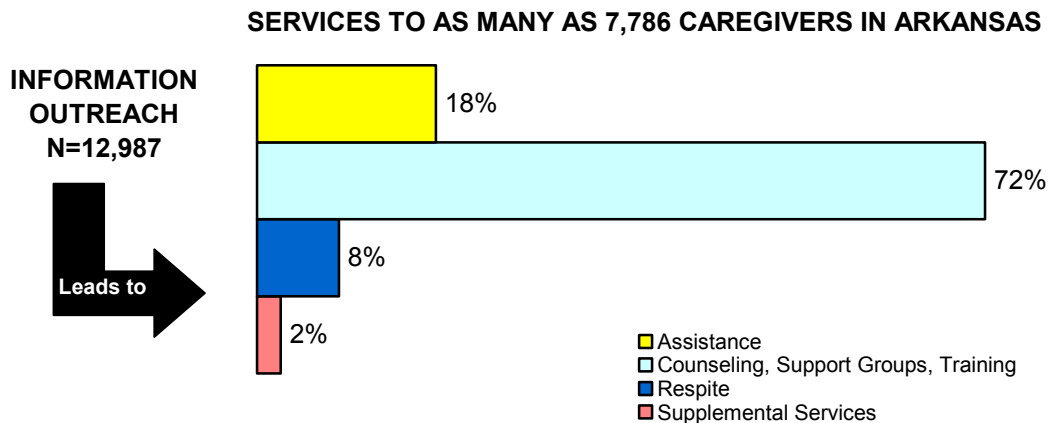
Bean Murray  
Arkansas Division Of Aging & Adult Services  
P.O. Box 1437-5530  
Little Rock, AR 72203-1437  
Phone: (501)-682-8511 Fax: (501) 682-8155  
e-mail: [bean.murray@mail.state.ar.us](mailto:bean.murray@mail.state.ar.us)

### Administrative Structure

Provides caregiver support for the first time as a result of the passage of Title III. To gather information on program needs, Area Agencies partnered with an advertising agency to administer focus groups.

The NFCSP in Arkansas is fully implemented with the exception of the grand parenting component. Cost sharing is implemented on an agency-by-agency basis, with some caregiver in-home services such as personal care and chore.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

Statewide efforts include developing and implementing a statewide informational campaign using TV, radio ads and program brochures. Arkansas also offers one-hour informal educational presentations each month on topics of interest to caregivers; provides in-depth workshops that include informational topics as well as opportunities to develop hands-on skills; and annually distributes calendars with health tips and lists caregiver resources.

Six of eight Area Agencies combined funds and developed a Web page, statewide toll-free number, and created an additional section dedicated to caregiving for the newspaper, *Aging Arkansas*. A video training program is being developed that can be “checked-out” at the local Area Agency.

### **Consumer/Family Direction**

Several Area Agencies provide a combination of vouchers/checks for services under the NFCSP. The caregiver completes appropriate paperwork before reimbursement.

### **Assessment**

At this time, Arkansas does not employ a uniform assessment of caregiver needs.

### **Opportunities**

- Arkansas participates in the ASPE and RWJF-sponsored *Cash and Counseling Demonstration and Evaluation* where Medicaid section 1115 waivers allow care recipients to receive Medicaid benefits as a cash payment, to develop their own care plans and spend their allowances however they choose, including hiring a family member, to meet their disability-related needs. See <http://www.hhp.umd.edu/AGING/CCDemo/>
- Building on its experience giving Medicaid beneficiaries an allowance for their personal care needs, Arkansas is launching a new program to expand consumer direction to other Medicaid-funded services. In the *NextChoice Program* recipients of Medicaid nursing home benefits may voluntarily exchange their benefit to purchase the support services they require to live successfully in the community, including hiring a family member to meet their care needs.

### **Information Links**

Arkansas Division of Aging and Adult Services  
<http://www.state.ar.us/dhs/aging/>

**A R I Z O N A**  
**NFCSP INFORMATION PROFILE**

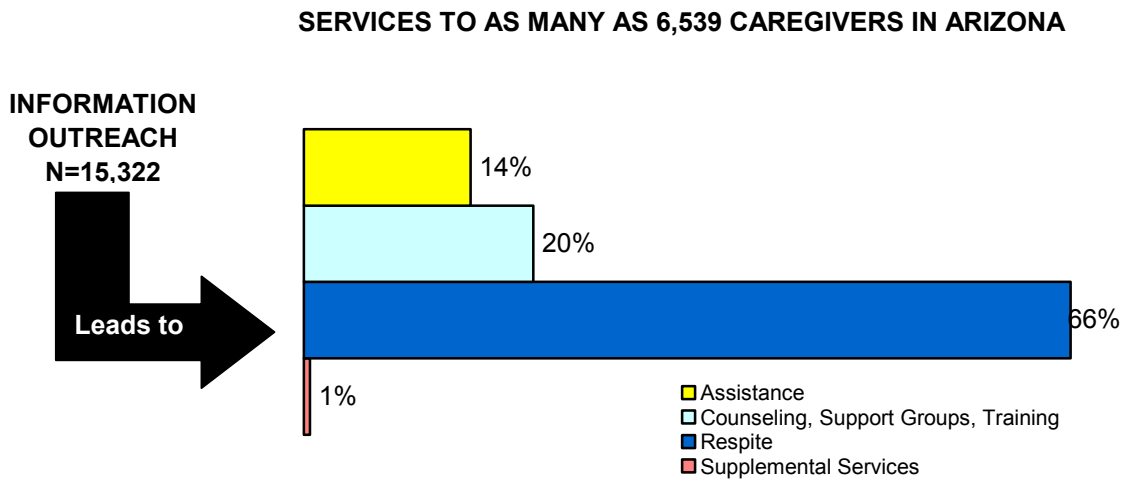
**NFCSP State Contact**

Chris Andrews  
AZ DES, Aging & Adult Administration  
1789 W. Jefferson, 950A  
Phoenix, AZ 85007  
Phone: (602) 542-4446 Fax: (602) 542-65756  
e-mail: [candrews@mail.de.state.az.us](mailto:candrews@mail.de.state.az.us)

**Administrative Structure**

The NFCSP builds on existing state programs serving family caregivers. Arizona has pooled funds with Area Agencies for respite activities. Cost sharing has been implemented for respite services.

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Statewide and local efforts include establishing an area plan priority; providing additional support for *Kinship and Grandparent Raising Grandchildren* programs; and establishing *Caregiver Resource Zones* in public libraries.



### Consumer/Family Direction

Although Arizona does not have a formal consumer directed system, in some instances, a contract provider offers three options for the caregiver to choose from, providing some flexibility. Both concerns and opposition have been expressed about how to set up and manage payment to family caregivers.

### Assessment Standards

(Information is forthcoming).

### Opportunities

- The Pima Council on Aging of Arizona is a recipient of an AoA-sponsored NFCSP innovation grant to develop, test and implement a culturally proficient model of family caregiver support to meet the needs of Mexican-American caregivers and elders. The project design uses focus groups to define the needs of community caregivers and develop program activities. It also provides caregiver-defined services, including peer support, workshops and training on caregiving techniques, community resources, and social activities. For more information go to: <http://www.arizonacaregivers.org/pcoa.html> or [www.pcoa.org](http://www.pcoa.org)
- The United Cerebral Palsy of Southern Arizona is a recipient of an AoA-sponsored NFCSP innovation grant to increase services to grandparents and older caregivers who are raising children with mental retardation or developmental disabilities. The project is identifying barriers to access and implementing a voucher system to access services. The *Special Needs and Behavioral Resource Manual*, the *Respite Care* pamphlet, the *Trainers Guide*, and the *Individual Education Plan Manual* can be accessed from the UCPSA website at <http://www.ucpsa.org>. An additional product, *Grandfamilies: Kin caregivers in Southern Arizona* is available in VHS and DVD formats. For more information contact Jane Latane at: [Jlatane@ucpsa.org](mailto:Jlatane@ucpsa.org) or Yolanda Sevillano at: [ysevillano@ucpsa.org](mailto:ysevillano@ucpsa.org).

### Information Links

Arizona Department of Economic Security/ Caregivers – Home and Community-Based  
<http://www.de.state.az.us/senior/caregivers.asp>

Arizona Grandparents and Other Relatives Raising Children  
[http://www.casey.org/cnc/documents/kinfacts\\_az.pdf](http://www.casey.org/cnc/documents/kinfacts_az.pdf)

Arizona – Caregiver.com – Support Group Directory  
<http://www.caregiver911.com/supportgroups/state/AZ.htm>

**C A L I F O R N I A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

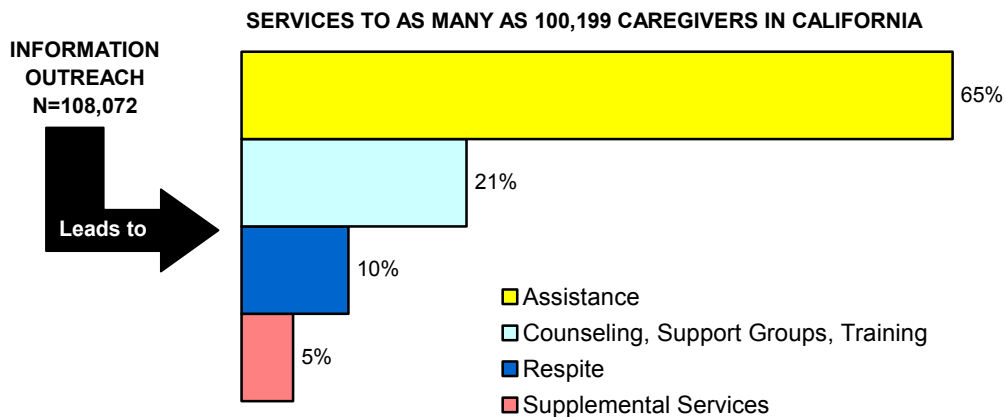
Sherry Hanna  
 Department Of Aging  
 1600 K Street  
 Sacramento, CA 95814  
 Phone: (916) 322-0783 Fax: (916) 324-1903  
 e-mail: [Shanna@aging.ca.gov](mailto:Shanna@aging.ca.gov)

**Administrative Structure**

State statute has recognized family caregivers since 1979. Two state agencies administer explicit caregiver support programs, the Department of Aging for the National Family Caregiver Support Program; and the Department of Mental Health for the Caregiver Resource Centers (CRC)(statewide since 1989). With two state agencies administering explicit caregiver support programs, administrative challenges abound in relation to program standards, service package, reporting requirements, and others. CRCs are limited by insufficient respite funding, statewide service consistency and focus (serving caregivers of the cognitively impaired).

Each Area Agency is not required to provide all 5 core service components, but an Area Agency must explain how services are being addressed in the PSA.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Partnering with the University of California at Berkeley to conduct inventories of caregiver resources available in the state, convene focus groups to better understand caregiver needs, and conduct research on best practices in providing caregiver services.
- Developing an *Aging Resource Kit*, 1-800 statewide number.
- Employing a *Mobile Van Tour* to reach remote, hard-to-access areas.

Efforts of specific Area Agencies include: Implementing public service campaigns, a Mobile Van Tour, and a training curriculum targeted to minority caregivers.

### **Consumer/Family Direction**

In-Home Support Services Program (state/federal funding) offers consumer direction and permits payment to family caregivers. The state-funded CRC program is a model for other states, providing a range of services and respite options, including payment to families to provide respite services. Through the NFCSP, some Area Agencies offer emergency cash assistance and service vouchers to caregivers for the purchase approved goods or services.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- Recent caregiver policy initiatives include a \$500 tax credit (2000) and the first paid family leave bill in the nation, expanding on the federal family medical leave act (2002).
- The American Society of Aging (ASA) of California is a recipient of an AoA-sponsored NFCSP innovation grant to develop and implement a training program to increase the skills and knowledge of professionals providing needed services to family caregivers. This includes two approaches: 1) a web-based/CD-ROM curriculum, and 2) a teleconferencing/ e-seminar program. ASA is collaborating with the American Nurses Association, the American Occupational Therapy Association, and the National Association of Social Workers. Forthcoming grant products include: project planning materials; a survey instrument; modules of family caregiving (most converted to CD ROM); case studies including an expert question and answer section; an extensive resource list; Trainers Manual; presentations prepared for over 10 workshops; marketing and outreach materials; 10 on-line web seminars; CD ROMs of web seminars; CEU applications and several reports.
- The Asian Community Center of Sacramento Valley, Inc. of California is a recipient of an AoA-sponsored NFCSP innovation grant to sustain and support Asian American and Pacific Islanders family caregiver efforts through a community-based wellness, lifelong learning and information program. Forthcoming grant products include: the Asian Community Center brochure; the “virtues” of caregiving brochure; Adult Day Program poster; Fact Sheet on Caregiving and the Asian Pacific Islander Family Caregiver Services; news articles that feature caregivers; the Drop-In Respite brochure; and Transportation Service outreach materials.

- The Aging and Adult Services Employment and Human Services of Contra Costa County California is a recipient of an AoA-sponsored NFCSP innovation grant to provide assistance, support, educate and empower family caregivers of older persons who have been placed in or are transitioning back to the community after receiving care in skilled nursing facilities. Forthcoming tools include *Dual Care Plans*; *Modified Assessment Tool for Caregivers*; policy and procedures; a marketing and outreach plan; and a multi-disciplinary and multi-agency case conferencing format.
- The Family Caregiver Alliance, National Center on Caregiving of California, is a recipient of an AoA-sponsored NFCSP innovation grants to complete a 50-state survey of federal and state-funded caregiver support programs, including the NFCSP, state general revenue funds, Medicaid waivers, systems change grants and other state funding streams. Survey results are forthcoming.
- The University of Southern California Andrus Gerontology Center, National Resource Center on Supportive Housing and Home Modification is a recipient of an AoA-sponsored NFCSP innovation grant to create and stimulate improved systems of supportive services that increase utilization of environmental coping strategies by caregivers. USC plans to educate the *Aging Network* on how to effect systems change in delivering home modification and assistive devices. For more information see: <http://www.usc.edu/48hrs>
- 2001 Legislation/Enacted – California SB 739 indicates the Department of Aging must establish guidelines designed to ensure the quality of services provided with the NFCSP funds.<sup>†</sup>

### Information Links

California Caregiver Resource Center:

<http://www.dmh.cahwnet.gov/SpecialPrograms/Caregiver/caregive-overview.asp>

California's Family Caregiver Support Program Findings & Recommendations:

[http://cssr.berkeley.edu/aging/pdfs/CFCS\\_ExecSumm.pdf](http://cssr.berkeley.edu/aging/pdfs/CFCS_ExecSumm.pdf)

For more detailed information on California, see Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

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<sup>†</sup> Source: National Conference of State Legislators, July 2003.

**C O L O R A D O**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

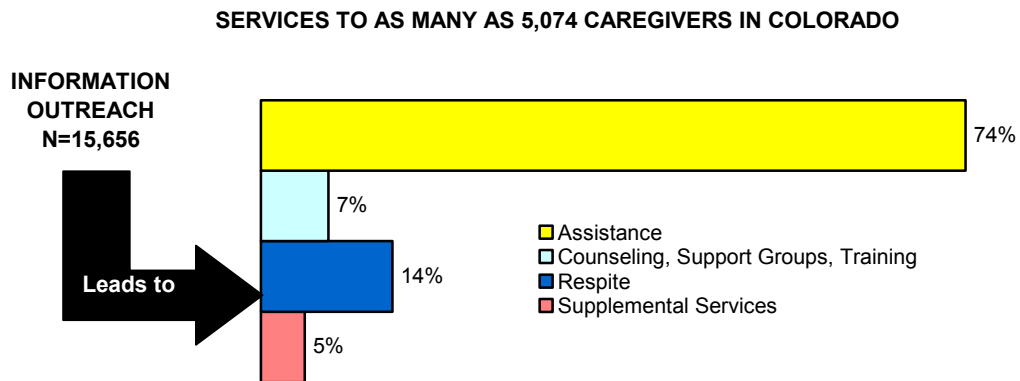
John Treinen or Susan Cornejo  
 Division Of Aging And Adult Services  
 Department of Human Services  
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 Ground Floor  
 Denver, CO 80203-1714  
 Phone: (303) 866-2800 Fax: (303) 866-2696  
 e-mail: [John.Treinen@state.co.us](mailto:John.Treinen@state.co.us) | [Susan.Cornejo@state.co.us](mailto:Susan.Cornejo@state.co.us)

**Administrative Structure**

Colorado had one Area Agency on Aging who was able to build their family caregiver services based on an existing program. The balance of the state implemented the NFCSP from grass roots when the federal funding became available.

Area Agencies organized local town hall meetings to obtain input from their communities on needs and priorities for the caregiver program.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Participating with Older Women’s League (OWL).
- Developing a state website and promotional campaign.
- Coordinating *Thou Shalt Honor* family caregiver documentary with PBS Station to include a phone bank.
- Providing promotional information via a *CareVan* (associated with *BenefitsCheckUp* of Colorado) throughout the state.
- Disseminating 30,000 copies of a detailed *Caregiver Resource Guide*.
- Collaborating with Area Agencies to maximize public awareness using TV and radio stations.

### **Consumer/Family Direction**

Area Agencies provide funding to caregivers in the form of vouchers to purchase respite and supplemental services, including transportation.

### **Assessment Standards**

The State Unit on Aging has developed an Intake form that includes a caregiver component. Some AAA’s have implemented this assessment tool. The goal is to have a statewide assessment tool that includes a caregiver component.

### **Opportunities**

- The University of Denver Institute of Gerontology of Colorado is a recipient of an AoA-sponsored NFCSP innovation grant to demonstrate an empowerment-oriented intervention that increases the value of older care-receivers in self-care, use of services and support networks, communications skills and other aspects of care-receiving that assists their caregivers and improves the quality of the overall care process. A project summary report is forthcoming.
- 2002 Legislation – Colorado enacted HB 1067, creating the NFCSP to provide money to Area Agencies on Aging for caregiver support services and services to family caregivers of older individuals and to grandparents or older individuals who are relative caregivers of children.<sup>s</sup>

### **Information Links**

Colorado Department of Human Resources:

<http://www.cdhs.state.co.us/default.htm>

Division of Aging and Adult Services:

<http://www.cdhs.state.co.us/oss/aas/index1.html>

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<sup>s</sup> Source: National Conference of State Legislators, July 2003.

**C O N N E C T I C U T**  
**NFCSP INFORMATION PROFILE**

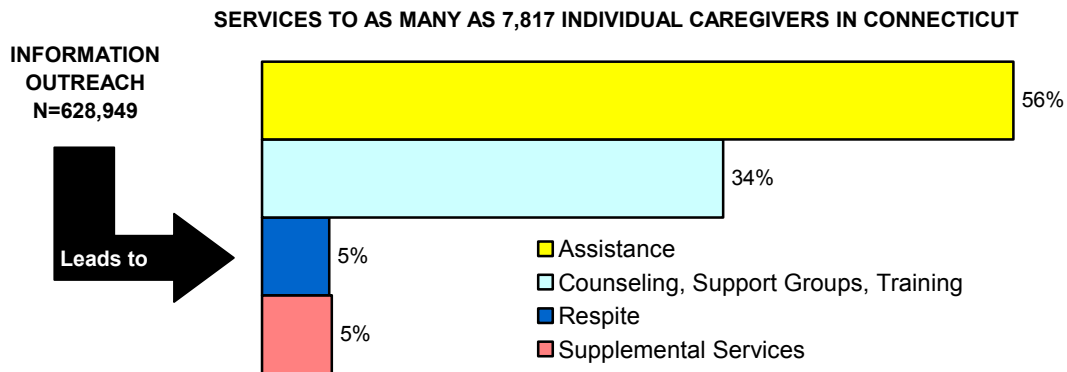
**NFCSP State Contact**

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**Administrative Structure**

Connecticut had a state caregiver program prior to Title IIIE. The NFCSP builds on this existing state program. That Program provides support to caregivers who have loved ones with Alzheimer’s disease through their State Alzheimer’s Care Program.

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Efforts of specific Area Agencies include:

- Adopting innovative caregiving-related education materials/activities created by other states.
- Developing a caregiver section in libraries
- Establishing a caregiver-to-caregiver network
- Developing a staff training manual.

### **Consumer/Family Direction**

Area Agencies provide funding to caregivers in the form of vouchers to purchase supplemental services.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- State government has been active in leading the policy debate about work and family. Connecticut has passed the first law on family and medical leave in 1989.
- 2001 Legislation/Enacted – Connecticut HB 6909 indicates that any state agency, when developing or modifying any program that provides assistance or support to people with LTC needs, will, to the maximum extent feasible, include provisions that support caregiving provided by family members and other informal caregivers and promote consumer directed care.<sup>†</sup>

### **Information Links**

Caregiving (Connecticut Division of Elderly Services)  
<http://www.ctelderlyservices.state.ct.us/ProgramsFrm.htm>

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<sup>†</sup> Source: National Conference of State Legislators, July 2003.



**DELAWARE**  
**NFCSP INFORMATION PROFILE**

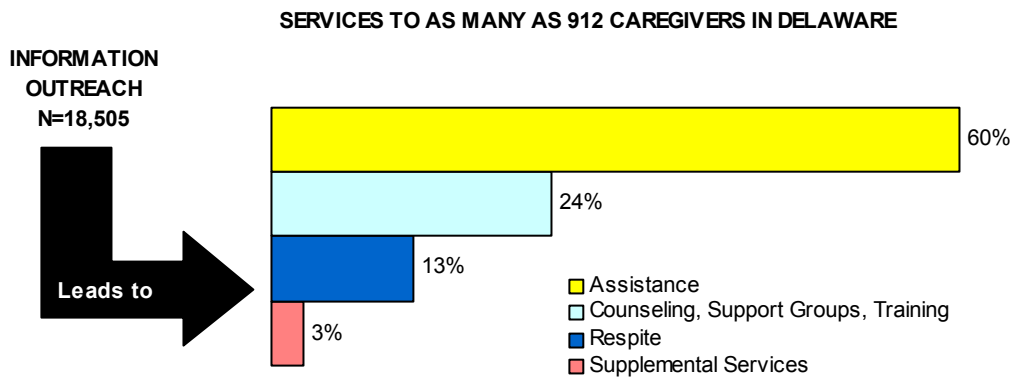
**NFCSP State Contact**

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**Administrative Structure**

The Division Social Worker/Case Managers determines eligibility and caregivers who qualify for Title III-E supplemental assistance services, particularly home modification and emergency response system services.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Developing a major public relations campaign using a comprehensive media and materials package. As part of this campaign, Hispanic community leaders joined forces to discuss strategies to reach out and serve the Hispanic community in Delaware.
- Participating in a community-based partnership with *CareVan – Community Action to Reach the Elderly* to provide information about community services such as the Division’s caregiver support program in remote, hard-to-access areas.
- Working in cooperation with, and serving as a resource to the state’s Title III-E efforts, there is a state-based Economic Development Office Resource web page; designed to increase elder care awareness to employers and employees. The importance of these issues to employers’ overall economic development are emphasized; and employers can access information about childcare, family and medical leave and elder and adult services on this site.

### **Consumer/Family Direction**

Delaware is interested in developing consumer/family directed caregiver options in the future.

### **Assessment Standards**

State Unit has specifically designed a caregiver assessment tool for the NFCSP.

### **Opportunities**

- Delaware is developing a tool for the State Unit on Aging to gather reporting requirement information.

### **Information Links**

Caregiver Information and Support (Division of Services for Seniors and Adults with Physical Disabilities).

<http://www.dsaapd.com/caregive.htm>

**DISTRICT OF COLUMBIA  
NFCSP INFORMATION PROFILE**

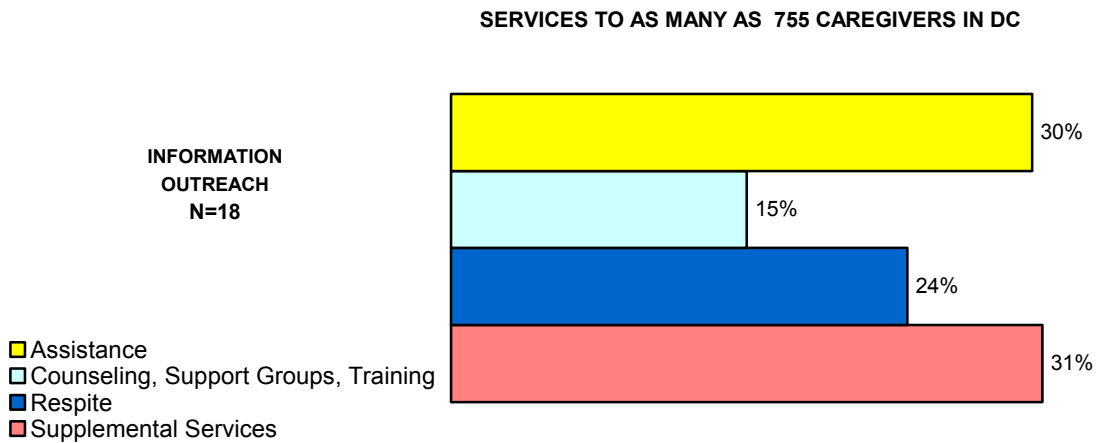
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**Administrative Structure**

The NFCSP builds on a locally funded plan for the *Caregiver Institute* program that serves family caregivers.

**Services/Number of Caregivers Served – FY 2002**



### Public Awareness/Education

Public awareness/ education is of a general nature.

### Consumer/Family Direction

Caregivers enrolled in the *Caregiver Institute* and caregivers receiving stipend funds from other programs arrange for the services they need. The Institute and grantees allow participants to use funds to pay family members and friends for services. No state policy has been issued, but the Office on Aging has approved this practice. Cash is provided to caregivers to reimburse them for the services they have purchased. Cash may be used to purchase in-home respite, institutional respite, supplies or whatever the caregiver needs to reduce their caregiving burden, with prior approval.

### Assessment Standards

Employs a *Caregiver Intake Form*.

### Opportunities

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- The American Association of Retired Persons (AARP) of the District of Columbia is a recipient of an AoA-sponsored NFCSP innovation grant to develop and implement a training program to encourage the formation of coalitions and strengthen family caregiver coalitions. Reports and resources are forthcoming.
- The ARC of the United States of the District of Columbia is a recipient of an AoA-sponsored NFCSP innovation grant to build service capacity to *Aging Network* constituents and disability provider organizations through cooperative planning, coordinating and supportive services to older caregivers of children and adults with intellectual and developmental disabilities. Technical assistance and training is provided throughout the United States. Grants products include: *The Wit to Win: How to Integrate Older Persons with Developmental Disabilities Into Community Aging Programs* (<http://www.uic.edu/orgs/rrtcamr/witowin.htm>); *Help for Caring: A Manual for Area Agencies on Aging Aiding Households with a Person with a Developmental Disability* (<http://www.uic.edu/orgs/rrtcamr/helpforcaring.htm>); *Key Issues in Working with Carers/Grandparents* (<http://www.uic.edu/orgs/rrtcamr/familygrandparents.pfd>); *Key Issues in Working with Older Carers* (<http://www.uic.edu/orgs/rrtcamr/oldercarers.pdf>); *How the Social Security Administration Defines Disability for Social Security Benefits Eligibility* (<http://thearc.org/afcsp/agingcaregiver.htm>); *Appealing a Decision by the SSA for Disability Benefit Eligibility* (<http://thearc.org/afcsp/agingcaregiver.htm>). Also see, *Aging Family Caregiver Support*, The Arc, US (<http://www.thearc.org/afcsp/agingcaregiver.htm>); and *The Arc's National Training Project on Helping Older Families*, RRTC on Aging with DD, University of ILL at Chicago (<http://www.uic.edu/orgs/rrtcamr/familya.html>).
- Generations United of the District of Columbia is a recipient of an AoA-sponsored NFCSP innovation grant to establish the National Center on Grandparents and Other Relatives Raising Children which develops and coordinates groups of experts to provide technical assistance and training to the *Aging Network*. This project also publishes and disseminates training materials and tracks state laws and programs. Grant products include over 10 fact sheets on

*Grandparents and Other Relatives Raising Children* and several publications. For more information visit <http://gu.org> or call (202) 638-1263.

- The National Association of Area Agencies on Aging of the District of Columbia is a recipient of an AoA-sponsored NFCSP innovation grant to strengthen the ability of Area Agencies on Aging and Title VI grantees in serving family caregivers through a local, state and national campaign to involve physicians in identifying caregivers and referring them to the NFCSP. *Making the Link: Connecting Caregivers with Services through Physicians* will produce a Project Toolbox; a sample Physician Resource Kit; and various PowerPoint presentations.
- The National Association of State Units on Aging of the District of Columbia is a recipient of an AoA-sponsored NFCSP innovation grant to identify barriers, challenges, opportunities and recommend potential approaches to link caregivers with existing state home- and community-based services. The project is convening a series of national teleconferences and developing a series of educational materials to assist state units on aging in their leadership role of developing statewide caregiver programs. Forthcoming grant products include system development guides; research briefs; and executive summaries. The first in a series of system development guides, *Systematic Development of the Family Caregiver Support Program: Considerations for the Services Package*, provides an in-depth look at the family caregiver support program services package (see <http://aoa.gov/prof/aoaprogram/caregiver/caregiver.asp>) or <http://www.nasua.org/> for more information.

### Information Links

(Information is forthcoming).

**F L O R I D A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

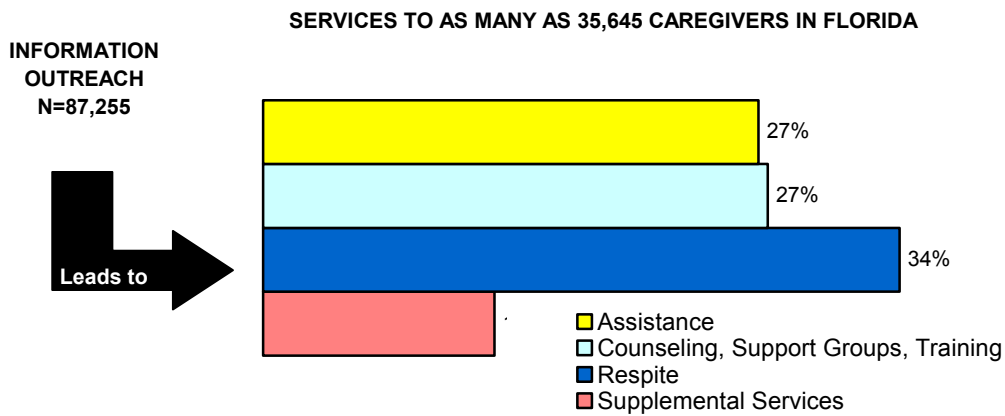
Ron Taylor  
 Department Of Elder Affairs  
 Suite 315  
 4040 Esplanade Way  
 Tallahassee, FL 32399  
 Phone: (850) 414-2000 Fax: (850) 414-2004

**Administrative Structure**

The NFCSP builds on several existing programs serving family caregivers in Florida, including the Alzheimer’s Disease Initiative, Home Care for the Elderly, Senior Companion Program, and Respite for Elders Living in Everyday Families (since 1997), AmeriCorps Programs (since 1996), and the Cash and Counseling Demonstration and Evaluation.

Under the NFCSP, some, not all Area Agencies offer all 5 core caregiver service components. Florida encourages its 11 Area Agencies to reach out to non-traditional service providers (grandparent programs, faith-based organizations, civic groups, etc.) to ensure services are targeted to the needs of diverse populations.

**Services/Number of Caregivers Served – FY 2002**



### Public Awareness/Education

Florida established an *Outreach Resource Center for Culturally Diverse Elders*, targeting caregivers/consumers with information on Medicare fraud and abuse while extending opportunities to learn about available caregiver services.

Efforts of specific Area Agencies include: radio and television programs; training programs; development of a *Caregiver Manual* and *Resource Guide* (English and Spanish); and links to faith-based organizations, grandparents, low-income, rural caregivers.

### Consumer/Family Direction

Area Agencies contract with *Community Care for the Elderly* providers for the provision of the HCE program. Approved caregivers receive a *Basic Subsidy* to reimburse some of their expenses each month for caring for the client, and may receive a *Special Subsidy* for other necessary services and essential supplies. Caregivers may be approved for up to three HCE clients in their home. HCE clients must be age 60+, at risk of nursing home placement, and financially eligible.

Florida has built consumer direction into the NFCSP so that consumers have the option of paying family and informal caregivers to provide respite and personal care.

### Assessment Standards

Applies a uniform statewide assessment for home- and community-based services.

### Opportunities

- Legislative initiative gives grandparents raising grandchildren the same legal status as natural or foster parents to access financial supports.
- The Alliance for Aging, Inc. of Florida is a recipient of an AoA-sponsored NFCSP innovation grant to demonstrate a 24-hour crisis respite and referral system for caregivers of elders and adults with disabilities. This will increase the flexibility and convenience of current services, provide crisis respite for elder caregivers of children and adults with disabilities, recommend ways to reduce stress, and minimize or prevent future crisis events. Reports and resources are forthcoming.
- The Hospice of the Florida Suncoast is a recipient of an AoA-sponsored NFCSP innovation grant to establish and evaluate a multifaceted national project on end-of-life issues providing hospice, palliative care professionals, and family caregiver with in-depth training on caregiver concerns. Forthcoming grant products include journal articles (on the model, results of the needs assessment, and outcomes of the community caregiver program); a national *Caregiving at Life's End Train-the-Trainer Program*; a toolkit of resources and training materials to provide the *Caregiving at Life's End* program in your community. For more information contact (727) 586-4432 or email [caregiving@thehospice.org](mailto:caregiving@thehospice.org) or visit The Hospice website at <http://www.thehospice.org/caregiving>
- Florida participates in the ASPE and RWJF-sponsored Cash and Counseling Demonstration and Evaluation where Medicaid section 1115 waivers allow care recipients to receive Medicaid benefits as a cash payment, to develop their own care plans and spend their allowances

however they choose, including hiring a family member, to meet their disability-related needs. (see also NJ, AR). <http://www.hhp.umd.edu/AGING/CCDemo/>

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- 2002 Legislation/Enacted – Florida enacted HB 27e to appropriate funds for Alzheimer caregiver support programs.<sup>u</sup>

### Information Links

Caring for an Elder (Florida Department on Aging)  
<http://elderaffairs.state.fl.us/doea/english/caring.html>

For more detailed information on Florida, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

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<sup>u</sup> Source: National Conference of State Legislators, July 2003.



**GEORGIA  
NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

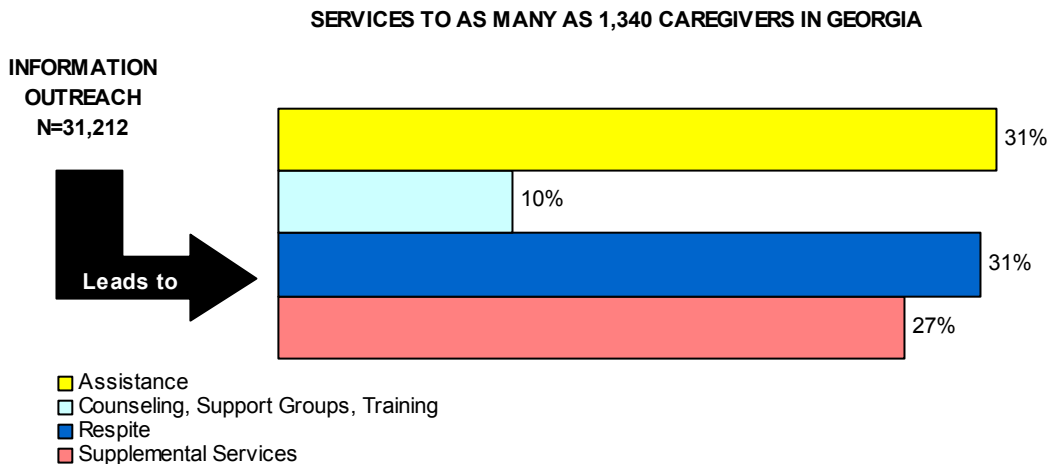
Cliff Burt  
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 Phone: (404) 657-5336 Fax: (404) 657-5285  
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**Administrative Structure**

Developing caregiver programs within the broader HCBS system, facilitating the coordination of services of the NFCSP with its Medicaid Waivers, state-funded and Older American Act services. Funding from the NFCSP enabled the Division to significantly expand the scope of services available in the state through the already established *Georgia Caregiver Resource Center*. Offers caregiver access via a single entry point called, *Gateway*.

The State Unit implemented a cost-share with a sliding fee scale for state-funded Home and Community Based Services (HCBS) some time ago, and has extended that initiative to allow cost share for Title III services.

**Services/Number of Caregivers Served – FY 2002**



### Public Awareness/Education

Statewide activities include two published reports of information gathered from caregiver focus groups for legislators, policy makers, and service providers. The report data also supports local program planning efforts and provides the foundation for continuous improvement in the quality of service delivery.

The *Georgia Caregiver Resource Center* funds regional caregiver-training events each year for families and professionals. Plans to expand mobile day care program to increase access to rural caregivers.

All twelve Area Agencies in Georgia have pooled funds to publish a quarterly magazine, *Georgia Generations*, covering an array of topics (grandparents raising grandchildren, depression, legal issues, prescription drugs and others) and distributed in non-traditional venues (physician offices, pharmacies, and others). Several Area Agencies on aging have developed multi-faceted programs for grandparents raising grandchildren.

### Consumer/Family Direction

Seven Area Agencies have self-directed programs (five are funded with Title III-E demonstration grant monies; two are funded through regular Title III-E funds). Some Area Agencies reimburse caregivers for expenses listed on care plan with adequate documentation. A variety of supplemental service options are available via vouchers.

### Assessment Standards

Has no uniform assessment of caregiver needs, however, a pilot project is field-testing a new caregiver burden scale.

### Opportunities

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- The Rosalynn Carter Institute for Human Development of Georgia, is a recipient of an AoA-sponsored NFCSP innovation grants to expand a collaborative network of professional and family caregiver groups, called CARE-NETS. Comprised of family caregivers, educational institutions and businesses, CARE-NETS develop service and educational programs to meet the needs of caregivers. Forthcoming grant products include a journal article, *Building Effective Community Networks: The Rosalynn Carter Institute CARE-NET Prototype*; a manual, *Caregivers Together: Establishing Your Own Community Caregiving Network (A Practical Guide)*; a process evaluation survey; the *Community Caregiving Capacity Index* assessment tool; and a variety of outreach materials (brochures, handouts, presentations, presentations, and program summaries).
- The Georgia Division of Aging Services is a recipient of an AoA-sponsored NFCSP innovation grants to increase service options available to caregivers by developing five self-directed voucher care projects in rural areas that can be replicated in other states. Forthcoming grant products include a *Replication Guidebook* and a video intensive on self-directed care. Oral testimony by Maria Greene before the U.S. Senate Special Committee on Aging Hearing on

*Innovations in the Implementation of Family Caregiver Supports on Consumer-Directed Care*, May, 2003 is available through the Georgia Department of Human Resources, Division of Aging Services.

### **Information Links**

Georgia Division of Aging Services

<http://www2.state.ga.us/Departments/DHR/aging.html>

**H A W A I I**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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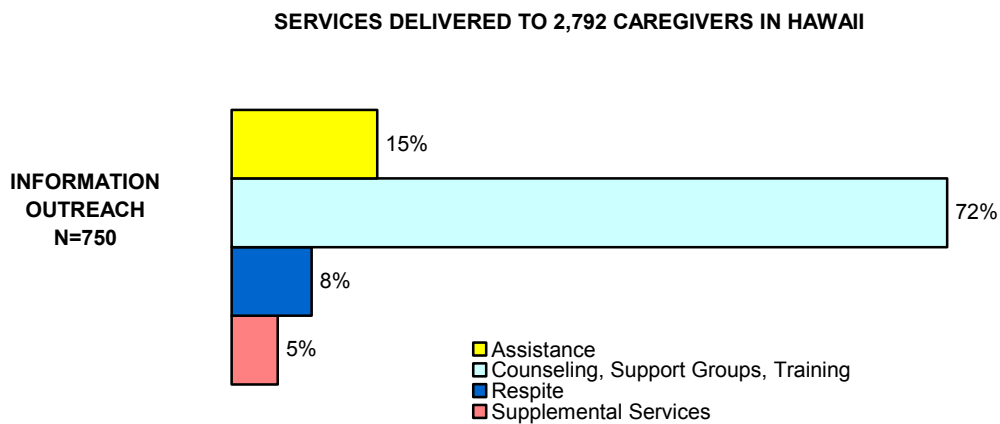
**Administrative Structure**

Provides a formalized system of caregiver support as a result of the passage of the NFCSP. Because of the NFSCP funding, adult day care in Maui County was able to expand.

The needs of the caregivers and the resources of the AAA vary by PSA therefore few Area Agencies provide all 5 core service categories.

Supplemental services are a key component of the caregiver support program, filling an important gap in service delivery. Types of supplemental services include bath modification, installation of adaptive equipments and safety devices, transportation, legal assistance, personal care and development of a caregiver guide.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Public awareness/education is of a general nature.

### **Consumer/Family Direction**

(Information is forthcoming).

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- Extended families most commonly live together in one household.
- The University of Hawaii at Mano, Center on Aging, John A. Burns School of Medicine is a recipient of an AoA-sponsored NFCSP innovation grant to work with community partners to explore the impact of group-targeted messages and individually-tailored support on end-of-life planning by multi-ethnic caregivers of elders receiving long-term care services. Forthcoming grant products include pretest/posttest questionnaires; procedural information; flyers, four booklets (*Advance Care Planning, Planning Ahead, Preparing to Say Goodbye, Help for the Bereaved*) in three languages (English, Samoan, Ilocano); press releases; focus group summary; and outreach materials. For more information visit <http://www.hawaii.edu/aging>
- 2001 Legislation/Enacted – Hawaii SB 597 indicates that supporting family caregivers of adults with disabilities is a long-term goal of the state.<sup>v</sup>

### **Information Links**

(Information is forthcoming).

For more detailed information on Hawaii, see Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

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<sup>v</sup> Source: National Conference of State Legislators, July 2003.

## I D A H O NFCSP INFORMATION PROFILE

### NFCSP State Contact

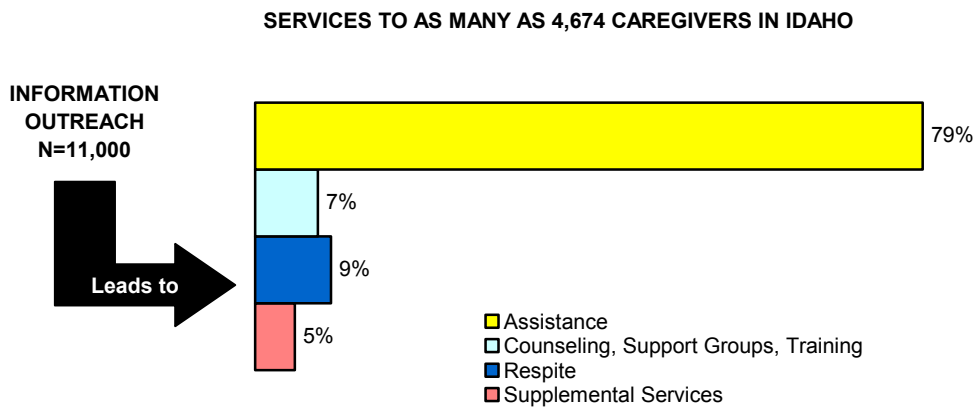
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### Administrative Structure

The NFCSP builds on a small program of case management and respite in Idaho.

For caregivers of related children 18 and younger, Idaho has built on the efforts of a small local coalition, creating the *Idaho KinCare Coalition*. The *Coalition* cultivates the development of support groups statewide and connects the grandparents raising grandchildren programs (supported by some Area Agencies and other agencies in the state) to available resources. This endeavor has been made possible via a 2-year Brookdale Foundation grant, support from AARP, and NFCSP Title III-E funds.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

Statewide efforts include:

- Developing a *Caregiving Resource* book for Area Agencies.
- Administering caregiver support groups.
- Targeting homebound and rural caregiver populations.

Efforts of specific Area Agencies include sponsoring a caregiver conference; offering Adult Day Care programs in rural communities; conducting community listening sessions, and caregiver retreats.

### **Consumer/Family Direction**

Although state has no policy for caregivers to hire family members, some Area Agencies either provide funding to caregivers in the form of cash as an emergency service to grandparents raising grandchildren or vouchers for respite services.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- 2002 Legislation – Idaho enacted SB 1481 to appropriate the entire NFCSP federal grant to the state Commission on Aging.<sup>w</sup>

### **Information Links**

Family Caregiver Support Program (Idaho Commission on Aging)  
[http://www.idahoaging.com/programs/ps\\_caregiver.htm](http://www.idahoaging.com/programs/ps_caregiver.htm)

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<sup>w</sup> Source: National Conference of State Legislators, July 2003.

**ILLINOIS  
NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

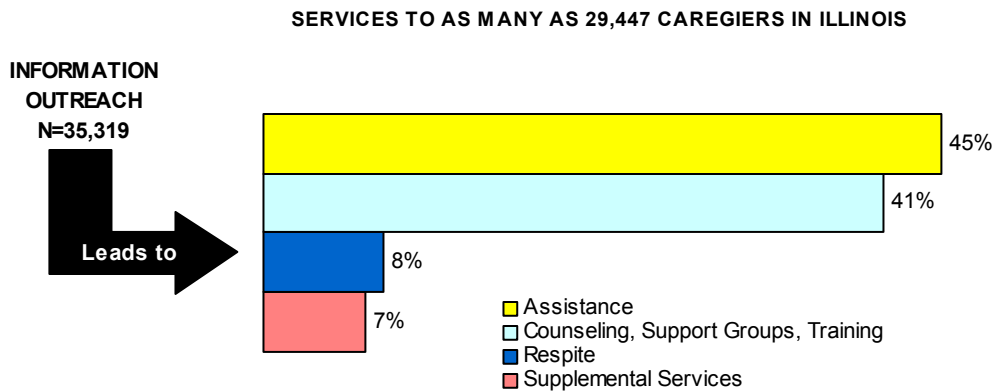
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 email: [joseph.lugo@aging.state.il.us](mailto:joseph.lugo@aging.state.il.us)

**Administrative Structure**

The NFCSP builds on the *Grandparents raising Grandchildren* program originally supported by The Brookdale Foundation (in 1996). Currently, there are over 80 statewide support groups for grandparent caregivers.

Illinois has established more than 100 *Caregiver Resource Centers* throughout the state within existing, familiar locations such as senior centers, libraries, case management units, and county health departments to serve as visible entry points for caregiver services. Area Agencies have the flexibility to designate the Caregiver Resource Center in their area and design the type of service delivery model best suited to the strengths of the local. This approach has provided for easier identification/ recognition of entry points by caregivers seeking services in each community.

**Services/Number of Caregivers Served – FY 2002**





### **Public Awareness/Education**

Statewide efforts include: an aggressive outreach campaign to help family caregivers self-identify and seek help. Components include a family caregiving website; television/radio PSAs (English/Spanish); a 30 minute television program; information on Title III-E inserted in over 300,000 customer utility bills; and newspaper columns on family caregiving appearing in over 150 statewide newspapers.

Efforts of specific Area Agencies include: presentations to 18 local police chiefs, support groups and trainings hosted by faith-based institutions, information on Title III-E in church bulletins and newsletters, billboards, and customized grocery receipts. Area agencies have provided outreach to ethnic and limited English-speaking caregivers, including Assyrian, Chinese, Russian, Korean, and Ukranian populations through use of pictorial/audio storyboards and interaction with local case coordinators in order to link minority caregivers to the system.

### **Consumer/Family Direction**

Although no formal consumer/family directed system exists, a number of focused efforts are underway at specific Area Agencies, including administering pilot programs, family meetings, family-first strategies, and family counsels.

### **Assessment Standards**

At this time, no uniform assessment of caregiver needs is in place. Various assessment forms have been developed by Area Agencies.

### **Opportunities**

- State Unit on Aging has expanded its Website (below) to include caregiver information and direct links to Area Agencies on Aging.
- Easter Seals of Illinois is a recipient of an AoA-sponsored NFCSP innovation grant to meaningful solutions to the concerns and questions of caregivers about transporting older adults. This project will produce an extensive transportation solutions package for the *Aging Network* that includes a video, informational booklet, and a list of helpful products and resources for family caregivers and volunteer drivers. This “toolkit” is currently accessible on-line at [http://www.easter-seals.org/ntl\\_trans\\_care](http://www.easter-seals.org/ntl_trans_care). A facilitator’s manual, *Transportation Solutions for Caregivers: A Starting Point*, includes presentation materials on CD ROM as well as talking points and evaluation strategies.
- The Healthcare Consortium of Illinois is a recipient of an AoA-sponsored NFCSP innovation grant to establish a caregivers assistance registry that will improve identification and support of caregivers and expand access to in-home respite services by enhancing coordination among service providers in four predominantly African –American communities on Chicago’s south side. Forthcoming grant products include program-related materials (Caregiver Database Registry, training sessions and related instruments, resource information on caregiver support services, In-Home Respite Program, caregiver coordination council); grant administration materials; marketing information (advertising materials and grant summary); and the evaluation framework (interview protocols, summary of case manager interviews, compendium of articles and resources).

- The Illinois Department on Aging is a recipient of an AoA-sponsored NFCSP innovation grant to provide supportive services to frail older caregivers who are the parent, legal guardian or family member caring for an adult child with developmental disabilities. The project works to maximize independence through employing a holistic family approach and using joint waivers and shared resources with the potential of cost-cutting. Forthcoming grant products include a one-page synopsis; brochure; *The Future is Now: A Future Planning Training Curriculum for Families and Their Adults Relatives with Developmental Disabilities* (includes *Family Caregiver Workbook*); and *Future Planning Resource Guide*.
- Mather LifeWays of Illinois is a recipient of an AoA-sponsored NFCSP innovation grant to implement a regional family caregiver education project to deliver a cadre of experienced trainers who will work with a coalition of local aging service providers to improve caregiver outreach, service referrals and follow-up. The products of the Powerful Tools for Caregivers project include the *Train-the-Trainer Program* and *Caring with Confidence* newsletter. To access additional information visit: <http://www.tools4caregivers.com> and <http://www.matherlifeways.com> or contact Susan Rothas at: [srothas@matherlifeways.com](mailto:srothas@matherlifeways.com)
- 2003 Legislation /Passed House – Illinois passed HB1087, creating the aging family caregiver assistance program; HB 1196, creating the Family Caregiver Act; and HB 2268, creating a bipartisan Health Care Reform Commission that makes recommendations to the governor regarding delivery of LTC services, including utilizing family and friends for informal caregiving.<sup>x</sup>

#### Information Links

Illinois Family Caregiver Support Program (Illinois Department on Aging)  
<http://www.state.il.us/aging/1caregivers/caregivers-main.htm>

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<sup>x</sup> Source: National Conference of State Legislators, July 2003.

**I N D I A N A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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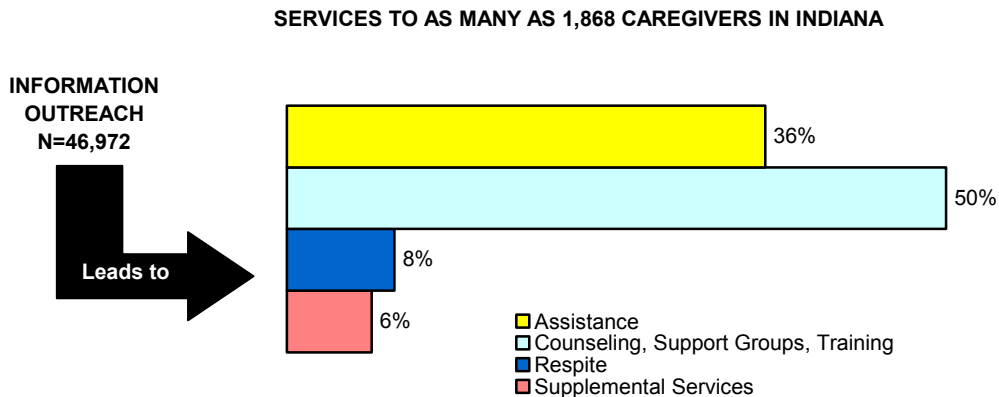
**Administrative Structure**

Specific caregiver support programs were not in place prior to the passage of Title III-E.

Implementation efforts include a *shift in thinking*, placing emphasis on the family caregiver in care planning. Indiana offers single point-of-entry for all home and community-based programs at the local level via Area Agencies.

Area Agencies provide any or all of the 5 core NFCSP services.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

The Area Agency Association in Indiana has developed brochures and public service announcements for the NFCSP.

Area Agencies work collectively on publicity and outreach, pooling funds to develop a statewide caregiver campaign. Several Area Agencies have unique websites promoting the NFCSP. Others have worked to utilize libraries in rural communities to make information and assistance available to caregivers. This includes information, training and support groups.

### **Consumer/Family Direction**

Consumer direction is being piloted in the state-funded CHOICE program, but not in the NFCSP or Medicaid waiver. Both the CHOICE program and Medicaid waiver have extensive waiting lists. The NFCSP has allowed some families to get services while a relative is on a waiting list for other programs via a voucher.

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- Indiana sees an opportunity to better educate Baby Boomers and the elderly on caregiving and related self-care issues.
- Indiana is working towards incorporating more consumer-directed options via vouchers so that caregivers may purchase needed services.
- 2003 Legislation/Passed Senate – Indiana SB 493 establishes a caretaker support program.<sup>y</sup>

### **Information Links**

(Information is forthcoming).

For more detailed information on Indiana, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

<sup>y</sup> Source: National Conference of State Legislators, July 2003.

**I O W A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

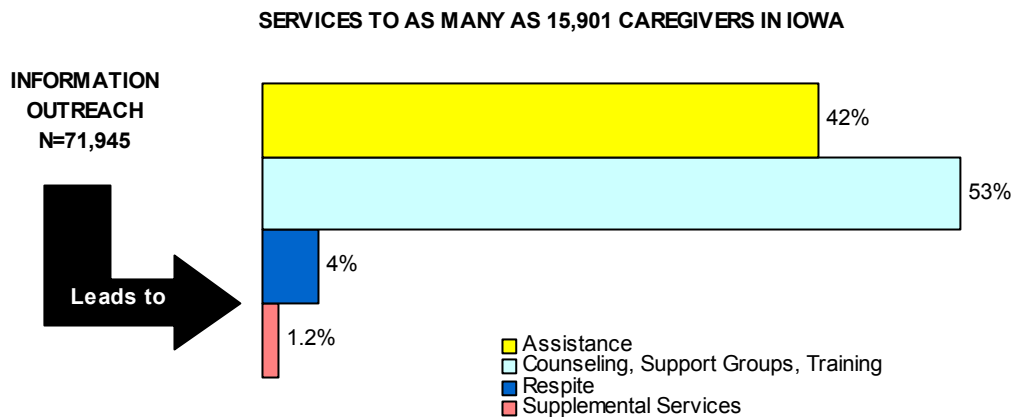
Nicki Stajcar, Consumer Protection Advocate  
 Department Of Elder Affairs  
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 Phone: (515) 242-3320 Fax: (515) 242-3300  
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**Administrative Structure**

The NFCSP is the first program in the state to focus on the needs of family caregivers in Iowa. Area Agencies offer all of the 5 core service components, but each provides a different level of service based on funding allocation.

The Area Agency on Aging Association provides leadership and coordination for the caregiver program. Efforts are coordinated between the State Unit on Aging and the Area Agencies. Each Area Agency on Aging has a designated *Family Caregiver Specialist* who receives continuous training on maintaining and updating the data on resources available in their respective area. In addition, the *Caregiver Specialists* receive training on 211 contact for older persons.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Iowa is developing a single-point-of-entry for caregiver access via a standard *Information and Assistance* network and toll-free number. A website and informational brochure have been developed.

Area Agencies have pooled some funding for joint activities, including promoting a consistent statewide identity, *Iowa Family Caregiver*.

### **Consumer/Family Direction**

Consumer direction level varies by Area Agency. Caregivers choose services to best meet their needs from a menu of service options provided by a care manager. Caregivers have the option of hiring family and friends to provide respite. Family and informal respite providers are paid through vouchers.

The developed care program goes to a steering committee comprised of a variety of service providers and volunteers for approval.

### **Assessment Standards**

Case management is strong at the Area Agency level for home- and community-based services. The Family Caregiver Specialists do direct assessment of caregivers. This assessment does not have to go through case management, although the specialist many times refers the caregiver to case management for services to the person for whom they are providing care.

### **Opportunities**

- 2003 Legislation/Enacted – Iowa enacted HB 386 to add “support for caregivers” in the state’s objectives for serving older individuals.<sup>z</sup>

### **Information Links**

Iowa Family Caregivers Support Program (Iowa Association of Area Agencies on Aging)  
<http://www.iowafamilycaregiver.org/>

For more detailed information on Iowa, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

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<sup>z</sup> Source: National Conference of State Legislators, July 2003.

**K A N S A S**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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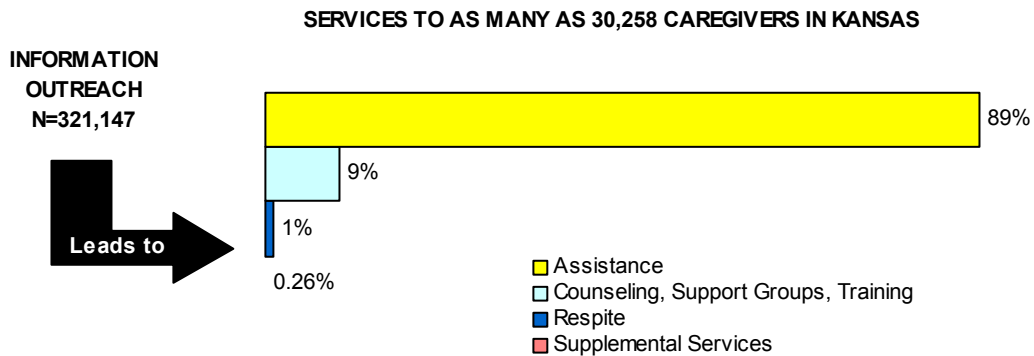
**Administrative Structure**

To better meet the needs of the Caregiver a "Flex Service" category was added to the list of supplemental services. This service is designed to provide support to the caregiver when other resources have been researched, are unavailable, and does not meet any other III-E service definition in the SUA taxonomy.

Six Area Agencies specifically offer grandparent services, including: information, assistance, repair/maintenance/renovation, support groups, and counseling for this caregiver population.

(Additional information forthcoming).

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Kansas has developed a *Caregiver Guide*, available on-line at: [www.agingkansas.org/kdoa](http://www.agingkansas.org/kdoa).

The Area Agency on Aging Association, through an Administration on Aging discretionary grant, developed the *Circle of Care Program*, a caregiver hotline and conducted a public information campaign in eleven public service areas.

Additional efforts of specific Area Agencies include a *Caregiver Van* that serves as a resource center in rural areas and a caregiver curriculum for training.

### **Consumer/Family Direction**

At this time, there is no formal consumer-directed caregiver service system.

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- The *Ten County Aging Board, Inc.* of Kansas is a recipient of an AoA-sponsored NFCSP innovation grant to support a statewide caregiver marketing and media campaign to increase public awareness of caregiving, provide caregiving tips, and inform people of available resources. Reports and resources are forthcoming.

### **Website Links**

*Caregiver Guide*  
<http://www.agingkansas.org/kdoa>



## KENTUCKY NFCSP INFORMATION PROFILE

### NFCSP State Contact

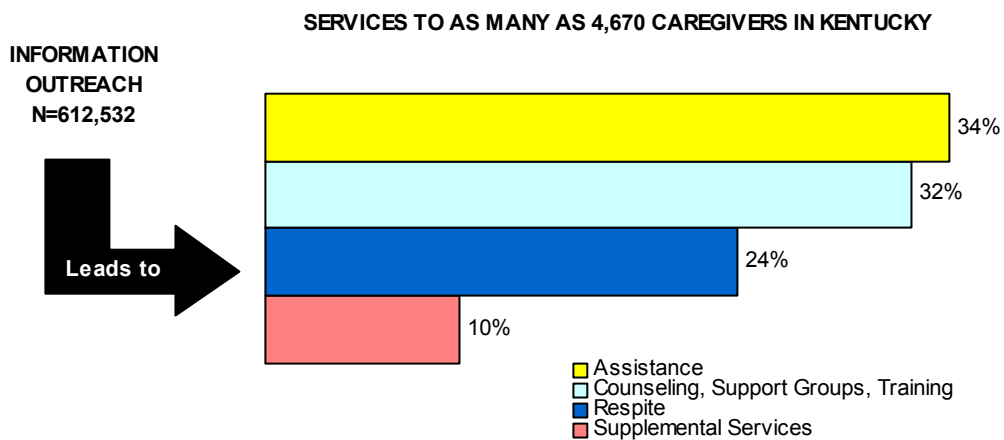
Phyllis Culp  
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Phone: (502) 564-6930 Fax: (502) 564-4595  
e-mail: [phyllis.culp@mail.state.ky.us](mailto:phyllis.culp@mail.state.ky.us)

### Administrative Structure

Kentucky is developing a single-point-of-entry-system for caregiver access within the AAA area.

Two Area Agencies have implemented cost sharing for support groups, respite and supplemental services.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

Statewide efforts include facilitating a networking and training opportunity for caregiver coordinators to share information and resources (on a semi-annual basis).

Efforts of specific Area Agencies include: administering a caregiver mental health symposium; picnic for grandparents with health screenings/training; Senior Expo; pre-paid postcards to access program information; caregiver support groups/training facilitated by university nursing students and held at the Barnes and Noble Book Store community room; and publications in local newspapers.

Training materials are targeted to Spanish-speaking, low-income, and deaf interpreters. Efforts of specific Area Agencies include coordinating a *Community Caregiver Coalition* to develop training modules for use in a variety of settings and developing a *Caregiver Manual* and presentation for corporate industry training to help employed caregivers access supports and services.

Outreach efforts to grandparent caregivers, caring for persons 18 years and under are significant.

### **Consumer/Family Direction**

Includes payments for family members in seven of twelve Area Agencies using vouchers for consumer directed respite or supplemental services.

### **Assessment Standards**

(Information is forthcoming).

### **Information Links**

(Information is forthcoming).

**LOUISIANA  
NFCSP INFORMATION PROFILE**

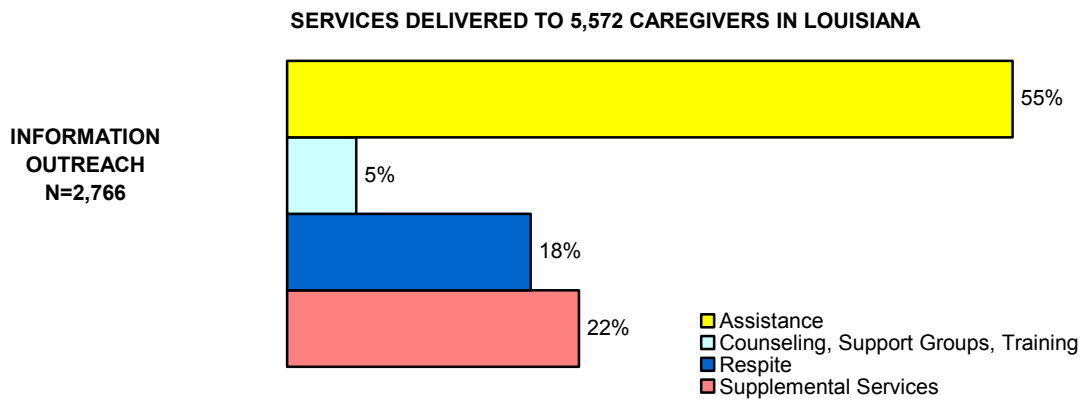
**NFCSP State Contact**

Mary Tonore  
Office Of Elderly Affairs, HCBS  
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Phone: (225) 342-9722 Fax: (225) 342-7133  
e-mail: [mftonore@goea.state.la.us](mailto:mftonore@goea.state.la.us)

**Administrative Structure**

The NFCSP is a new program in Louisiana as a result of passage of Title III-E. It is implemented by the State through contracts with Area Agencies.

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Statewide public education/awareness efforts include developing a slideshow and brochures for use in multiple speaking engagements.

**Consumer/Family Direction**

Louisiana is currently investigating the option of consumer/family directed caregiver services.

**Assessment Standards**

(Information is forthcoming).

**Information Links**

(Information is forthcoming).

**M A I N E**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

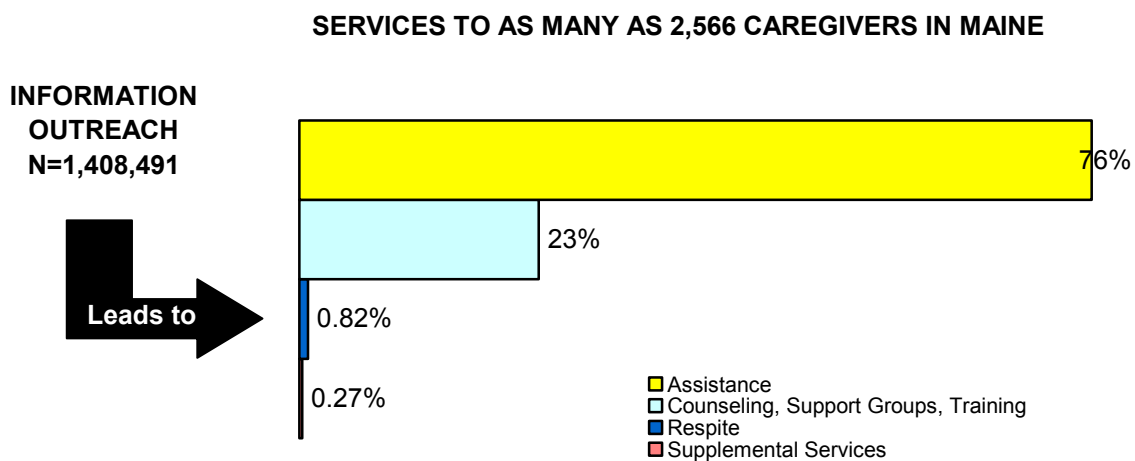
Mary Walsh  
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Phone: (207) 287-9207 Fax: (207) 287-9229  
e-mail: [mary.walsh@maine.gov](mailto:mary.walsh@maine.gov)

**Administrative Structure**

The NFCSP builds on existing state programs in Maine. These programs provide support to caregivers of people with Alzheimer’s disease or other dementia’s through the *State Alzheimer’s Respite Program* and the *Alzheimer’s Demonstration Project*. Maine also pays for respite services under the state-funded *Home Based Care Program* and the *Elder and Adults with Disabilities Medicaid HCBS Waivers*.

Maine has gone through significant reform to achieve a centralized an integrated long-term care system, but recognizing family caregivers who need support services themselves is a new concept. Maine operates a single-point-of-entry for HCBS, however, the NFCSP is not integrated into the HCBS system due to differing eligibility, service provision and reporting requirements; and state interest in preserving local flexibility. Area Agencies are required to set aside a portion of their base allocation for joint activities of statewide impact, and for grants to local community agencies or businesses. In addition, Area Agencies are providing 5 core caregiver services under the NFCSP.

**Services/Number of Caregivers Served – FY 2002**



Note: Without media contacts, 8,236 caregivers were served through information.

## Public Awareness/Education

Statewide efforts include:

- Developing a state-specific caregiver guide: *Connections, A Guide for Family Caregivers in Maine*.
- Implementing a toll-free number that may be accessed inside or outside the state. Instate calls are connected to a family caregiver coordinator; outside calls are connected to the Area Agency serving the region where the caregiver resides.

Efforts of specific Area Agencies include:

- Outreach at health fairs, conferences, and through Public Service Announcements, radio spots, development of a statewide logo for the program, training.

## Consumer/Family Direction

Under the NFCSP, Maine permits direct payments to family caregivers, regardless of whether they live with the older individual or not. Some Area Agencies provide funding to caregivers in the form of vouchers to purchase respite services.

## Assessment Standards

Maine administers a uniform assessment for all long-term care services, except the NFCSP. The NFCSP uses an Intake assessment tool that includes a caregiving component.

## Opportunities

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- The Eastern Area Agency on Aging of Maine, is a recipient of an AoA-sponsored NFCSP innovation grants, *Maine Primary Partners in Caregiving*, to demonstrate that primary health care is an effective and efficient point of caregiver intervention in a rural setting because caregivers are more likely to use information, support and training when a need is validated by a trusted healthcare provider and assistance is personally tailored to their needs. Grant products include: A Handbook for People Who Care: Caring for Parents and Other Older Relatives; Best Practice Manual; marketing materials; a variety of caregiver and resource fact sheets; and a number of presentations and publications. Materials are available by contacting Lenard W. Kaye, D.S.W. (email) [len.kaye@umit.maine.edu](mailto:len.kaye@umit.maine.edu)
- 2001 Legislation/Enacted – Maine enacted HB 655 to allocate monies for FY 2001 and FY 2002 to implement the NFCSP within the Bureau of Elder and Adult Services.<sup>aa</sup>
- 2002 Legislation/Enacted – Maine enacted HB 1441 to authorize the state Department of Human Services to use money from the Respite Care Fund to carry out the purposes of the NFCSP.<sup>bb</sup>

<sup>aa</sup> Source: National Conference of State Legislators, July 2003.

<sup>bb</sup> Ibid.

**Information Links**

Family Caregiver Support Program (Bureau of Elder and Adult Services)

<http://www.state.me.us/dhs/beas/nfesp.htm>

For more detailed information on Maine, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

## MARYLAND NFCSP INFORMATION PROFILE

### NFCSP State Contact

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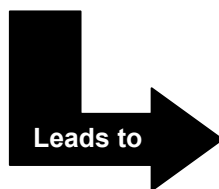
### Administrative Structure

NFCSP funds are used to bridge a gap between application and service provision in other services (for example, when there is a waiting list).

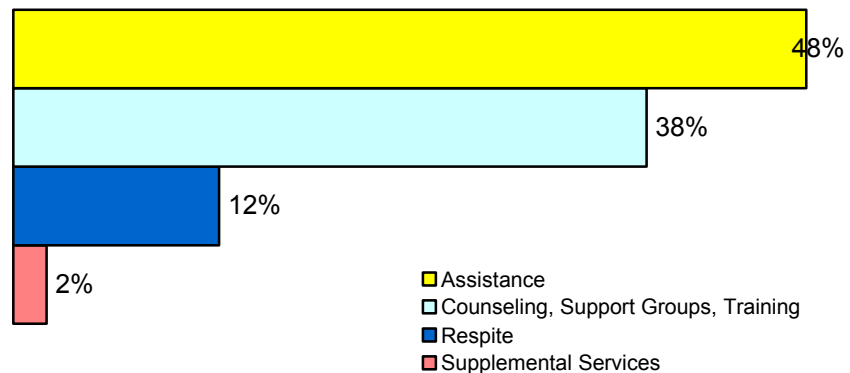
In Maryland the Information and Assistance (I&A) functions were integrated into their existing I&A functions, all the other services are brand new.

### Services/Number of Caregivers Served – FY 2002

INFORMATION  
OUTREACH  
N=34,549



#### SERVICES TO AS MANY AS 11,883 CAREGIVERS IN MARYLAND





### **Public Awareness/Education**

Maryland incorporates a “proactive” public awareness strategy by reaching out to caregivers early, before they encounter a crisis. A statewide initiative supporting working caregivers operates under the auspices of the State Unit on Aging. Employers collaborate to address working and caring issues.

Efforts of specific Area Agencies include: implementing a weekly Hispanic radio show for caregivers, and translation of written materials into other languages.

### **Consumer/Family Direction**

Although the state has not set a policy allowing caregivers to hire family members, there is significant interest in the consumer-directed model and promoting family-directed services. Some Area Agencies provide funding to caregivers in the form of vouchers or cash to purchase respite and/or supplemental services; others are waiting for more information and assistance with tax and fiscal issues. Caregivers may choose their own service providers, including family members.

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- The State Unit on Aging received an AoA-sponsored Alzheimer’s Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- Developed tool for State Unit on Aging to gather reporting requirement information.
- Significant interest exists in advancing consumer/ family-directed programs.
- Developed and launched Internet-based “message boards” for caregivers to link them to information and resources, and enable them to share information about their experiences.
- The National Family Caregivers Association (NFCA) of Maryland is a recipient of an AoA-sponsored NFCSP innovation grant to help family caregivers gain the knowledge and skills they need to interact more effectively with both health professionals and the healthcare system. *NFCA* is training a network of 500 workshop leaders to present a three-hour interactive workshop to 15,000 family caregivers. The workshop can be expanded to a six-hour session by including related topics and additional skills practice exercises. Project goals include expanding the geographic reach of the curriculum to all 50 states and the District of Columbia using innovative technologies. Reports and resources are forthcoming. For additional information go to: <http://www.nfcacares.org> or call 1-800-896-3650.

- 2001 Legislation/Enacted – Maryland SB 567 and HB 513 established the Maryland Caregiver Support Coordinating Council in the Department of Human Resources to coordinate statewide planning, development and implementation of family caregiver support services.<sup>cc</sup>

### **Information Links**

Caregiving (Maryland Department on Aging)  
<http://www.mdoa.state.md.us/Caregiving/>

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<sup>cc</sup> Source: National Conference of State Legislators, July 2003.

**MASSACHUSETTS  
NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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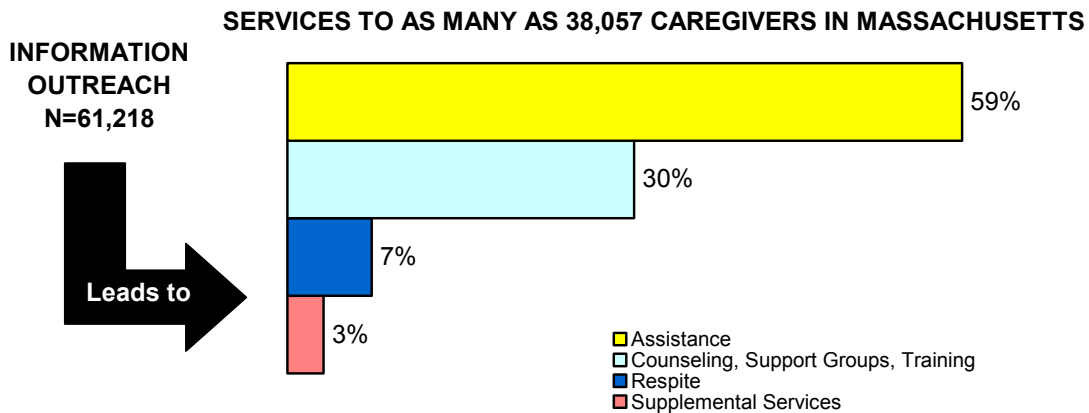
**Administrative Structure**

Massachusetts is developing caregiver programs within the broader HCBS system. State-funded *Aging Service Access Points* and Area Agencies on Aging provide services to older persons at the local level, serving as the single intake point for HCBS.

NFCSP builds on state programs serving family caregivers – MA Family Caregiver Support Program; Elder Care Advice Program; new models of respite care; Home Care Programs; implementation of the Consumer-Directed Care Program (Massachusetts’ version of Georgia’s Self-Directed Care Program); and Service Scholarships option (a one-time needs funding supplemental service option)

The NFCSP is implemented on a regional basis, in combination with its existing home care agency caregiving programs. The NFCSP will enable the *Massachusetts Home Care Corporations* in six newly created regions to select various models of service provision to primary caregivers of older care receivers. In addition, it will enable some regions to establish programs to assist 60+ grandparents and relatives who are the primary caregivers for children age 18 and younger.

**Services/Number of Caregivers Served – FY 2002**



### Public Awareness/Education

Promising support group initiative to reach underserved populations (non-English speaking, Information & Referral materials translated to Russian/Chinese) is currently under development (*Mobile Van Tour* to reach remote, hard-to-access areas).

Developed an I & A program, *Elder Care Advise Program* for family caregivers new to the role of caregiving. All Area Agencies participate by providing short-term, intensive, one-to-one assistance by telephone consultation or an in-home assessment to identify needs and provide resources/ referral.

### Consumer/Family Direction

Some Aging Service Access Points are developing consumer-directed caregiver models whereby individuals direct service providers with oversight from Access Points.

### Assessment Standards

A *Caregiver Intake* form is under development.

Telephone consultation or in-home assessment is employed to identify needs and provide resources to caregivers “new to the role of caregiving.”

### Opportunities

- Assessment instrument will collect basic demographic information on caregivers (under development).
- The *Massachusetts Executive Office of Elder Affairs* is a recipient of an AoA-sponsored NFCSP innovation grant to develop regional training centers for caregivers of deaf older adults via a multi-curriculum training program and a respite care center for the deaf. Forthcoming grant products include: a program evaluation report; marketing materials for both the Adult Social Day Care Program and Caregiver Resource Center (brochures, fact sheets, articles written for regional and statewide newsletters, newspapers and e-distribution lists); presentations for outreach and public education; *Resource Directory for the Massachusetts Commission for the Deaf and Hard of Hearing*; *Resource List for the Massachusetts Family Caregiver Support Program*; Training Curricula (3 modules); program monitoring materials, intake and assessment tools; and customer satisfaction surveys.
- 2001 Legislation – Massachusetts enacted HB 4800 to appropriate monies from the NFCSP to the Executive Office on Elder Affairs.<sup>dd</sup>
- 2002 Legislation – Massachusetts enacted HB 5300 to appropriate monies from the NFCSP to the Executive Office on Elder Affairs.<sup>ee</sup>

<sup>dd</sup> Source: National Conference of State Legislators, July 2003.

<sup>ee</sup> Ibid.

### **Information Links**

For complete information about eldercare and caregiver services in Massachusetts, visit <http://www.800ageinfo.com> or <http://www.eld.state.ma.us/caregiver> or call 1-800-AGE-INFO (800-243-4636)

Connection for Caregivers (Central Massachusetts Area Agency on Aging)  
<http://media.seniorconnection.org/>

**M I C H I G A N**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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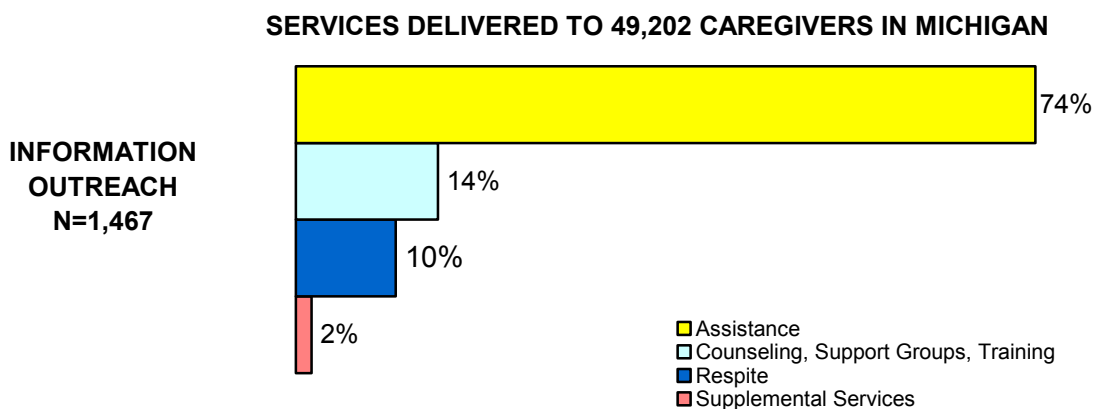
**Administrative Structure**

The NFCSP is implemented in conjunction with other caregiver support programs:

The *Caregiver Respite Program* - supported by \$5 million of Tobacco Settlement funds provides respite and adult day services to caregivers of older adults and disabled adults over the age of 18 years. Fifty percent of Caregiver Respite funds must be used to develop new, expand or support existing adult day programs (many of which expanded hours).

The *State Escheat Respite Program* - provides respite to caregivers of persons 60 years of age or older. Funds are provided through unclaimed reimbursements and payments from Blue Cross/Blue Shield. Escheat funds may also be used to support caregivers over the age of 60 years regardless of the age of the care recipient.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Public education/awareness is of a general nature. Area agencies on aging are currently planning a variety of initiatives.

### **Consumer/Family Direction**

Michigan does not prohibit self-directed care, which would allow the hiring of family members. Area Agencies have the option to provide funding to caregivers in the form of cash. Currently, none of the Michigan Area Agencies are exercising either option. Some Area Agencies provide vouchers to obtain respite and/or adults day services from approved providers.

### **Assessment Standards**

A web-based data collection/ reporting system is being developed to collect consistent information on caregivers across programs regardless of funding source.

### **Opportunities**

- The “respite service” definition has been expanded to allow caregivers to define “respite services” which may include other defined aging network services.
- The Center for Social Gerontology, Inc. of Michigan, is a recipient of an AoA-sponsored NFCSP innovation grants to use mediation to help resolve problems and disputes that occur when families face the physical, emotional and financial demands of providing long-term care to an older family member. The following products have been produced thusfar: *Access* newsletter article; brochures (*Family Caregiver Mediation/Shared Decision Making Services*, *Caring for an Older Person and Facing Difficult Decisions?*, *Caring for an Older Person or Considering Guardianship*); poster; flyer (*Take One, Take Two*); Oral testimony by Penelope Hommel before the U.S. Senate Special Committee on Aging, February 11, 2003, *Mediation: An Alternative Approach and Advance Planning for Less Restrictive Alternatives to Guardianship*; process materials; Ingham County Bar Association Article on project, September, 2003; and project trainings (agendas available). The major product, the *Replication Guide*, is forthcoming. Products will be made available on-line in the near future. For more information go to: <http://www.tcsg.org>.

### **Information Links**

Caregiver's Corner (Michigan Access to Seniors)

<http://www.miseniors.net/weassist/caregivers.asp?CatID=4&SubCatID=11>

**M I N N E S O T A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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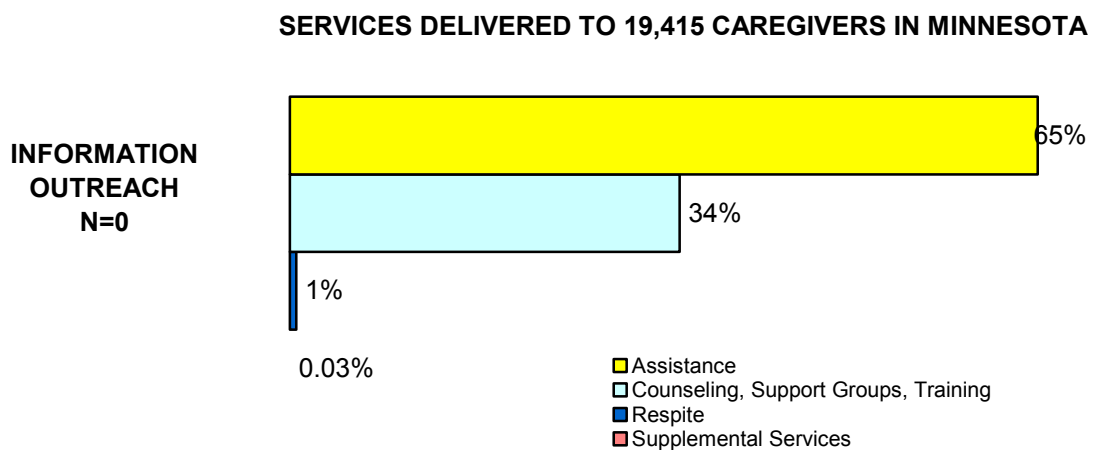
**Administrative Structure**

Minnesota’s *Caregiver Support Network* builds upon existing long-term care and aging service networks (including extensive grassroots volunteer and faith-based programs) and uses all possible funding streams including Medicaid waiver (with amended caregiver services), state grant programs, and private pay under a sliding fee scale. The NFCSP is integrated with other Title III programs.

Minnesota’s statewide *Caregiver Support Network* is organized regionally by the Area Agencies and includes *informal* (family and neighbor), *quasi-formal* (screened and trained volunteers), and *formal* (paid staff) components. For caregiver ease and flexibility, Minnesota is striving for multiple and coordinated access points, including *Senior LinkAge® Line* (the state’s I&R program), county pre-admission screening and case management systems, managed care health plans, clinics, employers, and faith-based organizations.

Services/supports include: all NFCSP services, “wrap-around” caregiver services (e.g., caregiver coach), and consumer-directed service models.

**Services/Number of Caregivers Served – FY 2002**





### **Public Awareness/Education**

Efforts include:

- Developing a PSA featuring the Governor's wife as the spokesperson for the NFCSP (2002) and a standardized caregiver education curriculum.
- Distributing of 10,000 Caregiver resource brochures (English & Spanish) and 8,000 caregiver journals (also electronic version).
- Expanding the Web-site.
- Preparing a public information package on caregiver depression.
- Developing culturally-specific trans-stop advertisements.
- Implementing a *Caregiver Coach Service*; consultation and education to nearly 500 grandparents raising grandchildren statewide.
- Providing consultation, peer mentoring, and education for caregivers of persons with developmental disabilities.
- Developing an employer-based education program.
- Developing a *Caregiver Getaway* program with consultation services and weeklong respite.

### **Consumer/Family Direction**

Services/supports include consumer-directed caregiver service models.

### **Assessment Standards**

Employs a uniform caregiver assessment and planning tool.

### **Opportunities**

- Employs consumer feedback mechanisms: customer satisfaction surveys and web-based listserv to advance caregiver services and supports.
- The Normandale Ministry for Healing and Wholeness of Minnesota is a recipient of an AoA-sponsored NFCSP innovation grant to develop model volunteer care teams to provide training, respite and resource counseling; and provide tools to help caregivers arrange for other community services as needed. Forthcoming products include a Family Caregiving Training Curriculum; an Evaluation Tool to Measure Caregiver Burden; a Volunteer orientation packet for Care Team Model; anecdotal caregiver evaluation regarding faith-based Care Team Model; and an Action Plan for replication of the faith-based Care Team Model in churches and other organizations.

### **Information Links**

CaregiverMN.org (Dakota Area Resources and Transportation for Seniors)  
<http://www.caregivermn.org/HomePage.asp>

## MISSISSIPPI NFCSP INFORMATION PROFILE

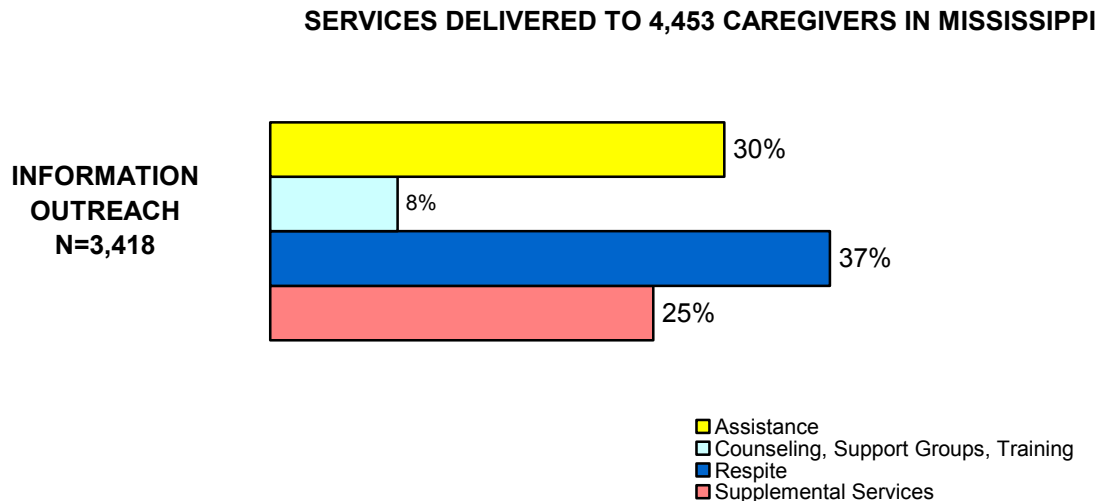
### NFCSP State Contact

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### Administrative Structure

The NFCSP is new to the State of Mississippi, providing caregiver services as a result of the passage of Title III-E.

### Services/Number of Caregivers Served – FY 2002



### Public Awareness/Education

Public awareness/ education is of a general nature. Statewide and locally, Mississippi responds to telephone inquires on the NFCSP.

### Consumer/Family Direction

The Division of Aging and Adult Services encourages consumer-directed caregiver services via technical assistance meetings to all Area Agency Program Coordinators, but no formal system is in place.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- The request from grandparents in some Planning and Service Districts are growing. During the month of May in one Planning and Service District, 205 caregiver calls were received. Of these, 37 were grandparents/relative raising grandchildren.

### **Information Links**

Family Caregiver Support Program (Mississippi Division of Aging and Adult Services)  
[http://www.mdhs.state.ms.us/aas\\_mfcsp.htm](http://www.mdhs.state.ms.us/aas_mfcsp.htm)

## MISSOURI NFCSP INFORMATION PROFILE

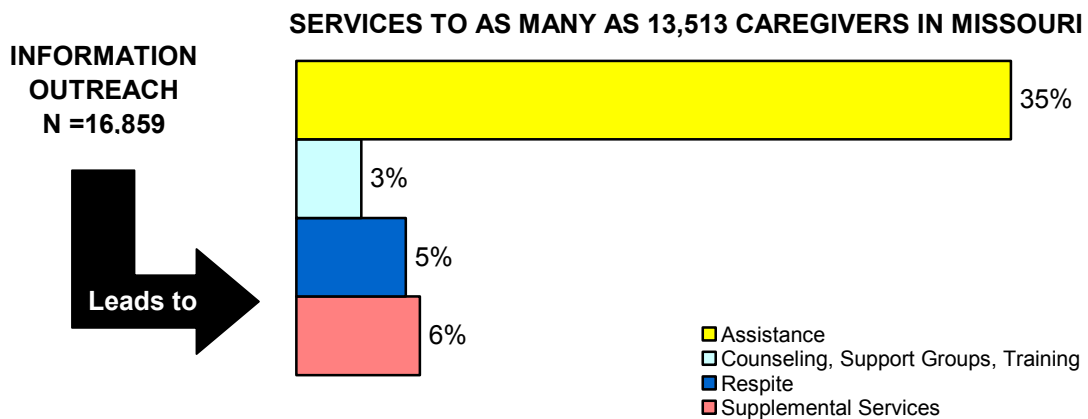
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### Administrative Structure

NFCSP builds on existing state programs that serve family caregivers.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

Statewide efforts include:

- Initiating a statewide network of 10 Area Agencies to develop a resource database, accessible from home computers, the Information & Assistance network, and the statewide toll-free number.
- Partnering with universities/medical schools, to convene focus groups to determine caregiver needs and inform development of culturally competent educational material.

Efforts of specific Area Agencies include:

- Pooling funds at the Area Agency level for joint activities.
- Developing PSAs, published newsletter articles, an interactive Website, cable and public television broadcasts, and movie theatre advertising to publicize the program.
- Launching a 2-year outreach program to reach geographically isolated individuals.

### **Consumer/Family Direction**

Missouri offers an option to allow caregivers to have a family member or friend provide care. Background checks of potential providers are required. At this time, one Area Agency provides funding to caregivers in the form of cash reimbursement for receipted service expenditures.

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- The *St. Andrew's At Home Services* of Missouri is a recipient of an AoA-sponsored NFCSP innovation grant to develop cost-effective eldercare management services that allows employed caregivers to provide quality care and continue working. The program established a business advisory council and a pilot project to evaluate alternative eldercare approaches and provide assessments and services to caregivers. Forthcoming grant materials include: brochures (*Balancing Life and Eldercare*, *The Choices You Want-The Solutions You Need*); and a *Caregiver's Quick Source- Guide to Meeting the Challenges of Caregiving*. For more information go to: <http://www.caringworkplace.com>

### **Information Links**

Missouri Caregiver Background Screening Service (Office of the Governor)  
<http://www.gov.state.mo.us/background/index.htm>

**M O N T A N A**  
**NFCSP INFORMATION PROFILE**

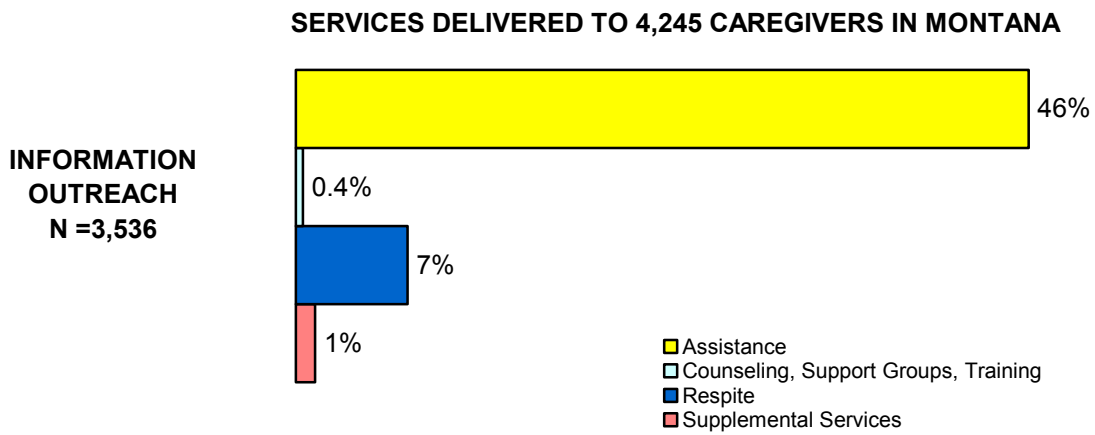
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**Administrative Structure**

Remains in the early stages of program development.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Sponsoring conferences on caregiving
- Creating information packages.
- Sponsoring television programs.
- Providing information/assistance trainings.

### **Consumer/Family Direction**

(Information is forthcoming).

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers (Blackfeet and Crow tribes only).
- 2003 Legislation/Adopted – Montana adopted SJR 18, requests Medicaid waiver to allow greater flexibility with family caregiving.<sup>ff</sup>

### **Information Links**

(Information is forthcoming).

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<sup>ff</sup> Source: National Conference of State Legislators, July 2003.

**NEBRASKA**  
**NFCSP INFORMATION PROFILE**

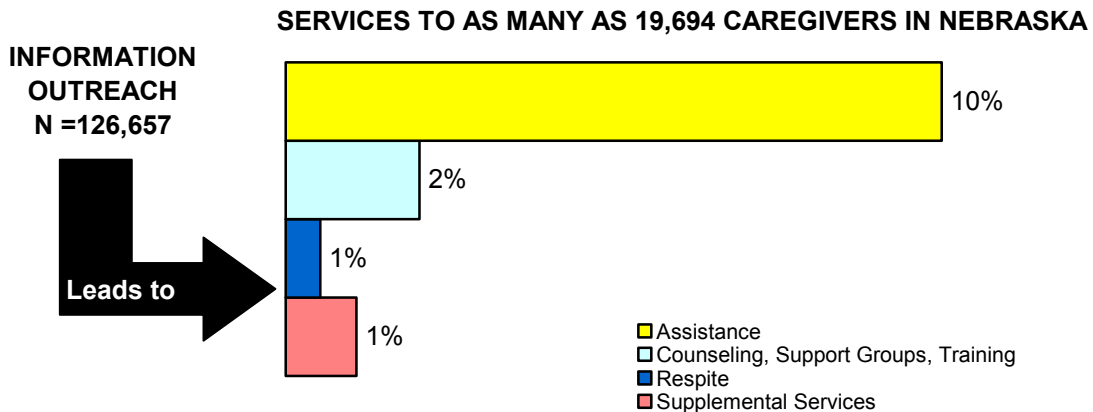
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**Administrative Structure**

One Area Agency in Nebraska had an active Caregiver Support Program with a full-time staff person prior to the enactment and funding of the NFCSP. Four of the remaining seven Area Agencies on Aging had Respite Programs of varying sizes. These Agencies used the NFCSP to build on existing programs, including *Lifespan Respite*.

**Services/Number of Caregivers Served – FY 2002**





### **Public Awareness/Education**

Efforts of specific Area Agencies include:

- Developing PSAs, radio and television announcements, newspaper ads/articles, and advertising in specialty magazines targeted to seniors and families.
- Making small annual grants available to support groups to help maintain their existence. In addition, scholarships have been issued in one locale to help caregivers attend conferences.

### **Consumer/Family Direction**

State has policy set allowing caregivers to hire family members. Area Agencies provide funding to caregivers in the form of cash (on a reimbursement basis) to purchase respite, incontinence supplies and emergency response systems.

### **Assessment Standards**

Requires program recipients to complete a *Caregiver Stress Survey* and a *Caregiver Capacity Assessment* to determine caregiver needs.

### **Opportunities**

(Information is forthcoming).

### **Information Links**

(Information is forthcoming).

**N E V A D A**  
**NFCSP INFORMATION PROFILE**

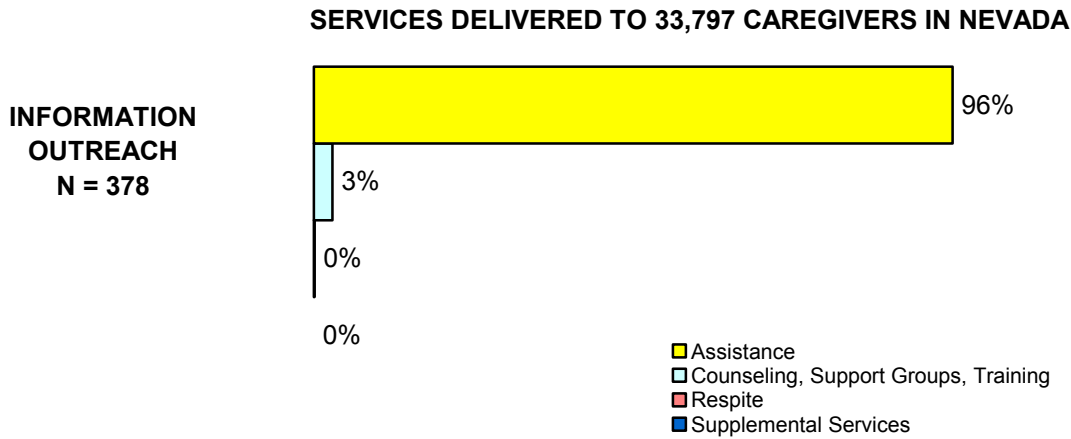
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**Administrative Structure**

NFCSP builds on an existing multi-faceted program. Title III-E funds support 3 core services - information, assistance, and respite for caregivers. Nevada has dedicated most of its Title III-E funds for the last two years toward development of its Single Point of Entry system for a more coordinated service system that will offer easy access to information and assistance for elders and their caregivers. The balance of the Title III-E funds has supported a respite program for grandparents caring for their grandchildren and partially funded another respite caregiver program. State Tobacco Settlement and Alzheimer's Demonstration funds also support caregiver services along with counseling and training.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Developing a Website.
- Conducting public outreach through the Nevada eldercare organization.
- Developing training materials through the Caregiver Support Center.
- Devoting part of the state *Elder Care Help Line* to caregiver issues.

Efforts of specific Area Agencies include monthly senior fairs and implementing a Caregiver Coalition.

### **Consumer/Family Direction**

To date, Nevada has no state policy allowing caregivers to hire family members. Funding is provided to caregivers in the form of vouchers to support service needs.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- Nevada is interested in conducting outreach to major employers.

### **Informational Links**

Nevada's Website for Caregivers (Nevada Division for Aging Services)  
<http://www.nveldercare.org/>

**NEW HAMPSHIRE  
NFCSP INFORMATION PROFILE**

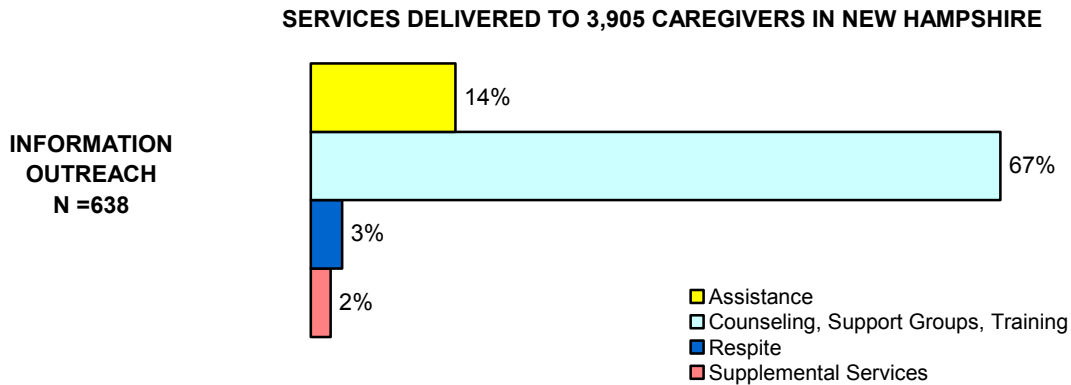
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**Administrative Structure**

Represents a new state that is providing caregiver support services as a result of the passage of the NFCSP. Currently it is operating in an early program implementation stage.

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Public awareness/ education is of a general nature.

**Consumer/Family Direction**

At this time, there is no formal consumer/family directed caregiver options in place.

**Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

**Opportunities**

- 2001 Legislation/Enacted – New Hampshire enacted HB 569 to establish a committee to study the information, training and support needs of family caregivers.<sup>gg</sup>
- 2003 Legislation/Enacted – New Hampshire enacted HB 831 to create a study commission on end-of-life care, including education and training of caregivers.<sup>hh</sup>

**Informational Links**

(Information is forthcoming).

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<sup>gg</sup> Source: National Conference of State Legislators, July 2003.

<sup>hh</sup> Ibid.

## NEW JERSEY NFCSP INFORMATION PROFILE

### NFCSP State Contact

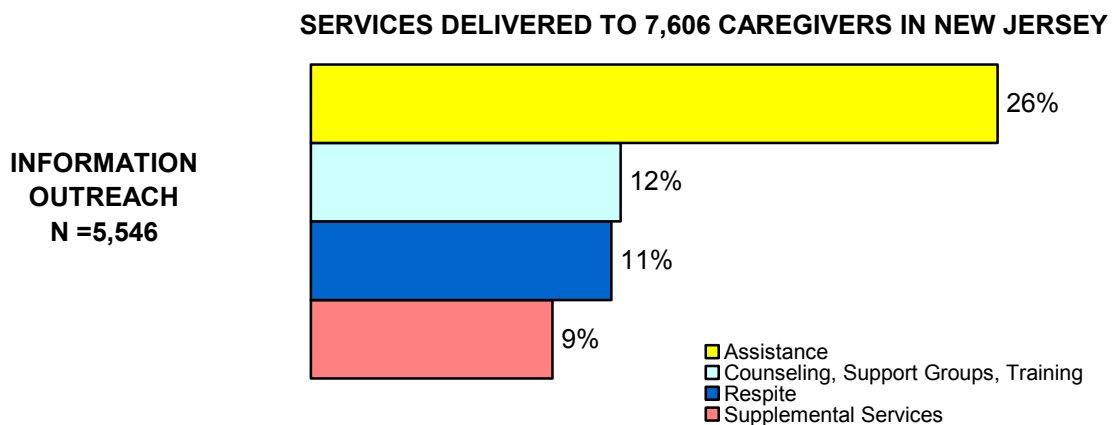
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### Administrative Structure

The NFCSP, administered by the Division of Aging & Community Services, builds on existing caregiver programs to provide a range of caregiver services throughout the state, including *Statewide Respite Care Program* (since 1984), *Adult Day Services* for individuals with Alzheimer's disease or related disorders (since 1987), and *the New Jersey Advisory Council on Elder Care* (since 1998)

As part of its AoA-sponsored innovation grant, New Jersey is integrating Title III-E services with Medicaid Waiver and state-funded programs for caregivers through *NJ EASE* (Easy Access, Single Entry System). Each Area Agency has developed a plan for the use of Title III-E funds based upon an assessment of caregivers' needs in the planning area. The plan must indicate how Title III-E is coordinated with other caregiver programs.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

The Department offers the *In-Home Caregivers Education and Support Program* for caregivers who require education and counseling on an individual basis. The AoA-sponsored NFCSP innovation grant also involves developing a training curriculum, Website; and uniform screening, assessment and planning tools.

Efforts of specific Area Agencies include:

- Using teleconferencing technology to bring medical monitoring, education and support, and socialization to homebound caregivers.
- Reaching out to a variety of diverse groups through translation of materials and funding for workers from those populations, including African-Americans, Chinese-Americans, Korean-Americans, Indo-Americans, Russian-Americans, Latinos, and Vietnamese-American populations.
- Conducting a telephone counseling service for caregivers who cannot leave their homes, with respite funding available to allow the caregiver to attend counseling outside of the home if necessary.
- Administering support groups and legal counseling for grandparents raising grandchildren, including those caring for developmentally disabled children up to 19 years of age.

### **Consumer/Family Direction**

There are no immediate plans.

### **Assessment Standards**

Caregiver and care-recipient needs are assessed using a uniform Comprehensive Assessment Tool (with caregiver component). The AoA-sponsored innovation grant will provide for an expanded tool for caregivers.

Under the state-funded In-Home Caregiver Education and Support Program, a registered nurse meets with the caregiver at home and develops a plan to meet the caregiver's education and counseling needs. In-home sessions, with a variety of professionals, are arranged in accordance with the plan.

### **Opportunities**

- The *New Jersey Department of Health and Senior Services, Division of Senior Affairs* is a recipient of an AoA-sponsored NFCSP innovation grant to expand *NJ EASE (Easy Access Single Entry)* system for senior services by adding a caregiver service component. This includes development of caregiver assessment and care planning tools; a staff caregiver training curriculum; policies, critical pathways and service protocols to guide consumer decision-making and worker actions; and a caregiver website. Forthcoming grant products include *NJ EASE* caregivers screening tool, assessment tool, planning tool, and training curriculum; CaregiverNJ [www.caregivernj.nj.gov](http://www.caregivernj.nj.gov); Area Agency on Aging – Statewide Respite Care Policy; diversity outreach strategies; Caregiver Resource Guide; Caregiver Best Practices Publication; Project Evaluation report; and Summary Report.
- New Jersey was one of the first states to pilot a model for a *Statewide Respite Care Program*, established by legislation as a fully state-funded program in 1988.

- New Jersey participates in the ASPE and RWJF-sponsored *Cash and Counseling Demonstration and Evaluation* where Medicaid section 1115 waivers allow care recipients to receive Medicaid benefits as a cash payment, to develop their own care plans and spend their allowances however they choose, including hiring a family member, to meet their disability-related needs (see AR and FL). <http://www.hhp.umd.edu/AGING/CCDemo/>

### Information Links

Caregiver New Jersey  
<http://www.caregiverNJ.nj.gov>



**NEW MEXICO  
NFCSP INFORMATION PROFILE**

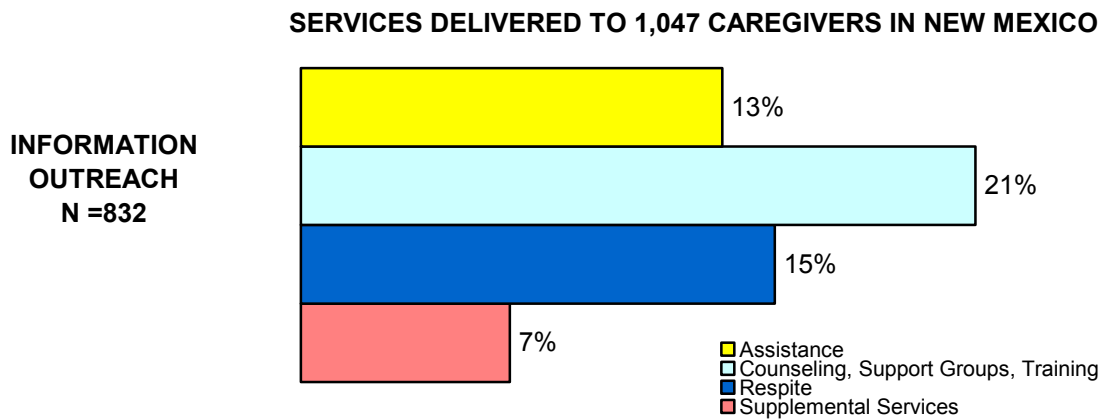
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**Administrative Structure**

(Information is forthcoming).

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Statewide efforts include:

- Implementing a *Train-the-Trainer* Initiative.
- Establishing a *Care Coordination Program*.

Efforts of specific providers include, caregiver newsletters, brochures, PSAs, and a telephone “call-in” during a national PBS broadcast on caregiving (*Thou Shalt Honor*).

**Consumer/Family Direction**

New Mexico is interested in promoting consumer-directed service options. At this time the *Cash and Counseling* model is included in their strategic State plan.

**Assessment Standards**

Employs a uniform assessment of caregiver needs (SAMS).

**Informational Links**

Caregiver Support (New Mexico State Agency on Aging)  
<http://www.nmaging.state.nm.us/talk.html>

**NEW YORK**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

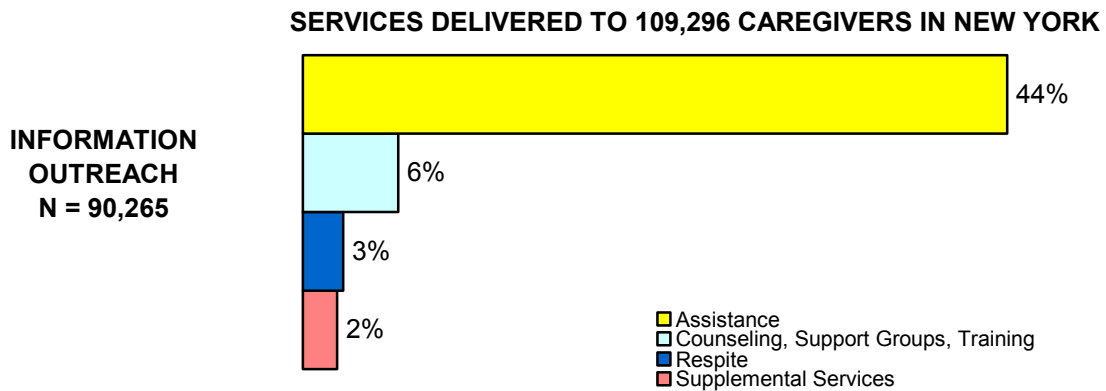
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**Administrative Structure**

The NFCSP in New York is a new program operated independently by the New York State Office for the Aging.

With the inception of the NFCSP, Area Agencies were encouraged to consider as a model the state-funded *Caregiver Resource Center*; which supports outreach, information, training, support groups, advocacy and resource libraries and operates in a limited number of counties.

**Services/Number of Caregivers Served – FY 2002**



### Public Awareness/Education

Public awareness/ education is of a general nature.

### Consumer/Family Direction

Reports no consumer/ family-directed service system, although state interest in expanding this service option has been expressed. An internal work group is examining the feasibility of State Office for the Aging policies on consumer-directed caregiver services.

### Assessment Standards

At this time, assessment of caregiver needs is not uniform.

### Opportunities

- The Senior Services of Albany, New York is a recipient of an AoA-sponsored NFCSP innovation grant to assess the effectiveness of telephone support groups for caregivers of frail elders. This multi-component group program includes emotion-focused and problem-focused coping strategies and support. The Senior Services Center collaborates with the State University at Albany, Institute of Gerontology in this endeavor. Forthcoming grant products include *Leading Telephone Caregiver Support Groups: A Manual for a Model Psychoeducational Program*; a *Telephone Support Group Program Participant Workbook*; and caregiver pre-test and post-test interview instruments.
- The Catholic Charities of the Diocese of Rochester New York is a recipient of an AoA-sponsored NFCSP innovation grant to develop and implement a training program that creates an integrated care management approach to support relative caregivers of grandchildren (*Kinship Care Resource Network*). The *Catholic Family Center* collaborates with 15 national and local organizations. Forthcoming grant products include fact sheets (adoption, education, foster care, legal custody and guardianship, and public assistance); flow charts; guidelines; flyers for various program functions; and a *Kinship Care Resource Guide*.
- 2002 Legislation/Enacted – New York enacted the *Most Integrated Setting Coordinating Council* to develop and oversee the implementation of a comprehensive, statewide plan for providing services to individuals of all ages with disabilities in the most integrated setting. The council evaluates the supports and services available to assist individuals of all ages with disabilities who reside in their own homes with the presence of other family members or informal caregivers.<sup>ii</sup>

### Information Links

Families and Caregivers (New York State Office for the Aging)  
<http://aging.state.ny.us/caring/index.htm>

<sup>ii</sup> Source: National Conference of State Legislators, July 2003.

**NORTH CAROLINA  
NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

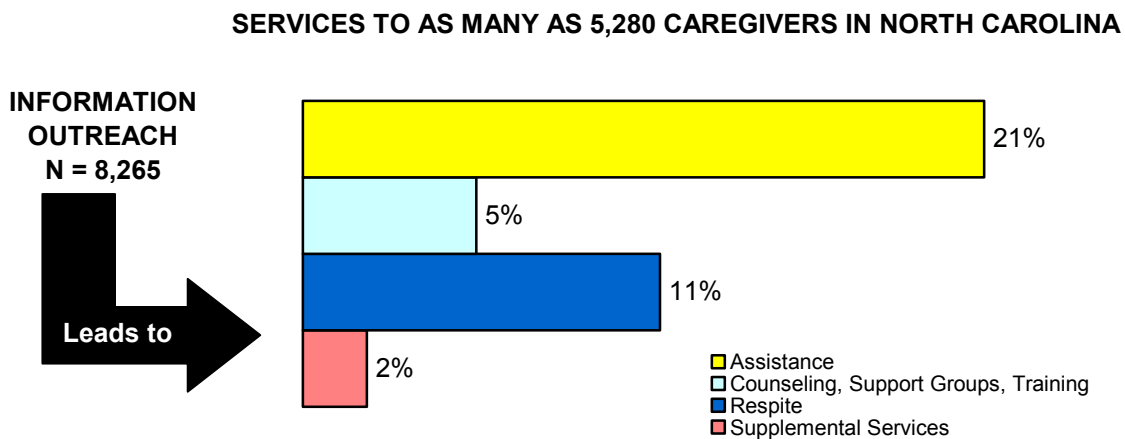
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**Administrative Structure**

Each Area Agency hires a *Regional Caregiver Specialist* to focus on building an infrastructure of dedicated community partners, public awareness, program development and consultation, documentation and oversight. The work of the Area Agency and its partners is reflected in a special section of its Area Plan. Cost sharing has been implemented for Title III-E services.

In the late 1980's, the North Carolina General Assembly established a state-funded *Respite Care Program*. The North Carolina Division of Aging worked with others to undertake a range of activities to assist family caregivers although these activities were not grouped under a single family caregiving program until 2001.

**Services/Number of Caregivers Served – FY 2002**



## Public Awareness/Education

Statewide activities include:

- Pooling resources to develop a statewide identity for the NFCSP, including a logo (*Circle of Care*) and tagline (*Completing the Care* – conveys program completes the circle by helping caregivers reach their full potential.)
- Forming a state-level steering team of leaders in business, the faith-based community, human services, public policy, charitable organizations and academia, raises awareness about caregiver needs across all settings to support family-friendly policies and leverage resources.
- Distributing over 40,000 resource guides (*Family Caregiving in NC*) statewide through partnerships with AARP, Cooperative Extension Service, the Carolinas Center for Hospice and End of Life Care, the Duke Family Support Program, and the NC Association of Area Agencies on Aging. Master training facilitators are state-sponsored for nationally recognized caregiving training, *Powerful Tools for Caregiving*; training facilitators are state-coordinated for Rosalynn Carter Institute's *Caring for You, Caring for Me* and end-of-life training program, *Respecting Choices*.
- Employing a *list-serve* to promote dialogue/ information exchange between the State Unit on Aging and the Area Agencies.

Activities of specific Area Agencies include:

- Planning a multi-year caregiver public awareness campaign, resource sections in public libraries, billboards/public service announcements, and presentations on local military bases.
- Developing a web-site (<http://www.fullcirclecare.org/>), as a key resource for caregivers statewide. The site links to other helpful sites, state and local resources and major public awareness activities.

## Consumer/Family Direction

Three Area Agencies provide funding to caregivers in the form of vouchers to purchase respite and supplemental services; one of these Area Agencies reserves one voucher per county for grandparents raising grandchildren. Other Area Agencies, though not using a voucher system have expanded consumer choice allowing funds to be used for an array of respite services including adult day services, in-home, and institutional respite. Although North Carolina has no state policy regarding the hiring of family members for caregiving, one Area Agency allows family to hire individuals with appropriate screening and oversight.

## Assessment Standards

At this time, there is no uniform assessment of caregiver needs.

## Opportunities

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- Developed instrument to collect basic demographic information on caregivers for state reporting system.

### **Information Links**

Family Caregiver Support Program

<http://www.dhhs.state.nc.us/aging/fcaregr/fchome.htm>

Help for Family Caregivers (North Carolina Division of Aging)

<http://www.dhhs.state.nc.us/aging/cargvr.htm>

Website developed by Area Agency

<http://www.fullcirclecare.org/>

**NORTH DAKOTA  
NFCSP INFORMATION PROFILE**

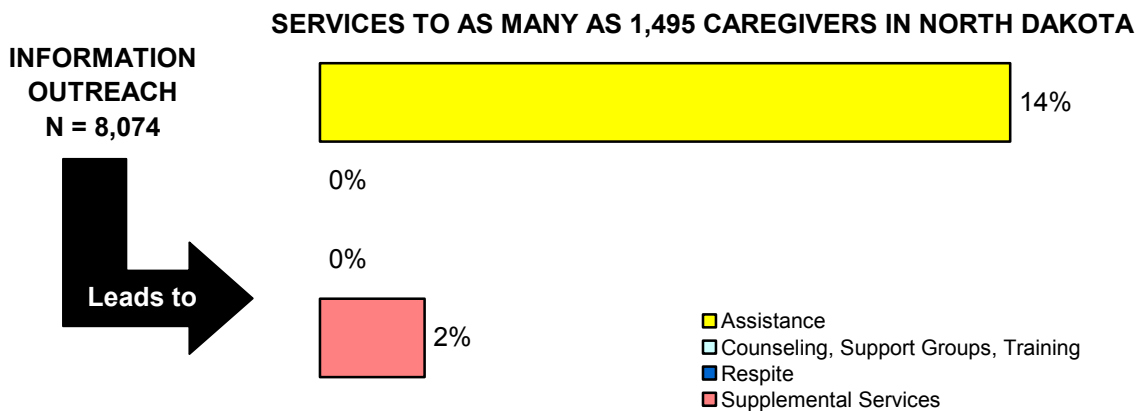
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**Administrative Structure**

Title III-E funds are used to enhance state-funded *Family Home Care Program* that provides reimbursement up to \$700 per month to an eligible family member providing caregiver services.

**Services/Number of Caregivers Served – FY 2002**





### **Public Awareness/Education**

Statewide efforts include:

- Designing a brochure and media campaign that targets children of older parents, grandparents and the general public.
- Developing 13 training modules for use by Caregiver Coordinators.
- Mapping out all caregiver services/Information and Assistance that are available in North Dakota for inclusion on the Web page (currently under development). The Website will be used by North Dakota Seniors Info-line and to improve access for long distance caregivers.

### **Consumer/Family Direction**

North Dakota has a policy of consumer directed care that allows caregivers family members to be paid for providing respite. Consumers choose provider, including family members, and determine the hourly rate paid for the service. Respite providers are reimbursed for providing services to eligible caregivers by Regional Human Service Centers.

### **Assessment Standards**

Administers uniform assessment of caregiver needs using a tool developed by the State.

### **Opportunities**

- 2001 Legislation/Enacted – North Dakota enacted HB 1012 to specify that it is the intent of the Legislative Assembly that the Department of Human Service determine the requirements related to the acceptance of federal family caregiver funds, including allowable uses, maintenance of effort and future funding projections.<sup>jj</sup>

### **Information Links**

(Caregiver Website is under development).

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<sup>jj</sup> Source: National Conference of State Legislators, July 2003.

**O H I O**

**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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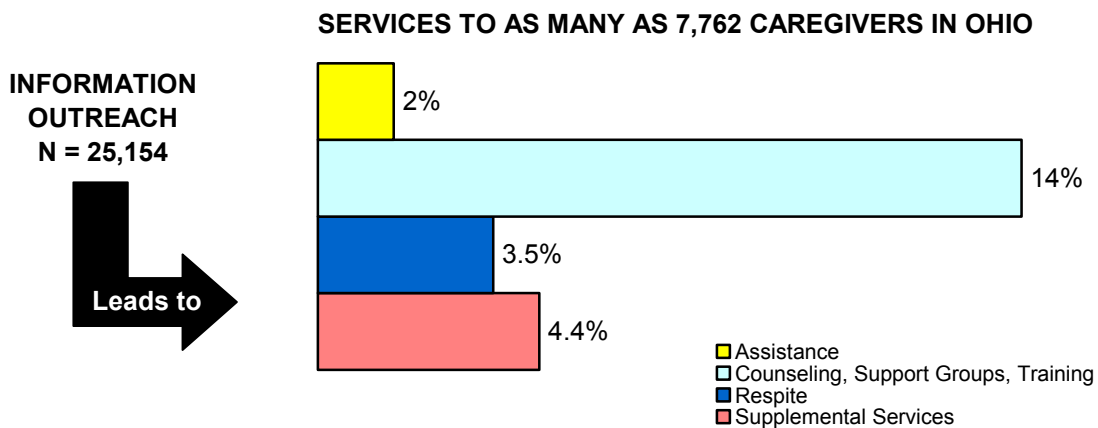
**Administrative Structure**

Developing caregiver program within the broader HCBS system, building on existing *Alzheimer's Respite, PASSPORT, Medicaid Waiver* and *Family Caregiver Support Programs*. The Navigator Program provides resources for caregivers caring for children.

Provides "one-stop shopping" and resources for grandparent caregivers raising grandchildren through Kinship Care Program.

The flexibility provided to each of the eleven Area Agencies allow for the predominant needs of the community to be met. Cost sharing has been implemented for respite and supplemental services.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Efforts include:

- Caregiver conferences, Website development, and implementing culturally appropriate caregiver information and training.
- Ohio is working to build awareness of the needs of working caregivers among employers and community-based leaders at FY 2003 Governor's Conference.
- Central Ohio Area Agency on Aging developed a caregiver education curriculum consisting of 4 two-hour sessions that address the range of caregiver needs.

### **Consumer/Family Direction**

Ohio does not allow hiring of family members for NFCSP and does not provide direct cash payments to families. Two Area Agencies either provide service vouchers or offer service reimbursement programs for respite and/or supplemental service options. In some cases, individuals may opt for tuition reimbursement for specialized training.

### **Assessment Standards**

Each Area Agency creates a unique tool or caregiver assessment component.

### **Opportunities**

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.
- Persons waiting for HCBS have been served by the NFCSP.
- The Council on Aging of Southwestern Ohio is a recipient of an AoA-sponsored NFCSP innovation grants to collaborate with the Area Agency District 7 to provide in-home training of informal caregivers in rural and urban areas. This project will produce an extensive manual, *COALA Client/Caregiver Informal Training Manual*; a variety of process materials; and an *Informal Caregiving Training Brochure*.
- The Ohio Department of Aging is a recipient of an AoA-sponsored NFCSP innovation grant to design and test an outcome-based system for enhancing the quality of caregiver support services. Recommendations of caregivers, older adults, the *Aging Network* and service providers will be used to develop a guide to improve the quality of caregiver support services delivered through the *Aging Network*.

### **Information Links**

The Ohio Long Term Care Consumer Guide (Ohio Department on Aging)  
<http://www4.state.oh.us/longtermcareguide/consumer/index.asp>

**O K L A H O M A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

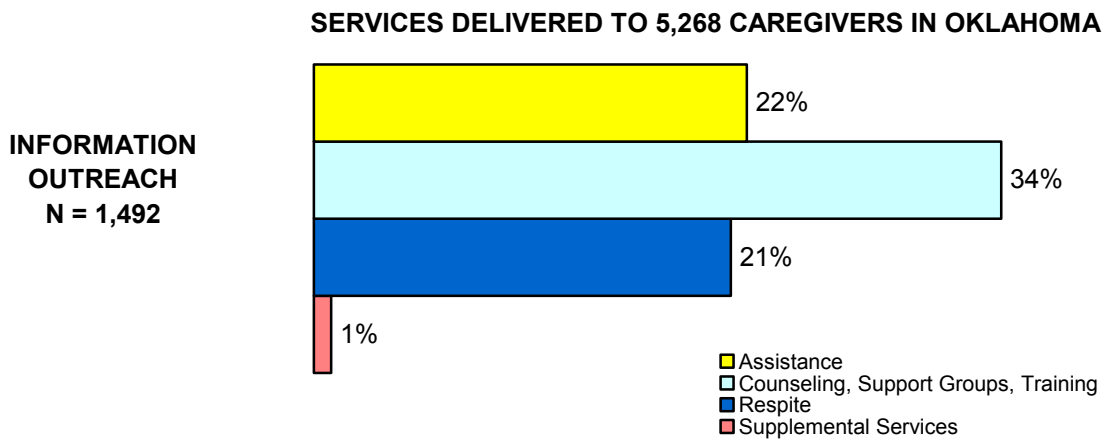
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**Administrative Structure**

Oklahoma began working with caregivers over a decade ago when the aging consortium developed the *Caregiver Connection*, a training program that the Area Agencies used across their planning areas in local communities. The NFCSP services have been planned and developed to meet the specific needs of caregivers identified through focus group meetings convened by the 11 Area Agencies. Since each Area Agency developed its own caregiver program, 11 very different programs emerged.

The Aging Services Division was an early partner of the caregiver respite voucher program called *Oklahoma Respite Resource Network (ORRN)*, an informal partnership of agencies that provide lifespan respite statewide. After passage of the NFCSP, all 11 AAAs joined the ORRN partnership. Each Area Agency decides how much FCSP money will go into respite services for their area caregivers. For applications, caregivers call the toll-free number of *Oklahoma Statewide Information and Referral (OASIS)*. OASIS forwards completed applications to the most appropriate funding source, where telephone interviews are conducted.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

- Area Agencies have utilized FCSP funds to raise awareness of family caregivers statewide through the use of all available media outlets. Caregiver and Grandparent Raising Grandchildren conferences and support groups pre-date the NFCSP in Oklahoma City and Tulsa, and, together with FCSP, are now held statewide by AAAs along with other caregiver services.
- Oklahoma collaborates with Title VI programs to develop education programs and support groups for Native Americans and tribal leaders.
- Caregiver and Grandparent Raising Grandchildren conferences and support groups pre-date the NFCSP in Oklahoma City and Tulsa.
- Strategy for outreach to rural areas is “personal touch.” Oklahoma works closely with home health agencies, existing caregiver projects, nutritional sites, senior centers, and the Advantage Waiver program.

### **Consumer Direction**

Family caregivers meeting FCSP eligibility guidelines are mailed \$400 (per 3 months) in vouchers that can be used to hire anyone they know and trust to provide respite. Respite providers may include adult day services, or family and friends (who do not live in the home and are age 18 or over). Caregivers sign and complete the vouchers with days/hours of service and hourly pay rate. Providers mail the vouchers to State Finance, and are paid directly. Vouchers are valid for 3 months and caregivers may reapply, as funding allows. Caregivers applying for vouchers are also referred to appropriate sources of alternative aging services and support to caregivers. Area Agencies and FCSP grantees assist caregivers in accessing the services they need.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- Caregiver satisfaction surveys show that caregivers are satisfied primarily because they can hire someone they know and trust and the system is user friendly.
- Oklahoma has enhanced coordination efforts with tribal organizations. When FCSP funds became available through Title VI, tribal governments contacted ASD and the AAAs to coordinate planning. Representatives from ASD and the AAAs have assisted in implementing caregiver programs under Title VI by inviting Title VI caregiver coordinators and trainers to attend caregiver training, during which training materials are provided.
- Many caregivers in Oklahoma are isolated by their caregiving responsibilities, living in remote rural areas with poor transportation. Nine of eleven Area Agencies are rural, the SUA has used its resources to develop materials for the rural Area Agencies and planning service areas.

### **Information Links**

Caregivers (Oklahoma Aging Services Division)  
<http://www.okdhs.org/aging/caregivers.htm>

**O R E G O N**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

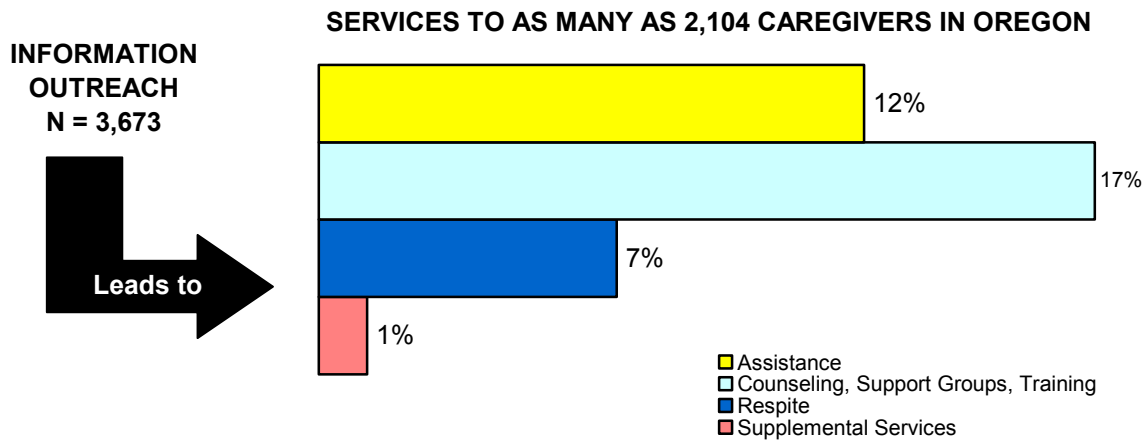
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**Administrative Structure**

The NFCSP in Oregon builds upon the work of the State's model *Lifespan Respite Program* operating since 1997. In addition to respite care, the program provides information and referral, outreach, and training. The NFCSP coordinates with the *Lifespan Respite Program* in areas where both operate, using a request for proposal process so other agencies, in addition to Aging Network agencies, may apply for and operate the program.

Several entry points at the local level. Program information, referral staff, and partners assist caregivers in accessing supports and information.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Efforts include:

- Maintaining information toll-free number.
- Pooling funds for Area Agency activities, sponsors a website for family caregivers (*Oregon Cares*), and implemented statewide *Powerful Tools for Caregiving* training program.
- Building community partnerships and designing a series of family caregiving workshops.

### **Consumer/Family Direction**

NFCSP services are unique to the 20 Area Agencies. Some offer family caregivers respite funds to hire a service provider. In certain situations, family members can be hired to provide respite. Through the *Caregiver Relief Fund* caregivers can qualify for up to \$300 to purchase respite services and/or supplemental services over a six-month period. Area Agencies provide funding to caregivers in the form of vouchers that pay the service provider directly.

### **Assessment Standards**

Employs a uniform assessment (with a minimal caregiver component).

### **Opportunities**

- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.

### **Information Links**

Caregiving (Oregon Department of Human Services)  
<http://www.dhs.state.or.us/seniors/caregiving/index.htm>

Website for Family Caregivers – Oregon Cares  
<http://www.oregoncares.org>

**P E N N S Y L V A N I A**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

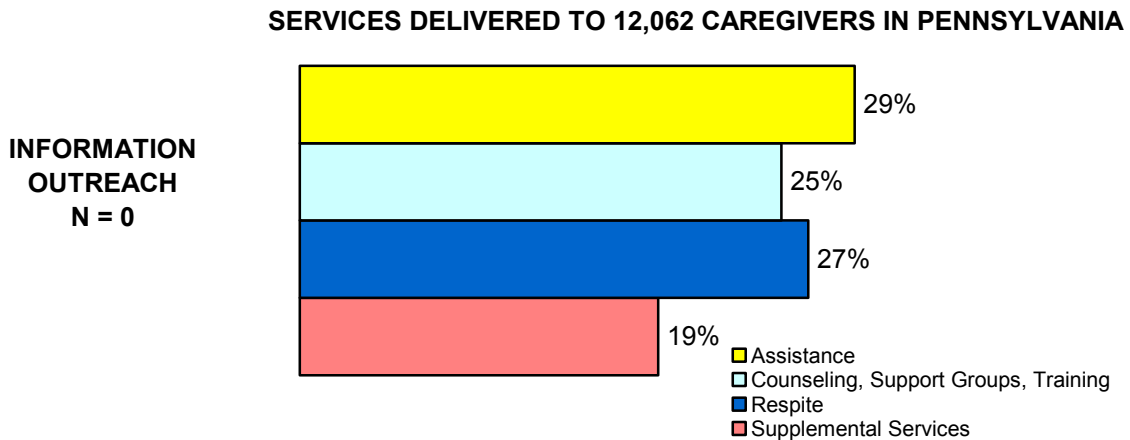
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**Administrative Structure**

Developing caregiver programs within broader well-developed HCBS system, including *OPTIONS* and *Medicaid Waiver* programs. State-funded *Family Caregiver Support Program* (begun in 1987 through state law) expands eligibility criteria to include non-relatives, individuals not living in the same household and older relative caregivers of children. Maintains a single-point-of-entry for all HCBS. Pennsylvania has implemented the NFCSP in combination with its state *Family Caregiver Support Program*, which is fully integrated into the State’s community-based long-term care system. Features of the state program include: engagement of caregivers in the planning process; baseline assessment of the caregivers’ stress level; maximizing/blending family and program resources; and allowing up to \$200 per month for services and supplies in addition to a lifetime maximum of \$2,000 for home modification or assistive devices.

The NFCSP enables the Pennsylvania Department of Aging to expand service provision to all older primary caregivers of older care receivers whether or not they are related and whether or not they reside in the same household. In addition, it allows the Area Agencies to establish programs to assist 60+ grandparents and 60 and older who are the primary caregivers for children age 18 and younger who live with them. The Pennsylvania FCSP continues to provide services to family caregivers of age 18 to 59 care receivers with dementia, as this part of the program is financed with state funds. Significant state investment has been made using lottery, tobacco and state general funds.

**Services/Number of Caregivers Served – FY 2002**





### Public Awareness/Education

Statewide activities include: developing an annual newsletter and a comprehensive *Family Caregiver Guide* (English/Spanish).

Efforts of a specific Area Agencies include: sponsoring a seminar on grand-parenting and alternative caregiver programs.

### Consumer/Family Direction

Reimburses caregivers for needed services and supply expenses (subject to a sliding scale). Caregivers can hire their own providers but family members cannot be paid respite providers. Under the state's Medicaid Home and Community-Based Waiver, family members (excluding spouses) can be paid to provide personal care and respite.

### Assessment Standards

Statewide policies and standards ensure a consistent approach to caregiver support, including a uniform assessment of caregiver needs. Comprehensive assessment tool used for NFCSP and others HCBS programs.

### Opportunities

- Pennsylvania is automating caregiver data collection.
- *Mid-County Senior Services* of Pennsylvania, is a recipient of an AoA-sponsored NFCSP innovation grants to evaluate the addition of Caregiver Care Management to its Adult Day Services and evaluate outcomes that reflect positive and negative aspects of caregiving. Forthcoming products include a replication manual for the *Adult Day Services Plus* program; and assessment and reassessment tools used for study subjects. For additional information contact Karen Reeve at (610) 353.6642 or email [ReeverK@MLHS.org](mailto:ReeverK@MLHS.org)
- The *Pennsylvania Department on Aging* is a recipient of an AoA-sponsored NFCSP innovation grant to implement a support system for older caregivers of adult children with mental retardation or developmental disabilities. The program is individually tailored and reimburses consumers for expenditures related to caregiving. Forthcoming grant products include: County-specific fact sheets; State-level fact sheet; referral form; PowerPoint conference presentation; brochure detailing outreach session; MR/DD caregiver education and award session; television coverage video of caregiver awards given to recipients; news article; and Care Management Training session materials.
- The *Pennsylvania State University, Gerontology Center* is a recipient of an AoA-sponsored NFCSP innovation grant to provide a structured, time-limited program of counseling to family caregivers and care recipients in the early stages of dementia. Through positive communications and active participation in their care, care recipients and their family caregivers will have a better understanding about the available services and preferences for care. Reports and resources are forthcoming.

- The *Philadelphia Corporation for Aging* of Pennsylvania is a recipient of an AoA-sponsored NFCSP innovation grant to develop a model health care and training intervention that targets African-American daughters who serve as caregivers. The intervention focuses on identifying the health related issues and caregiver challenges specific to the target populations. A clinical pathway protocol will be developed to assist other organizations in replicating the intervention for minority caregivers. Forthcoming grant products include: a work plan; interview process/procedures; assessment tool/procedures; care plan; telemedicine literature review; educational materials list; presentations; and summary reports.
- 2001-2003 Legislation/Enacted – Pennsylvania enacted SB 1 (2001), SB 5 (2002), and HB 648 (2003) to appropriate monies in state and federal funds for family caregiving programs in the Department on Aging.<sup>kk</sup>

### Information Links

Availability of Care (Pennsylvania Department on Aging)  
<http://www.longtermcare.state.pa.us/Index.asp?id=3&fs=2>

For more detailed information on Pennsylvania, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

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<sup>kk</sup> Source: National Conference of State Legislators, July 2003.

**R H O D E I S L A N D**  
**NFCSP INFORMATION PROFILE**

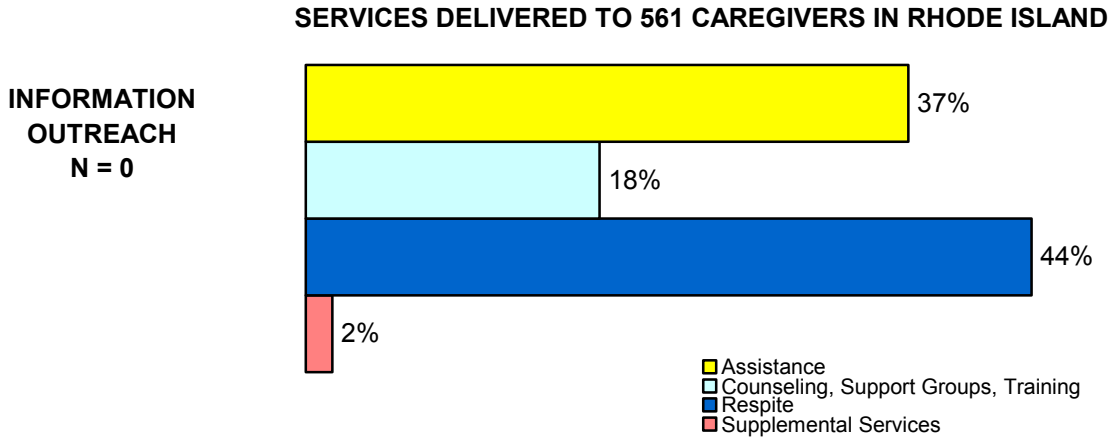
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**Administrative Structure**

The NFCSP builds on an existing state program. For twenty years the State Department of Elderly Affairs has funded with State and Federal funds a *Friendly Visitor/Respite Care Program* through the Catholic Diocese of Providence. This program provides a menu of visiting and respite care services. Recently this program has been expanded to include AoA Alzheimer’s demonstration funds and National Family Caregiver Support Funds.

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Statewide efforts include:

- Establishing multimedia activities and a senior journal.
- Establishing a statewide identity of caregiver program, including name and logo.

**Consumer/Family Direction**

State has a policy allowing caregivers to hire family members for respite.

**Assessment Standards**

Assessment of caregiver needs is uniform.

**Information Links**

(Information is forthcoming).

## SOUTH CAROLINA NFCSP INFORMATION PROFILE

### NFCSP State Contact

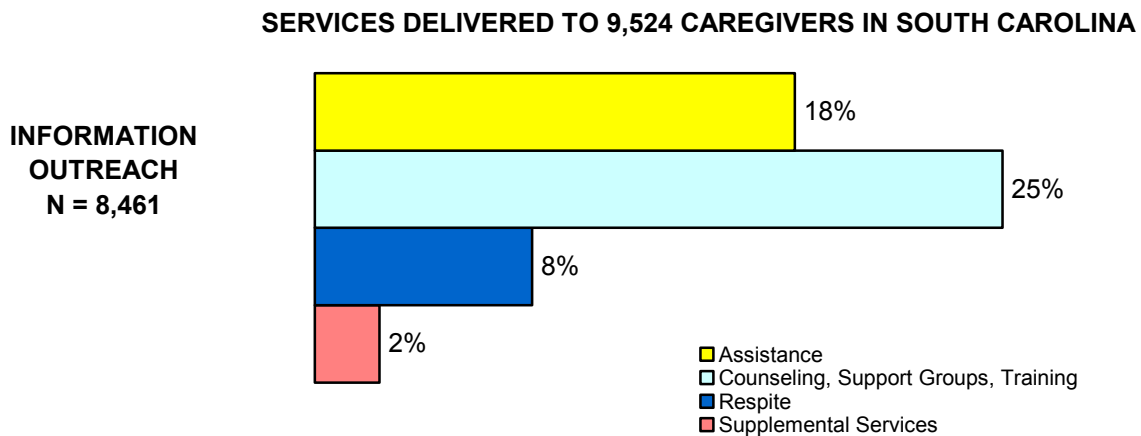
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### Administrative Structure

NFCSP builds on existing state programs serving family caregivers. Every Area Agency in the state staffed the NFCSP with a new full-time *Caregiver Advocate*. A statewide taskforce has developed principles and guidelines for program. Within this structure, Area Agencies are given flexibility to design and implement the program, thereby making it more consumer-centered. Cost sharing has been implemented for respite and supplemental services.

South Carolina collaborates with local groups/agencies serving diverse populations to reach out to diverse caregiver populations, including grandparents raising grandchildren.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

State pools funds with Area Agencies for joint public education/awareness activities. Efforts of specific Area Agencies include in-home caregiver training and support groups in rural areas.

### **Consumer/Family Direction**

Area Agencies provide funding to caregivers in the form of reimbursement vouchers to purchase respite and supplemental services. Consumer-directed caregiver services have been particularly well received in rural areas with few providers.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- Piloting a Web-based data collection system to meet NFCSP reporting requirements.
- The State Unit on Aging received an AoA-sponsored Alzheimer's Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.

### **Information Links**

Family Caregiver Support Program (South Carolina Department of Health and Social Services)  
<http://www.dhhs.state.sc.us/InsideDHHS/Bureaus/BureauofSeniorServices/service9442132003.htm>

## SOUTH DAKOTA

### NFCSP INFORMATION PROFILE

#### NFCSP State Contact

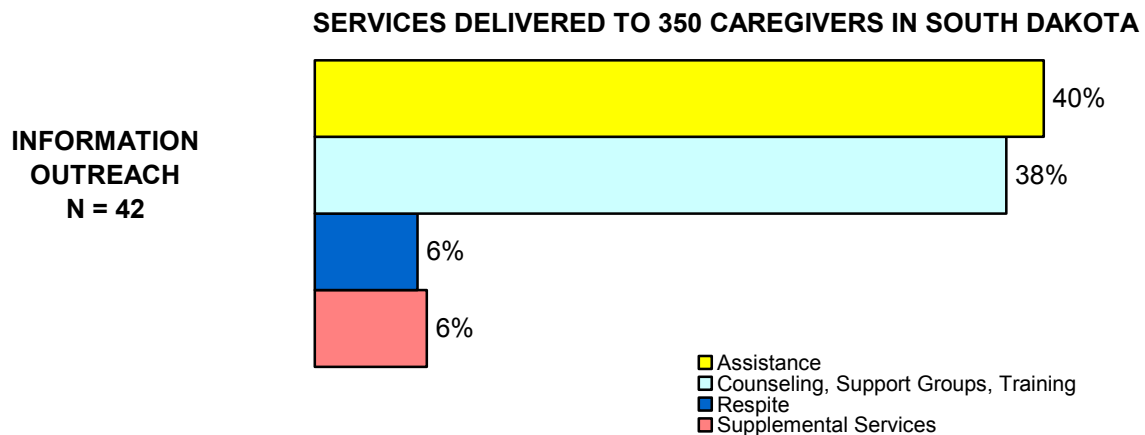
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#### Administrative Structure

The NFCSP in South Dakota builds on the existing *Respite Care Program*, serving individuals 18 and older. The NFCSP was launched in May, 2002.

South Dakota is a single planning and service area and does not have Area Agencies on Aging.

#### Services/Number of Caregivers Served – FY 2002



#### Public Awareness/Education

Efforts include:

- Developing press releases, publications, production of a new video, and updates to Website on the caregiver program.
- Developing and distributing Fact Sheets on caregiving, and articles in newspapers.
- Conducting presentations on the program.
- Developing a *Caregiver Manual for Social Workers*.

### **Consumer/Family Direction**

State has set a policy allowing caregivers to hire family members (exceptions: parent, spouse or child). Social workers work directly with caregivers who choose providers. Providers bill the State for payment of services.

### **Assessment Standards**

Administers uniform assessment of caregiver needs using *South Dakota Caregiver Assessment Tool* (with caregiver component). There is also a Caregiver Self Assessment which is available through the internet or given to Caregivers through information and referral.

### **Information Links**

Caregiver Support (South Dakota Adult Services and Aging)  
<http://www.state.sd.us/social/ASA/Caregiver/index.htm>



**T E N N E S S E E**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

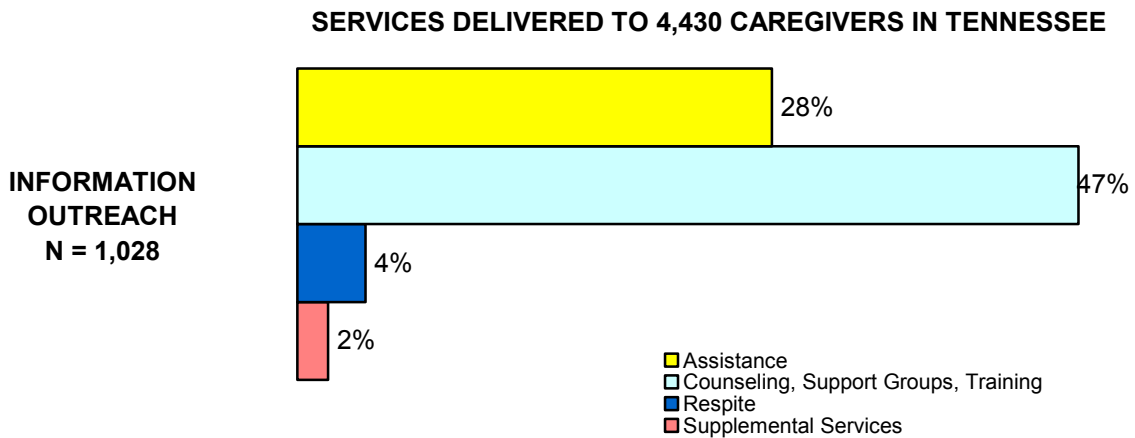
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**Administrative Structure**

The NFCSP is a new program within Tennessee. The program is operational in all planning and service areas.

Plans to implement cost sharing for Title III-E services within the coming year.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Public awareness /education is of a general nature.

### **Consumer Direction**

The State Unit on Aging is committed to developing a consumer-directed system of care in all of the programs it administers. The family caregiver program is the first OAA program to offer consumers a choice of providers. Additional elements of a consumer-directed system of care will be implemented over the next several years.

### **Assessment Standards**

Tennessee is working to implement a uniform assessment of caregiver needs.

### **Opportunities**

- Plans to implement a uniform assessment of caregiver needs.

### **Information Links**

National Family Caregiver Support Program (Tennessee Commission on Aging)  
<http://www.state.tn.us/comaging/caregiving.html>

**T E X A S**

**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

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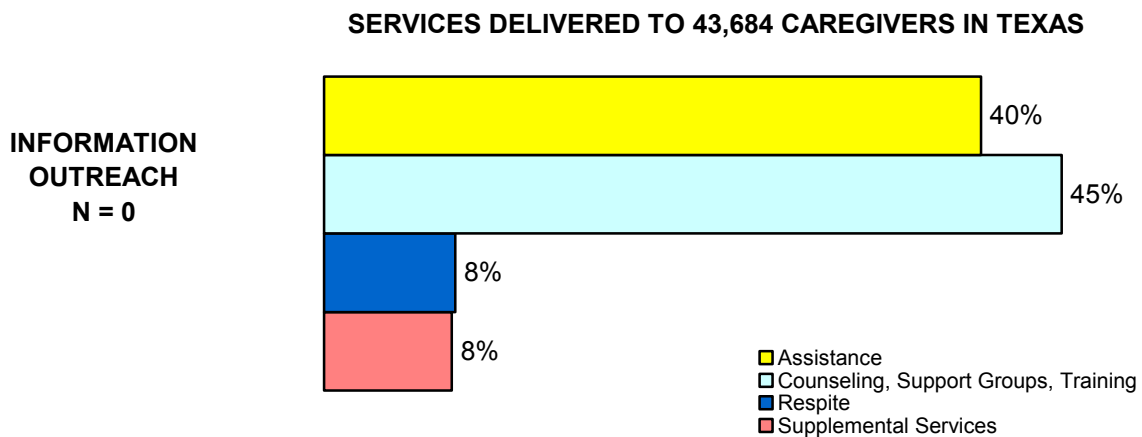
**Administrative Structure**

The addition of Title III-E dollars has allowed for expansion of existing services and development of collaborative relationships to expand the service base.

In-home services related to family caregivers are provided statewide, through all 28 Area Agencies on Aging. Respite services provided throughout the State of Texas include in-home respite, institutional respite, adult day care and hospice. Additional in-home services provided with NFSCP funds include Emergency Response, Home Delivered Meals, Homemaker, Personal Assistance, Telephone Reassurance and Visiting. Variation in the provision and availability of these services relates to funding levels and service priorities.

Every Area Agency provides information, referral and assistance, access and assistance, counseling support groups, respite and supplemental services.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Efforts include:

- Hiring a *Caregiver Coordinator* to conduct trainings and increase awareness of caregiver issues through public information campaigns.
- Funding seed grants to providers outside the aging network, including faith-based respite providers and other community organizations (\$15,000 each).

### **Consumer/Family Direction**

Options for caregivers are currently limited to respite vouchers; family members (except spouses) can be paid respite provider. The rule states that family members “not living in the household” are exempt, not specifically exempting a spouse, from being a paid respite provider. An example would be if an eligible elderly client is living with his granddaughter and her family, the granddaughter or any family member living in the home could not be a paid respite provider.

### **Assessment Standards**

(Information is forthcoming).

### **Opportunities**

- Identifies family caregivers as a constituency group under Health and Human Services Commission’s strategic plans for 2003-08. Priorities include expanding, developing and coordinating formal, informal and innovative supports for caregivers.
- Texas is sponsoring a comprehensive study of the caregiver program (under development).

### **Information Links**

Caregiving Resources (Texas Department on Aging)  
<http://www.tdoa.state.tx.us/CaregivingResources.htm>

For more detailed information on Texas, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program* (2002). Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

**U T A H**  
**NFCSP INFORMATION PROFILE**

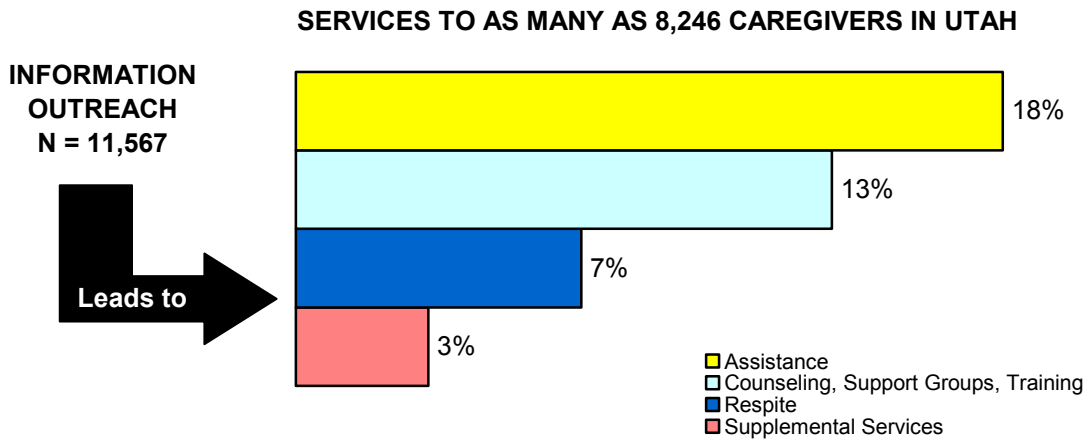
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**Administrative Structure**

Utah's NFCSP is building on existing programs serving family caregivers.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Surveying all state employees regarding caregiver needs.
- Creating a *Caregiver Handbook*.
- Establishing a statewide *Caregiving Coalition* (service providers, of Adult Day Care, Home Health and Hospice) to develop resources and disseminate information.
- Establishing a statewide speakers bureau and Website.
- Publishing the *Utah Spirit* (English, Spanish, and Russian).

Efforts of specific Area Agencies include participation in resource fairs and employing program advertisements at local movie theatres.

### **Consumer/Family Direction**

Utah has no state policy allowing caregivers to hire family members.

### **Assessment Standards**

Administers a uniform caregiver assessment, *Utah Caregiver Support Assessment Tool*.

### **Information Links**

(Information is forthcoming).

**V E R M O N T**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

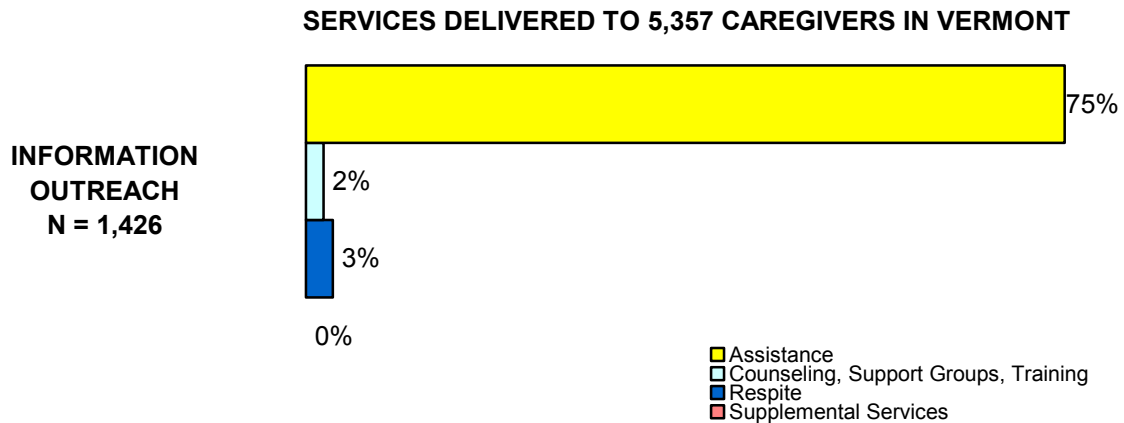
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**Administrative Structure**

Vermont builds its NFCSP on the existing services to caregivers that have been provided by elder advocates (care managers) stationed at its five Area Agencies on Aging.

**Services/Number of Caregivers Served – FY 2002**

Supplemental services are made available to caregivers from other resources.



**Public Awareness/Education**

Public awareness/ education is of a general nature.

**Consumer/Family Direction**

(Information is forthcoming).

**Assessment Standards**

At this time, employs no uniform assessment of caregiver needs.

**Information Links**

(Information is forthcoming).



## VIRGINIA NFCSP INFORMATION PROFILE

### NFCSP State Contact

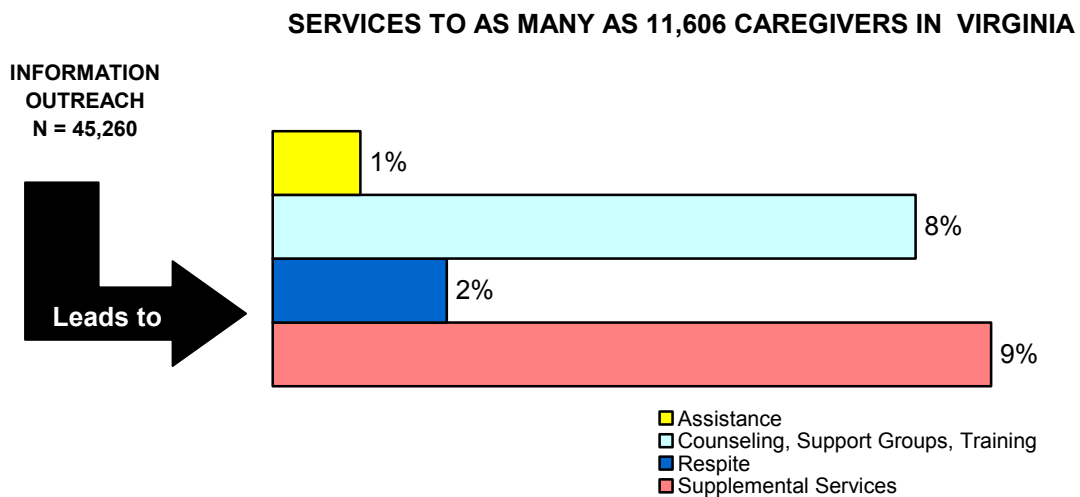
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### Administrative Structure

Virginia has implemented their NFCSP independently and does not build on existing state programs.

14 Area Agencies cost share for a variety of services, including in-home respite and community respite; chore services; companion services; transportation; and homemaker services.

### Services/Number of Caregivers Served – FY 2002



### **Public Awareness/Education**

Statewide efforts include:

- Distributing an array of supporting materials to Area Agencies (*Caregiver Resource Guide, Senior Connections Telecaregiver, Caregiver College, Training Manual for Preparing Volunteers, Women's Health Data Book, Helping Caregivers Find Support*).
- Sponsoring all-day trainings for Area Agencies on the NFCSP.

Efforts of specific Area Agencies include:

- Developing resource packets for caregivers.
- Sponsoring caregiver training at the Veteran's Administrations.
- Conducting town hall meetings.
- Developing a manual on *Telecaregivers*, and partnering with the Rural Health System.

### **Consumer/Family Direction**

Virginia does not allow caregivers to hire family members under the NFCSP.

### **Assessment Standards**

At this time, there is no uniform assessment of caregiver needs.

### **Opportunities**

- The Virginia Department for the Aging is a recipient of an AoA-sponsored NFCSP innovation grant to provide specialized services for male caregivers, particularly retired military personnel and men who live in rural and farming communities, who are less likely to share their concerns and challenges as a care provider or to seek services that can provide them with respite. Forthcoming grant products include: project brochures, presentations, client satisfaction survey, newsletters, bulletins, project flyers and other outreach materials.

### **Information Links**

Senior Navigator

<http://www.seniornavigator.com/>

**WASHINGTON  
NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

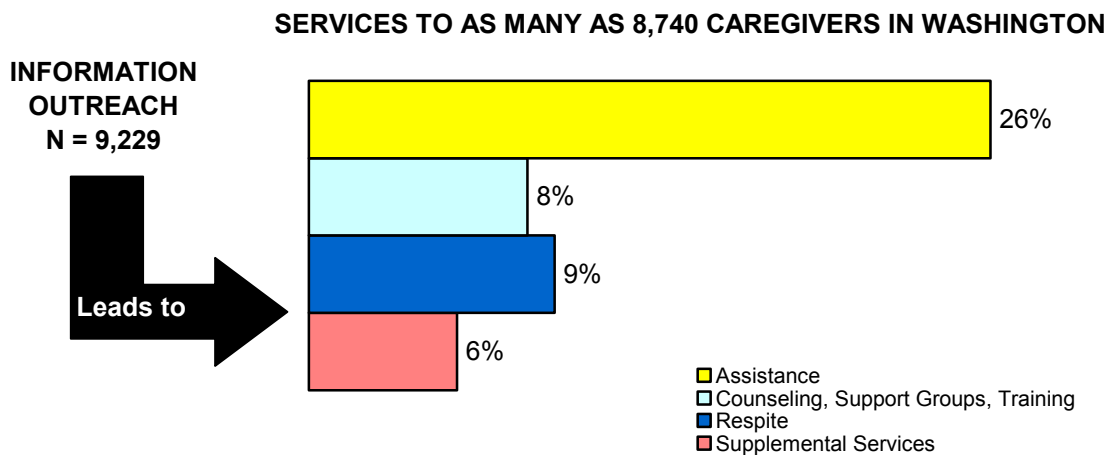
Hilari Hauptman/Lynn Korte  
 Aging & Adult Services Admin  
 Dept of Social & Health Services  
 P.O. Box 45650  
 640 Woodland Sq. Lp. SE  
 Olympia, WA 98504-5600  
 Phone: (360) 725-2556 Fax: (360) 902-7848  
 e-mail: [haupthp@dshs.wa.gov](mailto:haupthp@dshs.wa.gov) | [kortelm@dshs.wa.gov](mailto:kortelm@dshs.wa.gov)

**Administrative Structure**

Offers a single-point-of-entry for all state-funded LTC programs. The NFCSP in Washington State is operated in conjunction with the *State Family Caregiver Support Program* and the *State Respite Program* (since 1989). All 5-core caregiver services are available in almost every Area Agency region with 10/13 Area Agencies serving grandparent caregivers. Cost sharing has been implemented for respite services on a sliding fee scale.

The State Unit on Aging received an AoA-sponsored Alzheimer’s Demonstration grant from 1992-2000 to develop systems of care for persons with dementia and their family caregivers.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

Statewide efforts include:

- Developing a comprehensive *Caregiver Handbook* (English/Russian/Chinese/Spanish); an extensive caregiver training course, *Fundamentals of Caregiving*, (English/Spanish); a Website, and a Caregiver Kit.
- Implementing the *Powerful Tools for Caregiving Curriculum* and the annual *Kinship Care Awards*.
- Planning a developmental disabilities/aging family caregiver conference and a caregiving campaign.

Efforts of specific Area Agencies include:

- Piloting a *Personal Assistant Respite Care* and *Cash and Counseling Model*.
- Developing Chinese caregiver services and resources.
- Developing ethnic and working caregiver conferences, and a Cash and Counseling Model.
- Developing a *Tribal Grandparents Raising Grandchildren Resource and Information Guide*, and a *Communities in Faith Resource and Training Guide*.
- Developing caregiver kits.

### **Consumer/Family Direction**

In Washington, all elder service programs (Options, Supportive Home Care, Alzheimer's Family Caregiver Support Program, Waiver programs) incorporate consumer direction. Currently, respite policies do not include hiring family caregivers and consumer-directed service options are limited (unlike the Medicaid HCBS waiver program). Washington has funded an innovation grant to an Area Agency experiencing difficulty finding respite providers in rural areas with the intention of developing a program to allow caregivers to employ individual providers. The model includes paid training for the provider and background checks.

### **Assessment Standards**

Uses Contact Form by case managers, caregiver specialists, and Information and Assistance staff to screen the most immediate needs of caregivers. Caregiver assessment will be integrated into a state uniform assessment tool for all long-term care programs.

### **Information Links**

Help for Caregivers: You're Not Alone (Washington Aging and Adult Services Administration)  
<http://www.aasa.dshs.wa.gov/topics/caregiving/caregiving.htm>

For more detailed information on Washington, see *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since the Passage of the National Family Caregiver Support Program (2002)*. Family Caregiver Alliance, CA. This project was supported, in part, by a grant from the DHHS/Administration on Aging.

## WEST VIRGINIA NFCSP INFORMATION PROFILE

### NFCSP State Contact

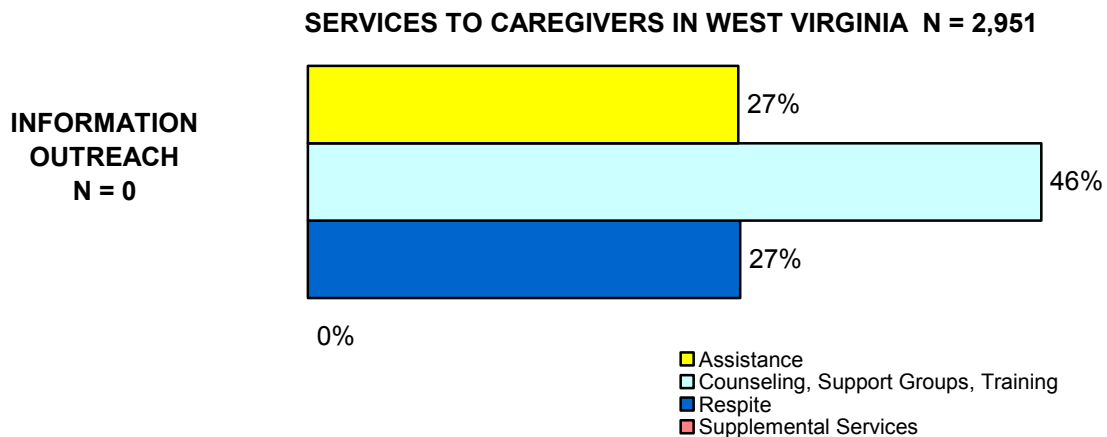
Jan Bowen, Director, Older Americans Act Programs  
WVA Bureau of Senior Services  
1900 Kanawha Blvd, East  
Holly Grove-Building 10  
Charleston, WV 25305-0160  
Phone: (304) 558-3317 Fax: (304) 558-5609  
e-mail: [jbowen@boss.state.wv.us](mailto:jbowen@boss.state.wv.us)

### Administrative Structure

The State of West Virginia has implemented its NFCSP independently and does not build on an existing state program.

West Virginia remains in the early stages of program development.

### Services/Number of Caregivers Served – FY 2002



**Public Awareness/Education**

Public education/awareness is of a general nature. Efforts of specific Area Agencies include the use of billboards, ads on pharmacy bags, Cable television ads, and notepads in physician offices.

**Consumer/Family Direction**

West Virginia is interested in advancing consumer/ family-directed caregiver options.

**Assessment Standards**

At this time, West Virginia has no uniform assessment of caregiver needs.

**Opportunities**

- 2003 Legislation/Enacted – West Virginia SB 626 provides an exception that relative caregivers providing in-home care is exempt from certain work requirements of the medical assistance program.<sup>11</sup>

**Information Links**

(Information is Forthcoming).

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<sup>11</sup> Source: National Conference of State Legislators, July 2003.

**W I S C O N S I N**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

Gail Schwersenska  
Bureau Of Aging & LTC Resources  
Department of Health and Family Services  
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PO Box 7851  
Madison, WI 53707-7851  
Phone: (608) 266-7803 Fax: (608) 267-3203  
e-mail: [schwega@dhfs.state.wi.us](mailto:schwega@dhfs.state.wi.us)

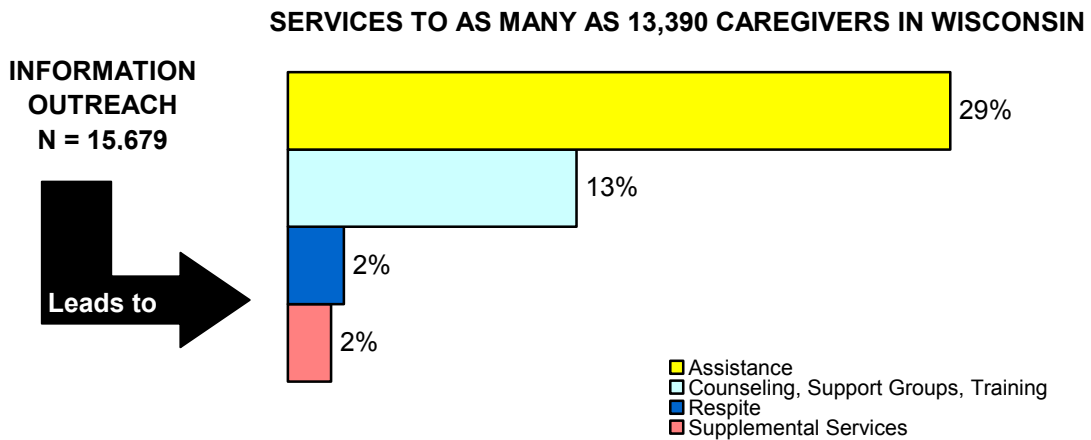
**Administrative Structure**

Wisconsin is developing caregiver program within the broader HCBS system. The Bureau of Aging and Long-Term Care Resources has established a policy on integrated services with other aging and HCBS programs.

The NFCSP builds on existing programs, including *Alzheimer's Family Caregiver Support Program*, *Community Options Program* (integrating caregiver support as part of an array of community-based long-term care services for persons with disabilities, frail elders and their caregivers), and *Lifespan Respite*.

Wisconsin is "proactive" in developing revised Area Agency and county plans to reflect Title III-E. No funds were issued to Area Agencies without an approved plan. State requires coordination with other agencies involved in caregiving in county plans; and delivery of all five services in any given area.

**Services/Number of Caregivers Served – FY 2002**



### **Public Awareness/Education**

- Most Area Agencies use *Powerful Tools for Caregivers* training materials.
- Wisconsin requires staff to meet certain core competencies.
- Reaches out to diverse populations, including Russian, African American, and Latino communities.

### **Consumer/Family Direction**

(Information is forthcoming).

### **Assessment Standards**

At this time, employs no uniform assessment of caregiver needs.

### **Opportunities**

- The NFCSP builds on the established Alzheimer's FCSP begun in 1986.

### **Information Links**

Family Caregivers Information (Wisconsin Department of Health and Family Services)  
<http://www.dhfs.state.wi.us/Aging/caregiver.htm>



**W Y O M I N G**  
**NFCSP INFORMATION PROFILE**

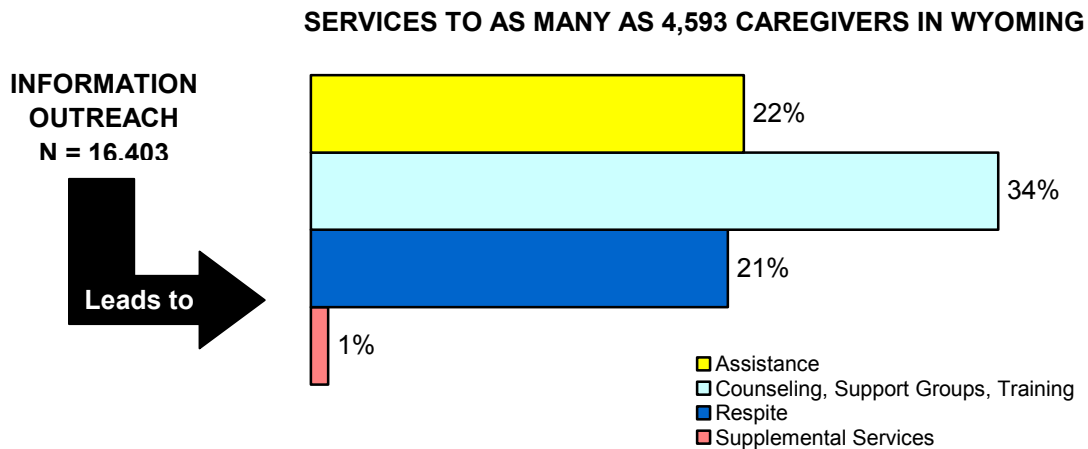
**NFCSP State Contact**

Edna Vajda  
WDH, Aging Division  
6101 Yellowstone Rd, Room 259B  
Cheyenne, WY 82009  
Phone: 800-442-2766 Fax: (307) 777-5340  
e-mail: [evajda@state.wy.us](mailto:evajda@state.wy.us)

**Administrative Structure**

(Information is forthcoming).

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Statewide efforts include: extensive trainings in quadrants of the state.

Local activities include: use of television, radio, and pamphlet promotions.

**Consumer/Family Direction**

Family members who provide respite care can hire family members as respite workers as long as they are employees of the senior center and meet the guidelines for employment of the center.

**Assessment Standards**

Employs uniform assessment of caregiver needs.

**Opportunities**

- Interested in assisting Senior Centers in retaining trained respite workers.

**Information Links**

(Information is forthcoming).

**G U A M**

**NFCSP INFORMATION PROFILE**

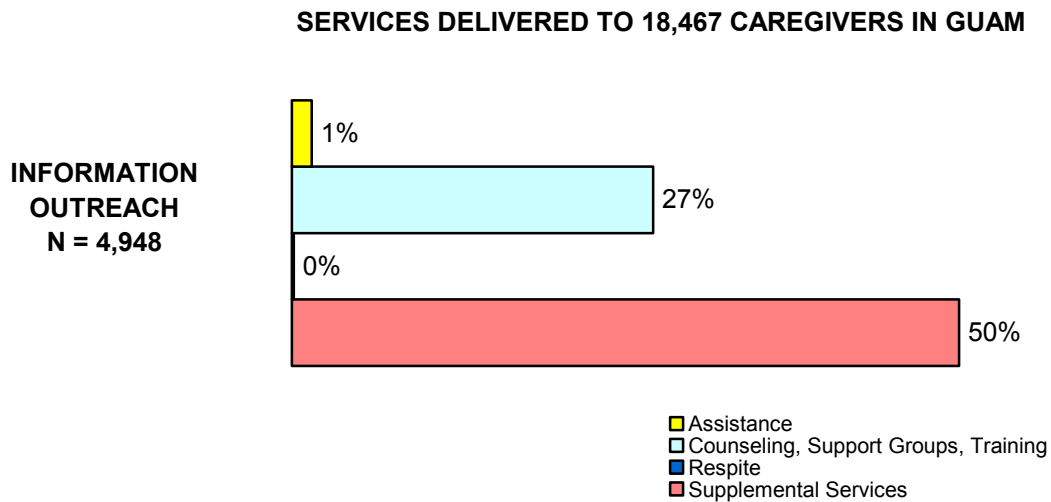
**NFCSP State Contact**

Gerrie Gumataoto  
FCSP Project Coordinator  
Division of Senior Services  
Department of Public Health & Social Services  
Government of Guam  
PO BOX 2816  
Hagaina, Guam  
Phone: 011 (671) 475-0263 Fax: (671) 477-2930  
e-mail: [gtgumat@mail.gov.gu](mailto:gtgumat@mail.gov.gu)

**Administrative Structure**

(Information is forthcoming).

**Services/Number of Caregivers Served – FY 2002**



**Public Awareness/Education**

Efforts include developing culturally sensitive training videos. Many caregivers come from neighbor islands such as Commonwealth of the Northern Mariana Islands and Federated States of Micronesia.

**Consumer Direction**

State Units on Aging provide funding to caregivers in the form of vouchers for the purchase of supplemental services.

**Assessment Standards**

Reports uniform assessment of caregiver needs that includes a caregiver component.

**Information Links**

(Information is forthcoming).

## PUERTO RICO NFCSP INFORMATION PROFILE

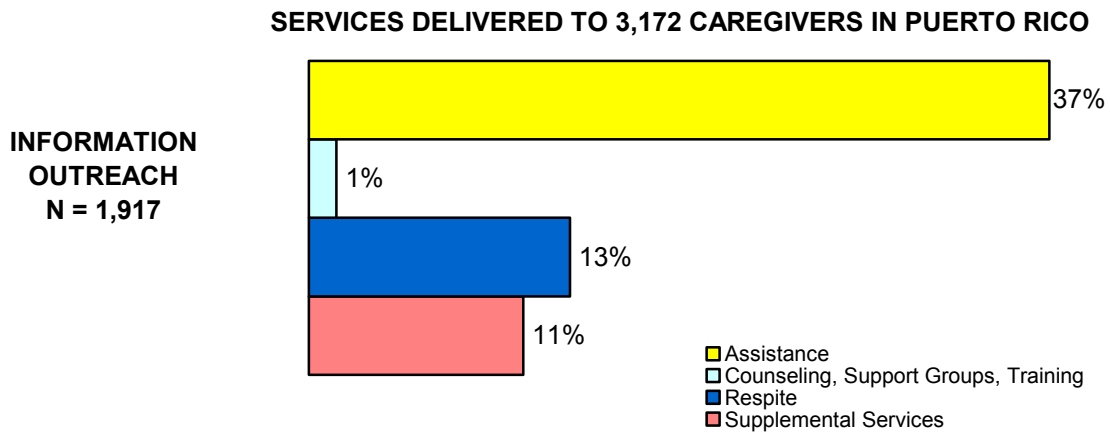
### NFCSP State Contact

Juanita Aponte, Program Director  
Gov's Office for Elderly Affairs  
PO Box 50063  
Old San Juan Station  
San Juan, PR 00902  
Phone: (787) 721-7835 Fax: (787) 725-2919

### Administrative Structure

Puerto Rico has implemented the NFCSP independently and does not build on an existing state program. The NFCSP is in the early stages of development.

### Services/Number of Caregivers Served – FY 2002



### Public Awareness/Education

Efforts include:

- Pooling funds with Area Agencies to develop promotional materials and brochures for island-wide use.
- Training employees from the Department of Families on the NFCSP in coordination with its Area Agencies and Special Communities Program.
- Developing a video, *Testimonials by Caregivers*. This video has been disseminated to Area Agencies and non-profit organizations
- Targeting rural and functionally illiterate populations.

**Consumer Direction**

At this time, Puerto Rico does not offer a formal consumer/family-directed caregiver service system.

**Assessment Standards**

Administers uniform assessment of caregiver needs, *Needs Profile/Follow-up Tool*, including a caregiving component.

**Information Links**

(Information is forthcoming).

**VIRGIN ISLANDS**  
**NFCSP INFORMATION PROFILE**

**NFCSP State Contact**

Eva Williams, Administrator  
Senior Citizen Affairs  
Dept. of Human Services  
#19 Estate Diamond Fredericksted  
St. Croix, VI 08840  
Phone: 340-778-0708 Fax: (340) 692-2062

**Administrative Structure**

The Virgin Islands has implemented the NFCSP independently and does not build on an existing state program. Remains in the early stages of program development.

**Services/Number of Caregivers Served – FY 2002**

(Information is forthcoming).

**Public Awareness/Education**

Efforts include:

- Developing *Resource Directories* comprised of all formal, public and private resources within the community.
- Coordinating with the University of the Virgin Islands to develop Adult Care Training for caregiver program staff and In-Home Respite workers.
- Developing promotional materials in English and Spanish languages.

**Consumer Direction**

Has not set a policy allowing caregivers to hire family members.

**Assessment Standards**

Administers uniform assessment of caregiver needs using an *Intake Form* that includes a caregiving component.

**Information Links**

(Information is forthcoming).

## END NOTES

<sup>1</sup> National Alliance for Caregiving and the American Association for Retired Persons (1997). Family Caregiving in the U.S.: Findings from a National Survey, Washington, DC. Note: No single data source lends itself to an estimate of the number of caregivers or economic value of their caregiving. Statistics vary according to the source and population specified in the sample. The statistics in this report are drawn from a telephone survey of a nationwide random sample of caregivers aged 18 and over.

<sup>2</sup> Doty, P. (1986). Family Care of the Elderly: The Role of Public Policy. *Milbank Memorial Fund Quarterly*, 64, 34-75.

<sup>3</sup> Arno, P.S. (2000). The economic value of informal caregiving. Presented at the American Association for Geriatric Psychiatry, Orlando, Florida, February 24, 2002. Expenditure data from The Centers for Medicare and Medicaid, Office of the Actuary, Levig, et. al., *Health Affairs*, 2002: 21. Note: This value is based on a mid-range estimate of 27.3 million caregivers @ \$8.81/hr.

<sup>4</sup> A Portrait of Informal Caregivers in America (2001). New Jersey, The Robert Wood Johnson Foundation.

<sup>5</sup> Whitlach, C.J. & Noellker, L.S. (1996). Caregiving and Caring. In J.E. Birren (ed.). *Encyclopedia of Gerontology*. New York, NY: Academic Press.

<sup>6</sup> Smith, G., Doty, P. & O'Keefe, J. (2000). Supporting Informal Caregiving. In *Understanding Medicaid Home and Community Services: A Primer*. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC.

<sup>7</sup> Montgomery, R.J. & Borgatta, E. (1989). The Effects of Alternative Support Strategies on Family Caregiving. *The Gerontologist* 29: 457-64.

<sup>8</sup> Wagner, D.L. (2001). Enhancing State Initiatives for Working Caregivers. Policy Brief No. 5. In, *Who Will Provide Care? Emerging Issues for State Policymakers*, San Francisco, CA: Family Caregiver Alliance.

<sup>9</sup> Montgomery, R.J. & Borgatta, E. (1989). *Ibid.*

<sup>10</sup> Smith, G., Doty, P. & O'Keefe, J. (2000). *Ibid.*

<sup>11</sup> A Compendium of HHS Caregiver Support Activities (2003). U.S. Department of Health and Human Services, New Freedom Initiative Caregiver Support Workgroup, Washington, DC.

<sup>12</sup> Fox-Grage, W., Coleman, B. & Blancato, R.B. (2001). *Federal and State Policy in Family Caregiving: Recent Victories but Uncertain Futures*. San Francisco, CA: Family Caregiver Alliance.

<sup>13</sup> A Portrait of Informal Caregivers in America (2001). *Ibid.*

<sup>14</sup> Smith, G., Doty, P. & O'Keefe, J. (2000). *Ibid.*

<sup>15</sup> Early program findings indicate that states offer one or more of the following services under the supplemental services category: home modifications, assistive technologies, emergency response systems, equipment, incontinent supplies, transportation, money management, placement, homemaker, chore, visiting, legal assistance, peer counseling, translation/interpretation, personal care, material aid, service scholarships, home delivered meals, nutritional supplements, telephone reassurance, home safety interventions and emergency financial assistance.



<sup>16</sup> Satisfaction with Services For Caregivers: Preliminary Year Three Results, the U.S. Administration on Aging, Performance Outcomes Measures Project (2002). U.S. Department of Health and Human Services, Administration on Aging, Office of Evaluation, Washington, DC.

<sup>17</sup> Delivering on the Promise: Compilation of Individual Federal Agency Reports of Actions to Eliminate Barriers and Promote Community Integration, Report to the President On Executive Order 13217 (2002).

<sup>18</sup> See also Feinberg, L.F., Newman, S.L., & Van Steenberg, C. (November 2002). *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since Passage of the National Family Caregiver Support Program*. San Francisco, CA: Family Caregiver Alliance.

<sup>19</sup> Link, G. (2003). The Aging Network Implements The National Family Caregiver Support Program. National Association of State Units on Aging, Washington, DC. The full report is available at: [http://aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/Aging\\_Network\\_implements\\_NFCSP.doc](http://aoa.gov/prof/aoaprogram/caregiver/careprof/proguidance/resources/Aging_Network_implements_NFCSP.doc)

<sup>20</sup> A complete listing of all discretionary grants is posted on the AoA website at this link: [http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/nfcsp\\_projects/PromisingPractices.pdf](http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/nfcsp_projects/PromisingPractices.pdf)

<sup>21</sup> This work builds on the Family Caregiver Alliance's 1999 survey of state caregiver policies in 15 state caregiver support programs prior to the passage of the NFCSP. Eight *best practices* in state caregiver support and five *best practice programs* (California Caregiver Resource Centers, Pennsylvania Caregiver Support, New Jersey Statewide Respite Program, Oregon Lifespan Respite Program, and New York Consumer and Family Support Services) were identified. Additional findings from this report are available at: <http://www.caregiver.org/issues/execsum9910.html>

This work also builds on the Family Caregiver Alliance's 10-state case study that identifies commonalities and differences among the states, highlights crosscutting themes, offers issues for the future and presents individual state profiles that describe each state's approach to providing support services. This project was supported, in part, by a grant from the U.S. Department of Health and Human Services, Administration on Aging, Washington, DC. See, Friss-Feinberg, L. Newman, S., & Van Steenberg, C. (2002). *Ibid*. Additional findings are available at: [http://www.caregiver.org/national\\_center/10\\_state.htm](http://www.caregiver.org/national_center/10_state.htm)

<sup>22</sup> See also Friss-Feinberg, L. Newman, S., & Van Steenberg, C. (2002). *Ibid*.

<sup>23</sup> The Future Supply of Long-Term Care Workers In Relation to The Aging Baby Boom Generations, Report to Congress (2003). *Ibid*.

<sup>24</sup> Mahoney, K.J., Simon-Rusinowitz, L., Loughlin, D.M., Desmond, S.M., & Squillace, M.R. (In Press). Determining Personal Care Consumers' Preferences for a Consumer-Directed 'Cash and Counseling' Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Physical Disabilities. *Health Services Research*.

<sup>25</sup> Beyond 50, A Report to the Nation on Independent Living and Disability (2003). The American Association of Retired Persons, Washington, DC. See: [http://research.aarp.org/general/beyond\\_50.html](http://research.aarp.org/general/beyond_50.html)

<sup>26</sup> Niesz, H. & Martino, P. States that Allow Family Members to Act As Personal Care Assistants. OLR Research Report, February 21, 2003.

Evidence suggests that 42/48 states allow payment to family members in one or more of their home-care programs. Except for six states, formal training is not required in the consumer-directed option.

- <sup>27</sup> Simon-Rusinowitz, L., Mahoney, K.J., Loughlin, D.M. & Sadler, M.D. Paying Family vs. Non-family Caregivers in a Consumer-Directed Cash Option: Findings from the Arkansas Independent Choices Program. Symposium presented at The Gerontological Society of America Annual Scientific Meeting, November 24, 2002.
- <sup>28</sup> Foster, L., Brown, R., Phillips, B., Schore, J. & Carlson, B. (2003). Improving the Quality of Medicaid Personal Assistance Through Consumer Direction. *Health Affairs*, 162-175.
- <sup>29</sup> Dale, S., Brown, R. Phillips, B., Schore, J. & Carlson, B. (2003). The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs In Arkansas. *Health Affairs*. 566-575.
- <sup>30</sup> Foster, L., Brown, R., Phillips, B. Schore, J. & Carlson, B. (2003). Ibid.
- <sup>31</sup> Squillace, M & Firman, J. (2002), The Myths and Realities of Consumer-Directed Services for Older Persons. The National Council on the Aging, Research and Demonstrations Division, Washington, D.C.
- <sup>32</sup> Squillace, M.R. The Older Americans Act National Family Caregiver Support Program: *Compassion in Action*, Executive Summary. The U.S. Department of Health and Human Services, Administration on Aging, National Summit on Creating Caring Communities, Orlando, Florida, September 21-23, 2003.
- <sup>33</sup> Promoting Consumer Direction in Aging Services, Consumer Choice News, Issue 4, 2003. This publication of the National Association of State Units on Aging and The National Council on the Aging is supported by a grant from The Robert Wood Johnson Foundation. For more information on this project go to: <http://www.consumerdirection.org>.
- <sup>34</sup> Squillace, M.R. Myths and Realities of Consumer Directed Services. Presented at the House Older Americans Caucus, NASUA and NCOA, 2226 Rayburn Building, July 19, 2002.
- <sup>35</sup> Squillace, M.R. and Doty, P. (2002). Independent Choices: National Symposium on Consumer-Directed Care and Self-Determination for the Elderly and Persons with Disabilities Summary Report. U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy.
- <sup>36</sup> Information on sample caregiver assessment tools are located on the Administration on Aging website: <http://www.aoa.gov/caregivers> . See also, Friss Feinberg, L. (2002). The State of the Art: Caregiver Assessment in Practice Settings. National Center on Caregiving, San Francisco, CA: Family Caregiver Alliance.
- <sup>37</sup> Friss Feinberg, L. (September, 2003). What Do Caregivers Need? Caregiver Assessment & Evaluation. The Administration on Aging – National Summit on Caring Communities, Orlando, Florida. The National Center on Caregiving, Family Caregiver Alliance, San Francisco, CA.
- <sup>38</sup> Whitlatch, C. (September, 2003). What Do Caregivers Need? Caregiver Assessment, Evaluation, and Strategies for Intervention. The Administration on Aging – National Summit on Caring Communities, Orlando, Florida. The Margaret Blenkner Research Institute, Benjamin Rose, Cleveland, Ohio.



